

**Influences on the Decision to Place a Son or Daughter
with Learning Disability and Challenging Behaviour
into Alternative Care**

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy
in the Faculty of Medicine

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Alison M. Alborz

Hester Adrian Research Centre

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Abstract

The transition from home to alternative care is an important and potentially stressful event in the family life cycle. This thesis is concerned with identifying the factors that appear to be influential in the decision to seek an alternative residential placement for a son or daughter with learning disability and challenging behaviour. Secondary analysis is conducted on data from a series of studies by the Hester Adrian Research Centre which identified people, aged 3 to 87 years, with learning disability who had challenging behaviour in service settings in 1988 and 1995. The study uses uni- and multi-variate analyses on cross sectional and longitudinal data sets, as well as qualitative analysis of transcripts from parents who had experienced a move between 1988 and 1995.

The study demonstrates the importance of taking account of level of disability both intellectual and physical, in considering the influences on decisions to place a son or daughter in alternative care. Cross sectional data from the 1988 survey showed that those living in alternative care tended to be older, but people with good levels of intellectual ability were also likely to be male, whereas those with poor/low intellectual ability tended to have fewer physical limitations (ie mobility, continence and feeding problems). People with a fair intellectual level and less frequent episodes of challenging behaviour tended to live in the residential care.

Data from the 1995 survey and qualitative study revealed that challenging behaviour was a factor in many moves however it was rarely the primary impetus to move. Moves which were occasioned by challenging behaviour were 'crisis' moves and by their nature occurred very swiftly with a corresponding loss of control over placement destination for the people involved.

Most families were in the 'post parental' phase of the family life cycle (Olsen et al 1984). Examination of Essex, Seltzer & Krauss' (1997) transition profiles in relation to this group revealed only four examples of 'normative' transition explanations. The majority of moves falling under the 'stress process model'. An analysis of explanations of this type revealed three broad categories namely, forensic, involving actual or potential police involvement; family, comprising difficulties in the health or well being of parents or other family members; and service, involving a lack or loss of services.

'Normative' moves tended to occur for people with good intellectual ability, that is, they occurred for reasons of 'independence' or 'to do the normal thing'. The concept of 'independence' appeared incongruent to parents of people with more severe learning disability. This concept of 'normative' standards for people with learning disability had implications for the ethos of any new residence. Analysis suggested that parents of people with good intellectual ability may be more at ease with the idea of their son or daughter having a 'private' life separate from their parents. However, parents of people with poorer intellectual ability appeared to need total openness from care staff and to be informed about all aspects of their son or daughter's life. This was seen as necessary to ease anxiety and monitor care, especially if there were communication difficulties.

The literature highlighted a shortfall of residential provision in the UK (Emerson et al, 1996) and accounts from parents of funding difficulties encountered in maintaining or taking up places in preferred residential facilities point to the importance of availability of appropriate provision as a factor in placement.

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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The Author

The Author graduated from Manchester Polytechnic in 1984 with a BA. (Hons) in Psychology. After 2 years employment at Manchester Polytechnic on a research project concerning the abilities of design engineers, she was employed by the Hester Adrian Research Centre at the University of Manchester. Since that time she has largely been involved in a series of studies concerning people with learning disability whose behaviour challenges services, but has also worked on projects concerning young people with Down's syndrome and their families, provision of Audiological Services in the community and the assessment of Central Auditory Processing Disorder. More recently she has been involved in research on Primary Care Groups and Trusts. She is currently a Research Fellow at the National Primary Care Research and Development Centre, University of Manchester.

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Introduction

The subject matter of influences on decision making is complex. The literature review which follows this brief introduction attempts to cover those areas which are considered to be influential in the decision to place a son or daughter who has learning disability and challenging behaviour in alternative residential care.

Relevant literature was identified using CD ROM databases of research abstracts including Medline, Psychinfo and BIDS. In addition, references in the literature were hand searched. In chapter one the topic areas reviewed span psychological and sociological theory regarding the nature of caregiving and the relationship between caregiver and the person receiving care. This relationship is considered as one amongst other familial processes and internal influences which may determine action. In chapter two, areas of relevance external to the family are reviewed. Amongst these are current policy developments concerning the status of carers, their relationships with service providers, as well as proposed changes in legislation which recognises the rights of people with learning disability to make decisions on matters affecting them whenever this is possible.

The thesis takes a multi-disciplinary perspective to decision making in regards to placement in alternative residential care. This is done in recognition that many processes take place at a number of levels. At an individual level each member of the family may be influenced by factors such as their own personality or coping style, whilst at a family or community level, there may be historical and current influences on values and beliefs, as well as support received or costs incurred. Finally, despite the above, national and local policy influences the

availability and type of alternatives to family care, and these may also be very significant determinants of decisions to place a son or daughter with learning disability away from home.

The thesis also recognises that the extent of disability suffered by the individual may have implications for placement in terms both of the physical environment of proposed accommodation, as well as issues regarding the quality of care, which may be reflected in requirements for sensitivity in interpreting need in a person with, for example, poor communication skills. To this end care is taken to establish the intellectual and physical limitations of the people upon whom this thesis is based.

Study One uses uni- and multi-variate analyses to generate reliable indices for these personal descriptors. Data from service settings, collected at a time when all the people whose moves are explored were still living with their families, is investigated to establish whether there are any overall differences between people living in residential care and those living at home.

Study two extends work undertaken by Kiernan & Alborz (1995) which explored factors associated with moves from home by ten of the eighteen people studied in detail in this thesis. This investigation compared the 'movers' with the remaining people with learning disability and found that being at the younger end of the age range for the group, having injured a parent, and parents having problems with supervision, discriminated between the two groups. Study two narrows the focus to a comparison group of people of the same age and gender as the 'movers' group to establish whether there are factors apparent in service settings at the time when all participants lived in the family home which could distinguish those who had left home. In addition, for those whose parents were interviewed as part of the Queshi (1990) study, confirmation of findings in the literature regarding stress levels, social support and other

demographic details, is sought as far as possible. However, the findings from this study are limited by the small groups involved.

Study three uses qualitative analysis of responses to open ended questions in a semi-structured interview. This study provides a detailed examination of the processes involved in moving to alternative residential care. It seeks to document the antecedents to the decision to seek a placement, the process of moving and its effects on those involved, and the subsequent interactions between parent and son or daughter with learning disability, including relationships with their 'new family'.

In terms of theory the thesis aims to establish:

- the extent to which personal characteristics of the people with learning disability appear to affect placement (eg Meyers, Borthwick & Eyman, 1985)
- the extent to which parental characteristics are influential in moves from the family home (eg Johnson & Catalano, 1981; Townsend, Noelker, Deimling & Bass, 1989).
- how far stage in family life cycle had an effect on decisions to place (Turnbull et al, 1986).
- whether Essex et al's (1997) 'launching' profiles are reflected in moves made by this group of adults with learning disability and challenging behaviour.
- how these transitions compare to those analysed by Bigby (1990) and whether parental experiences of moves echo those detailed by Richardson & Richie (1989).

Chapter 1

Psychological and social theory on the nature of care giving, families and stress, and their relationship to parents caring for a son or daughter with learning disability.

- | | | |
|---|---|----------------|
| 1 | <i>The nature of care giving</i>
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Chapter 1

Psychological and social theory on the nature of care giving, families and stress, and their relationship to parents caring for a son or daughter with learning disability.

1 The Nature of Caregiving

A growing body of work now exists on defining the act of caregiving as it relates to the family. However the emphasis of much of this work has been on the practical aspects of caring with the less tangible areas left unexplored. Researchers such as Finch & Mason (1993) propose that it is not the activities involved in care giving that are important but the purpose or intent behind those actions.

Bowers (1987) analysed care given by family members to elderly relatives and produced a model of caregiving comprising five stages, which are. . .

Anticipatory care - where the carer speculates on the future needs of their relative and makes outline plans without the knowledge of their relative, 'just in case . . .';

Preventative care - which monitors the needs and well-being of the relative again in a discrete manner;

Supervisory care - where assistance is given, for example in taking medication, but with minimal awareness by the relative that they are being 'cared for';

Instrumental care - when practical assistance is given with the full awareness of the relative but may involve a degree of reciprocity in the relationship; and finally

Protective care - where the carer attempts to maximise the perception of independence on the part of the cared for person whilst also minimising awareness of failing abilities.

The latter type of care was described as the most stressful for carers to cope with but was later replaced by Bowers (1988) by *Preservative care* in which the carer attempts to preserve the cared for person's sense of 'self' and to maintain family connections, dignity, hope and sense of control.

Nolan et al (1996) broadened and extended several of the categories so that the conceptualisation might be applicable to carers more generally. Their revisions to the model occur primarily in two areas, the nature of Anticipatory care, and Protective/Preservative care. They also felt that Bower's categorisations should reflect the chronic nature of caring rather than appear specific and short term. The conceptualisations are listed below.

Type of caregiving	Bowers (1987)	Nolan, Grant & Keady (1996)
Anticipatory	Speculative in nature occurring before onset of caregiving relationship proper.	Speculative in nature occurring throughout caregiving relationship in relation to a variety of potential needs and transitions.
Preventative	Monitoring needs and well-being of person without their awareness.	As Bowers' model.
Supervisory	Assistance given but minimal awareness that person is 'cared for'.	As Bowers' model.
Instrumental	Practical assistance given in full awareness of person - degree of reciprocity involved.	As Bowers' model.
Protective	Attempts to maximise perception of independence and minimising awareness of loss of ability.	As Bowers' model. Not replaced but seen as a short-term stage in transition to receipt of care.
Preservative	Replaced 'protective care' (1988). Attempts to maintain sense of 'self', and dignity and hope.	As Bowers' model but also involves preservation of skills, abilities and interests.
(Re)constructive		Building on past to develop new constructive roles or gain skills to enhance identity.

Anticipatory care, was perceived to have potentially much greater impact on the lives of carer and cared for than Bowers' model implied (Wenger, Grant & Nolan, 1996). It was envisaged that anticipatory care may result in overt action such as inhibition of plans which would result in a move far away from an ageing parent, or prompt a parent to move home to a position closer to shops or adult children as they envisage their dependency increasing over time. Nolan et al (1996) suggest that anticipatory care extends throughout the caregiving period, beginning before dependency. In their conceptualisation they acknowledge that the position of parents of sons and daughters with learning disability may vary somewhat from that of other carers in that they care throughout the life cycle from first diagnosis, often as a small child. When that child is an adult, they propose Anticipatory care may include strategies for a time when parents are no longer able to provide care. Anticipatory care in this context they conclude is a cause of stress and high levels of anxiety. If this is so, one might expect to find evidence of anticipatory planning amongst families who are the subject of this thesis.

Nolan et al (1996) further elaborate on the concept of anticipatory care by defining two sub-types namely 'speculative' and 'informed'. *Speculative anticipatory care* involves decision making or planning with little or no information, advice and support. In contrast, *informed anticipatory care* involves the development of strategies with adequate advice, information and support.

The Nolan et al (1996) model of caregiving concurs with Bowers' (1987) conceptualization of *preventative*, *supervisory* and *instrumental* care, including both *protective* (Bowers 1987) and *preservative* (Bowers 1988) care but adds *(re)constructive care*. The latter three aspects of care (*protective*, *preservative* and *re-constructive*) are proposed to have a temporal relationship and to merge one into the other somewhat.

Nolan et al (1996) extend Bowers' idea of protective care, where the their relatives' awareness of their physical and/or mental deterioration is minimised, with the concept of preservative care which emphasises a maintenance of 'self'. Nolan et al (1996) kept the concept of *protective care* which they saw as a valid though short term measure which was not possible, nor necessarily desirable, to maintain in the long run.

Bowers' (1988) definition of *Preservative care* emphasised the maintenance of *former* 'self'. However Nolan et al's (1996) conceptualisation of preservative care proposed that the concept was more wide ranging, extending beyond the preservation of dignity, contacts and self esteem, to preservation of skills, abilities and interests throughout the period of caregiving. Researchers such as Brandstädter (1995) found that self esteem and psychological health may be optimized by assimilation and accommodative activities. The former aiming to maintain existing abilities and interests, and the latter to build new ones.

(Re)constructive care (Nolan et al, 1996) was envisaged as means by which the cared for person is helped to build upon the past to develop new constructive roles. In the case of people with learning disability it was suggested that carers use constructive care to build a valued identity for their son or daughter, a set of roles which they may fulfill.

In terms of the caregiving relationship between a parent caregiver with their son or daughter with learning disability it is apparent that there is a good deal of overlap with the nature of care given to other dependent groups. Although *anticipatory care* may have limited use as a concept with many people in this group, in terms of planning for a suspected or expected deterioration from full competency to dependancy, there are areas of future concern which may need prior consideration throughout the period of caregiving as suggested by Nolan et al.

Planning the best route through education and/or to obtain other support services to enable a child to reach their full potential may involve some of the same types of dilemma. It may, for example, lead to a parent moving house from one Local Authority Area to another in the belief that the services offered there are in some way superior. As indicated by Nolan et al (1996), there will be an element of anticipatory care in consideration of future living arrangements for older sons and daughters when living at home is no longer feasible or desirable.

Preventative care appears to assume a temporal deterioration in the condition of the cared for person the path of which may be steeper than in a person with learning disability. Certainly, there are people with learning disability who have specific conditions which lead to a deterioration in their health over a number of years and in such cases parents will also use strategies to monitor the condition of their son or daughter. However, as a concept 'general' preventative care appears to be of variable use in these circumstances.

Supervisory care, on the other hand, appears entirely consistent with the experience of caring for a son or daughter with learning disability as many require supervision in regards to personal care, welfare and medication. However, a major difference would appear to be the discretion with which this activity is conducted. Although many people with learning disability may be anxious to do as much as possible for themselves and gain in terms of their self esteem where they succeed, the visibility of supervision would appear less critical.

Instrumental care is likely to be provided to the majority of sons and daughters with learning disability although this will vary greatly with the level of disability involved. Those with more severe disability will need higher levels of practical care with, for example, dressing, washing and eating. On the other hand, those with a mild level of disability may not only be entirely

proficient in these skills, but actually provide useful assistance to their parents and family in general.

Protective, preservative and (re)constructive care for this group would appear to share some similarities with other 'cared for' groups, but also significant differences. Depending on level of awareness, a parent may well work hard to protect their son or daughter's sense of competence and enable them to complete tasks of significance to them, independently. The concept of preservative care, however, appears to be of less relevance to the group in that there is no 'former self' to preserve. Nevertheless, through constructive care, one appreciates that shaping and enhancing a person's capacity to care for themselves and undertake other significant and age appropriate tasks may well lead to feelings of mastery and thereby enhance feelings of self esteem and confidence.

Overarching and interweaving all the types of care outlined by Nolan et al (1996) is what they term their 'metaconcept', that is, reciprocal care. Omission of this aspect of the caring relationship they felt was a major limitation of Bowers' model however they recognised that her model was based on research with carers of elderly relatives who suffered dementia and therefore would have limited applicability to other groups. A growing literature documents caregiving satisfactions and it has been shown that even where the level of dependency may be high, there may be forms of reciprocal helping in terms of financial and material assistance, as well as gains in psychological well-being (e.g. Grant 1986, 1990).

The Caring Relationship

Work on the caring relationship itself has also been a subject of great interest in recent years. Heller, Miller & Factor (1997), for example, suggest that caregiving produces satisfaction as

well as burden and that these outcomes should be treated as two separate factors, rather than two ends of a single continuum. Their work in the USA suggests that in order to understand the influence of the person with learning disability on their parent, it is necessary to look both at the amount of extra work or stress engendered, as well as the positive benefits related to the caring role.

This aspect of caring, largely overlooked in the past, has gained more prominence in recent years. A major aspect of satisfaction, as indicated above, is lodged in reciprocity. That is, though caring for someone places many demands on a carer there are also benefits to be gained from the relationship. Davies (1980) proposed that where the person cared for is seen as valued there will be no problems in the relationship. Hirschfield (1981,1983) suggested that the cared for person may reciprocate 'by virtue of their existence'.

Nolan et al (1996) analysed areas of satisfaction in caring in terms of the perceived main beneficiary and source of the interaction. The sources of interaction providing benefit were seen as stemming from the inter-personal dynamic, the intra-personal or psychological orientation of the carer and/or the promotion of positive outcomes for the cared for person.

Inter-personal sources of satisfaction include those derived from the act of providing care for a loved one. Seeing the dependant person as happy and contented is a source of considerable satisfaction for carers (eg Penrod 1995). Although the intended beneficiary of such actions is without doubt the cared for person, the fact that carers perceived this as satisfying suggests that they too derive some benefit (Nolan et al 1996). *Intra-psychic sources* of satisfaction include those such as the perception that caring provides life with meaning and purpose (eg Davies 1980), allows the carer to develop a sense of competence and mastery (eg Pearlin et

al 1990), gives them a sense of achievement (Beresford 1994) and enables development of personal qualities such as patience and tolerance (eg Clifford 1990). In terms of intra-psychic sources of satisfaction, Nolan et al (1996) also highlight the fact that the entire family may derive benefits from a sense of shared purpose and decrease in materialism. In addition, satisfaction may be derived from a perception of repaying past kindnesses, or a 'hypothetical exchange' amounting to a sense that were circumstances reversed then the cared for person would have cared for them. Finch & Mason (1993) suggest that this type of perception provides the motivation to continue caring and is the basis of relationships involving the giving and receiving of help.

Finally it has been proposed that providing physical care fulfils a need to tend and nurture which is thought to be a predisposition in women (eg Lewis & Meredith 1988) and thereby meets needs in both parties. Nolan et al also suggest that satisfactions are apparent in promoting positive, and avoiding negative, outcomes. Taken to extreme, however, this may amount to a perception that the care provided is the best and that anything other is of an unacceptable standard (Grant & Nolan 1993). Carers may also derive satisfaction from the results of therapeutic input which may aid recovery, rehabilitation or development in the dependant person but also allows carers to develop skills, widen their interests and make new contacts.

Nolan et al (1996) suggest that carers perceive wide ranging and mutually beneficial satisfactions and rewards from caring. They state that eight out of ten of the greatest sources of satisfaction for carers relate to the those where the cared for person is the main beneficiary. In addition, they quote evidence that altruism may be described as a form of reciprocity (Abrams 1985) where satisfaction is derived from *knowledge* that they have done their best,

or is considered as expression of love . The fact that so many carers get a great deal of satisfaction from the act of caring, no matter how routine or mundane, is seen as crucial to the motivation to improve or maintain both party's quality of life.

As a consequence carers' standards in care are important and formal services are expected to provide an atmosphere in which the cared for person's needs will be met, their dignity maintained, and pleasurable activities provided. Nolan et al comment that services often fail to meet these criteria and therefore carers reject them, or if they accept them, they are subject to intense feelings of guilt. One of the prime motivations to continue caring has been found to be the desire to keep the cared for person out of an 'institution'. A desire reinforced by community care policy. Nolan et al comment that carers are often not opposed in principle to alternative residential care but find the standards in operation there at variance with their own, and therefore unacceptable. They stress that where a move from the family home is required greater recognition of difficulties from the carer's perception is required but that any support the family has received is likely to be withdrawn at this point. However this may be the time when additional help, particularly of a emotional nature may be needed most. There may be particular difficulties for carers when the caregiving period ends if they have perceived this relationship as having given purpose and meaning to their own life. They may be left with a void to fill.

Reciprocity in relationships of this kind is largely intangible, built on appraisal of what 'may be' and what 'might have been', that is, 'hypothetical exchange'. Bulmer (1987) proposed that a type of 'balance sheet' of past kindnesses and social interaction may exist in well established relationships. In this model reciprocating in interpersonal relationships is seen as developing across the life course. However for parents with a son or daughter with learning disability

there may not have been the opportunity to build such a 'balance sheet' or 'hypothetical exchange' based on past experiences. An exception to this may be those who have a less severe disability for whom there may be an expectation that they may take on roles within the family in terms of assistance with house work or companionship when their parent reaches old age. Where a person has a more severe disability it would appear that intangible sources of satisfaction may arise from acts of nurturance and provision of pleasurable activities, to see them well cared for and happy.

Heller et al (1997), in their research into support from adults with learning disability to their parent and its effect on caregiving satisfaction and burden, have shown that a lower level of functioning was associated with greater levels of caregiving satisfaction. However challenging behaviours were associated with experiencing a greater level of burden. When help, such as companionship or help with household chores, was provided by the son or daughter with learning disability greater levels of satisfaction and reduced levels of burden were experienced by the parents involved. This research suggests that some families may prefer their son or daughter to remain in the family home because of these caregiving rewards and the socio-emotional and instrumental support they give to the carer.

Reciprocity therefore appears to produce satisfactions and benefits to the individuals involved but eagerness to provide 'best care' may generate problems for carers, driving them to continue caring past the point at which the best interests of their dependant or themselves are being met. Examining 'satisfaction' may be a way to reveal poor emotional health on the part of the carer or fragile and potentially abusive caregiving situations. Nolan et al (1996) propose that carers who are unable to identify any positives in the caregiving relationship are likely to be near

breaking point. The use of satisfactions as indicators, as suggested by the above research, should be equally applicable to families with a son or daughter with learning disability.

In terms of other factors that might be expected to have an effect on the caring relationship Hayden & Heller (1997), in work in the USA, examined adaptation to caring between younger (55 years or less) and older (56 years or more) carers of adults with learning disability. This study explored two models of long-term care giving with apparently conflicting conclusions. The 'wear and tear' hypothesis (Johnson & Catalano 1981) predicts that long-term experience of stress would result in a depletion of physical and psychological resources. The 'adaptation model', on the other hand, suggests that long-term caring would result in better adjustment to the care giving role (Townsend, Noelker, Deimling & Bass 1989).

The study found no difference in the size of social network or average number of support services received. However, there were differences in perceived burden, number of unmet service needs and use of coping strategies, with older carers reporting significantly less burden. Differences were not associated with characteristics of carers or those they cared for, nor with the pattern of services they received. The findings may reflect the higher expectations of younger care givers that the service system should help them. Older care givers, on the other hand, may have lower expectations of services and be more comfortable with 'getting by'. Younger carers on the whole cared for adults aged 20-29 years (89%), the number of older carers with a son or daughter in this age group was substantially lower (41%). This may reflect bias in the sample in that those parents whose son or daughter had more urgent need for service input may have left home and therefore their carers would not be found on any list of people receiving service input. In addition, as the policy context in which the offspring grew up had changed latterly, (i.e. the introduction of a right to education), the effect

may have been due to an historical low level of services experienced by older carers. Support for this notion comes from Todd, Shearn, Beyer & Felce (1993) who found greater service support for younger families and that the level of service planning for adults 25 years old or more was severely deficient.

Much of the above theorising on the nature of family care was based on carers of family members with dementia or the elderly and as such the 'genesis' of the caregiving period differs from that of a parent caring for a son or daughter with learning disability. In dementia, or indeed advancing old age, a gradual decline is often experienced during which attempts may be made to 'normalise' the affected person's daily life by both the person themselves and their 'would be' carer. In the case of parents with a son or daughter with learning disability, their realization that there is a problem may be generated by a failure to develop the normal childhood milestones and be confirmed with a medical diagnosis. In this situation it is often the carer or parent alone who needs to come to terms with the situation. In many cases the child will be entirely unaware of the extent to which s/he falls short of 'normal'. In the case of those with mild levels of learning disability, which may not have been identified until well into the school years, although the child may be aware that s/he does not perform as well as peers in school, there will nevertheless be no 'former' ability level to maintain.

The development of caring 'expertise' for carers of people with dementia, the elderly and children with learning disability may have much in common. It is arguable that the learning curve experienced is like that of any new parent with a baby, in that they will gradually learn to 'read' behaviour and be able to respond appropriately to needs. A major difference for these carers, however, is that their loved one will not 'grow out of it' entirely. Given the above, the experience of parents with a son or daughter with learning disability differs from

those caring for an elderly relative to the extent that a decision is made to 'take on' the caring role (Nolan et al 1996). A son or daughter is already 'taken on' and it is currently unusual for a family to reject their child when they discover s/he has a disability.

In both caring situations, however, an end is reached either through an inability to cope any longer, or the death of the person cared for or their carer. In the case of a family of a son or daughter with learning disability alternative care may also be sought to provide them with a greater sense of independence from the family. In the elderly, a decision to make a placement in alternative residential care is often precipitated by a health crisis in the relative. For families caring for a son or daughter with learning disability it is more likely to be a crisis occasioned by the behaviour of the son or daughter, or a health crisis on the part of a carer, which precipitates a move. Nolan et al suggest that carers of elderly relatives have an opportunity to discuss preferences in terms of alternative care with the relative early in the caregiving period. Many families with a member with learning disability do not have this opportunity due to severe limitation in the cognitive abilities of their son or daughter. However they suggest that both types of carer experience persistent guilt over the decision to place their relative in alternative care which may last for many years. In both cases it appears likely that there are similar deficits in decision making on residential care. Nolan et al (1996) highlight the fact that there is often a lack of criteria on which to base a selection. Where the move is at time of crisis there is little time to make a thorough search for alternatives. Additionally, having made a choice, there is no guarantee that a place will be available when it is required. This theme will be explored in greater depth later in this chapter.

Social Support and Help-seeking Behaviour

Research has identified one of the main factors which enables a carer to lead a fulfilling life as the moral and, more particularly, the practical help which may be provided from a wide network of family members, neighbours and friends. Prosser & Moss (1996) in work based on elderly parents of people with learning disability found that caregiving was mainly provided by parents, with relatively little support from siblings or other members of the wider community of friends and neighbours. This situation was not influenced by size or proximity of their network of family and friends. Even in households where siblings were still resident care was performed by the parent with little support

The number of people who may be considered part of one's social network is potentially limitless, however the conceptualisation of social support in these terms has not proved helpful. Much research in this area in the UK has adopted the idea of a more limited support network. Such studies have shown that comparatively few people play active support roles within wider social networks (eg Glendinning, 1983; Grant, 1986). Evidence from other studies show that membership of a support group is rarely static with members being replaced by others from the wider social network (Hammer, 1983). Grant (1993) points out that support is not always reliable, effective or long term, neither is it universally regarded as helpful. The amount of support available has also been shown to vary with the type of help required. For example it has been suggested that approximately one third of social network members would provide support in an emergency, whereas only a little more than one fifth provide support with everyday matters (Wellman, 1981). Where support is given on a long term basis only a very small number of individuals have been shown to be involved and these people are most usually blood relatives (e.g. Green, 1988).

Supportive social networks such as these have been associated with well-being and more positive attitudes (Dunst, Trivette & Cross 1986). In a study of support to adults with learning disability Grant (1993) found that support was provided overwhelmingly by mothers with some input from fathers in matters requiring heavy lifting, transport, household repairs. Similarly, in a study of carers of young adults with learning disability who have challenging behaviour, Qureshi (1990) found that most household and care tasks were performed by mothers with limited support from fathers and rare input from other members of the household. Grant (1993) also reported support from siblings to be less than that from fathers. However although siblings grow up and move away from home, there was evidence that the sibling relationship did not cease. Where there was support this was generally restricted to members of the same household or members of the immediate family.

Support networks have been described as having four main functions which are stress-buffering, provision of practical and emotional support, to screen and refer to formal agencies, and as a backdrop against which attitudes, values and norms may be established (Gourash, 1978). The content of relationships with members of the support group may be shaped by these norms and values and therefore individuals may not be interchangeable. That is, the function of a relationship with one person may not be substituted by a relationship with another (Bulmer 1986). Stability in relationships with others has been argued to be important for adjustment, however, for a person with long term care needs, such stability may turn to stagnation with the same carers facing the same duties or responsibilities with no prospect of relief (Nolan et al, 1996).

Grant (1993) proposed that the situation where support is provided only by members of the immediate family, particularly those in the same household, may be explained by a normative

framework of care-giving and help-seeking behaviour. In this framework little is expected of the extended family other than moral support, tolerance, respect and help in a crisis. Over time, Grant found that support networks were more likely to decrease than increase and that professional input became more prominent. This was explained mainly by the introduction of a 'key worker' system in the geographical area in which the study took place. However there was no evidence that professional support was replacing support from family members, although it did appear that professional input was replacing some support from friends and neighbours. Grant suggested that it may be acceptable to families that professional help be substituted for support at the outer edges of their network. Losses in the networks of family members, he suggests, were due to life-cycle changes rather than evidence of an uncaring attitude. Increases in professional support were most often seen where the person with learning disability also had severe physical limitations. Increases were not evident where the person had increased dependency due to behaviour 'problems'.

Increasing frailness or incapacity in the carer also required the support network to adapt to these limitations and reassign responsibilities (Grant 1993). Changes in network membership tended to occur independently of any changes in level of functioning of the person with learning disability. Grant concluded that there is evidence that support networks can change appreciably in size and membership over quite short periods of time but that one type of network member was not necessarily able to provide the type of support formerly provided by another.

For families with a son or daughter with learning disability this would suggest that early in the caregiving relationship, normative caregiving values may be adopted as many of the tasks being carried out are similar to those required for any small child. In these circumstances

instrumental help is largely provided to the mother by members of the immediate family who live in the same household. Occasional additional support being provided by members of the extended family, in particular by grandparents. However, over the family life cycle the demands for care do not change normatively, resulting in a mismatch between 'normative' caregiving demands for that part of the life cycle and 'actual' demand which, in some cases, will have become more arduous with the increasing size and strength of the child.

The research quoted above suggests that although demands may increase, caregiving values or attitudes are likely to remain unchanged. This may result in a parent continuing to provide, and expecting to provide, the majority of care in the midst of changes which amount to a reduced number of people to call on for support. Grandparents may become too frail and siblings may move away from home to establish an independent life for themselves. The research also suggests that parents do not call on statutory services to provide the same function as a relative who is no longer available to help. However, it suggests that they may accept some help from services if that support was formerly provided by a person on the outer edges of the support network, suggesting that its function might be infrequent or less demanding.

Family Systems

Family systems theories have gained increasing prominence over recent years as a means to understand relationships and difficulties within families through which interventions may be used to alleviate problems. Bowen (1966) was one of the first theorists in this field. He identified that all human emotional systems exhibit common patterns of behaviour as a means to defuse anxiety, a key generator of anxiety being either too much closeness or too great a

distance in a relationship. He noted that individuals may have sensitivities to certain situations or conditions which have been passed down through the generations.

Minuchin (e.g. Minuchin & Fishman 1981) developed a model along similar lines. Families were said to have patterns or rules that they adhered to. The systems within families were said to comprise dyads (two people sharing), coalitions or close allies, and triangles (where a third person is caught up in the difficulties between two others). Minuchin also described hierarchies within families based on age as being important and stated that healthy families were those in which there were clearly defined but permeable boundaries between individuals.

A closely related theory is Transgenerational theory (Lieberman 1979) which states that beliefs and behaviours pass through families consciously and unconsciously. It proposed that family legends or stories convey rules or expectations so that, for example, a long dead family member might exert influence on later generations. Lieberman described these as 'scripts'. In 'repetitive scripts' patterns from the past are repeated. For example a child may take up the same profession as a parent, may marry at a similar age, and have the same number of children. In 'corrective scripts', however, the opportunity is taken not to repeat past behaviour. For example, to allow a child greater freedom when the parent remembers having a very restrictive childhood.

Family systems theories have proved very useful in understanding situations where relationships within a family have become disrupted. That is, an analysis of the family system has provided an effective basis for therapy (e.g. Brown, 1999; Walls, 1998). The family members of people with learning disability are subject to the same influences from within or without the family itself in the same way as anyone else. They will have their own personal

histories which colour their relationships with each other member, as well as with wider society. Although this type of analysis provides a very useful base to therapy, analysis of the families involved in this thesis was not considered relevant. The available data only allows for a superficial examination of the relationship between parent and son or daughter. However, it was considered essential to take family level effects into consideration in looking at the influences on the decision to seek alternative care for the person with learning disability. To this end it was felt important to consider the family life cycle.

Family Life Cycle

When analysing interactions between family members it is important to consider the stage a family has reached in its own life cycle. The stages, and development of families, have been studied for many years and have a bearing on understanding how families negotiate change over time and, indeed, respond to challenges occurring at any particular stage.

Family life cycle theory is concerned with the development and transitions within families as they travel through time. The family life cycle was originally proposed to have eight stages (Duvall, 1957). Subsequently various researchers modified and extended these as seemed appropriate to their theoretical position (eg Rogers, 1960). One theoretical framework which has gained particular attention is that of Olson et al (1984) who incorporated seven developmental stages into their model. This model was the basis for the work of Turnbull, Summers & Brotherson (1986) relating the family life cycle to the experiences of families with a member with learning disability and is described below. In their work they emphasise the importance of viewing the behaviour and needs of family members in the context of the family unit. They state that these aspects of an individual cannot be accurately, nor fully, understood if attention focuses on that person alone.

Turnbull et al (1986) conceptualise the family systems framework as comprising four elements. *Family structure*, which is defined in terms of the resources and characteristics of the family and individual members, is the input to the model. *Interaction* amongst family members provides the process through which family members fulfil their functions. *Functions* are the outputs of the system and are defined by the roles which individual members adopt within the family unit. Finally, the *life cycle* reflects the continual process of change which the family undergoes as it develops over time.

The *family life cycle* is the dynamic element of the family system in that, over time, normative and non-normative change alters family structure and/or its functional priorities and thus the way the family interacts. This cycle is composed of four elements - developmental stages and transitions, structural changes, functional changes and socio-historical changes.

Life events are considered by Turnbull et al (1986) to be stressors when they require a change in an otherwise stabilized pattern or routine of family life and therefore may be a key source of stress. They suggest that families with a member who has learning disability may not negotiate the transitions between developmental stages in the same way as those families who do not have a son or daughter with a learning disability, and so are in the paradoxical position of dealing both with change and 'chronicity' - a chronic demand on the family. That is, the person with learning disability remains in an earlier level of development and dependency past the time when chronologically one might expect their care needs to diminish.

The *developmental stages* in the family life cycle include - couple, childbearing, school age, adolescence, launching (ie where a child leaves home), post-parental and aging (Olson et al 1984). Turnbull et al (1986) state that these stages generalise to the majority of families in

society. They suggest that the stages may be regarded as a series of relatively stable plateaux, each with its own priorities in terms of developmental tasks and responsibilities assumed by differing individuals within the family. They quote as an example parental affection, which is typically expressed to infants by intimate physical contact and bonding. As the infant grows into adolescence and young adulthood, parental affection is more likely to be expressed through communication, respect for individuality and 'letting go'. Life cycle progression, they propose, represents an increasing shift of responsibility from parents to offspring and their offspring's extra-familial contacts.

Turnbull et al argue that a key aspect of development is the change required within families in the way they carry out functions. As such these stages are grounded in age-role expectations and defined in terms of the oldest child (Hill & Rodgers, 1969). Indeed Hill (1970) suggested that attempting to generalize about families without taking stage of development into consideration would result in an inability to account for a large degree of variation in the data.

Developmental transitions are encountered when families are in the process of shifting from one stage to the next and involve a marked shift in family interaction. Transition may be normative or non-normative. Normative changes may be expected to be short term, predictable and to happen in the majority of families (McCubbin et al 1980). Olson et al's (1984) study showed transitions related to launching created the greatest amount of family stress. Indeed some theorists have suggested that even greater stress is encountered when such transitions occur off-time, that is outside the period when they might be expected to take place (e.g. Neugarten, 1976).

In the case of families with a son or daughter with learning disability parents often continue to assume responsibility for functions far past the time when one might have expected them to relinquish these duties had the person not been disabled. This entails families having to adapt to the increasing independence of non-disabled children whilst at the same time coping with the continued dependence of their son or daughter with learning disability. This has been found to be especially difficult where the person with learning disability is the eldest child and his or her younger siblings overtake them in terms of independence and role responsibilities (Breslau, 1982).

Turnbull et al (1986) highlight the fact that timing for launching, or seeking alternative residential care, is difficult for families of a person with learning disability in that they lack some of the usual markers of adult independence. These markers may be in terms of continuing higher education, self-sufficiency in a job, or marriage. They state that there is a highly consistent finding in the literature that parents have concerns over the future for their sons and daughters with learning disability. They state that a major coping strategy for parents is passive appraisal which emphasises the need to live for today rather than plan for tomorrow (e.g. Birenbaum 1971; Bristol & Schopler 1983).

Turnbull et al (1986) suggest that it is important that research should take into account the interaction effects between members (or subsystems) within and outside the family, alongside those of the person with a disability. In terms of family functions they stress the importance of assessing the positive as well as the negative impact of a son or daughter with learning disability on their family. This conclusion reflects the findings of many studies described above in that the effects of the caring relationship on the parties involved is mediated both by the extra demands made on carers and the satisfaction they enjoy in fulfilling this role.

In terms of this thesis, issues around the decision to find alternative residential care for a son or daughter with learning disability and challenging behaviour occurs against a background of unfulfilled 'markers' of the advent of adulthood. Young adults with learning disability are often unable to achieve self sufficiency in terms of skills and employment, unlikely to leave home due to marriage and, apart from opportunities for residential treatment, will be unlikely to move away from home for further education. In addition, this 'launching' phase may occur outside the usual time period when one would anticipate such a change to take place. These times of change are conceived as increasing stress levels within families and to be particularly distressing when occurring 'off-time' (Neugarten, 1976). This model would predict, therefore, that the period during which a person with learning disability leaves home would be a time of particular stress for the family. One of the purposes of this thesis is to examine the relationship between stage of family life cycle and placement decisions.

Theories of Stress and Coping

One of the factors most widely associated with a breakdown in the carer / cared for relationship has been intolerable stress levels in the carer. Consequently stress and coping have been widely studied in the carer literature. Parker (1990) suggests that high levels of stress over a long period may affect the ability of carers to continue caring. When stressors related to a son or daughter with learning disability combine with other family stressors to produce a crisis, the family may cope by removing the stressors, including placing their son or daughter away from home. However, the family's own resources and positive perceptions of the situation may buffer the impact of the stressors and allow the family to cope (Heller & Factor 1993). In order to illuminate the effects of high stress levels on caregiving it is necessary to examine the models of stress and coping that have influenced recent thinking about the relationship between stressful events and their contribution to changes in family life.

A number of models of the stress process have been proposed. The most basic model reflects a stimulus response pattern where the individual is seen as merely reacting to an event, that is, an occurrence that may be characterised as 'stressful'. This model has been reflected in checklists of carer stress (e.g. Holmes & Rahe, 1967; Robinson 1983). However, such models are too simplistic, assuming as they do that all events will be equally stress provoking, occur with equal frequency over time and experienced in the same way for every person at particular points in their history (Nolan et al, 1996; Lazarus, 1999).

A second stream of work, closely related to the above, has concerned stress as a response to severe or major life events. This model proposes that the greater the number of such life events occurring close together in time, the greater will be the stress experienced. Time is a key variable in this model as the same number of life events spread over a greater period of time would be assumed to produce a correspondingly lower level of stress (eg Dohrenwend & Dohrenwend, 1974). Life events may well have a contribution to the overall level of stress experienced and therefore should be taken into account, however it is unlikely that they account for all stress experienced. This model suffers the same type of difficulties as those described above as it does not take account of individual differences in response to significant life events.

One of the most influential and widely used models of stress and coping was developed by Lazarus & Folkman (1984). This transactional model emphasises the cognitions and behaviours generated by stressful episodes. In this model, the importance of individual differences has become increasingly clear. A particular event may be defined as 'stressful' and will evoke a response in the vast majority of those who experience that event. However, the degree to which any one person would experience a stress reaction varies. Reactions to

stressors cannot be predicted without taking variables such as personality traits and previous life experiences into account (Lazarus, 1999). It is, therefore, the person's perception of an event that is the main determinant of level of stress experienced.

Coping in this context is regarded as a dynamic process shifting over time in response to continually changing demands of the situation and the individual's interpretation of them (Lazarus & Folkman, 1984). In this process an event is *primarily appraised* as having significance and to be stressful to the person. The event may be appraised to involve harm or loss (where this has already occurred), threat (where there is a possibility of damage in the future), or challenge (a positive experience providing a chance for mastery). These appraisals are not thought to be mutually exclusive. *Secondary appraisal* follows, evaluating the coping options. This appraisal may also form part of the coping response, for example, where one seeks information or advice on how to deal with the stressor. Secondary appraisal may result in a problem focussed coping strategy which attempts to change the nature of the stressor, or an emotional focussed coping strategy which involves reappraisal of the event to reduce the threat posed (Lazarus & Folkman 1984; Lazarus, 1999).

McCubbin and Patterson (1983) proposed the Double ABCX model of stress and coping. As with the transactional model it involves an interaction between event perceptions and actions where A is the event and B the resources available to deal with the event. C is the person's perception of the event and X the resulting level of stress experienced. However, Orr (1991) suggested that the model should read ACBX acknowledging that coping resources used depends not only on the features of the event (A) but the person's perception of that event (C).

Tunali & Power (1993), in their study of stress and coping in families of a son or daughter with learning disability, describe two different 'problem focused' approaches to coping apparent in the literature. These they described as taking a 'behavioural' focus, that is, centring around problem solving skills or strategies for family management and a 'resource based' focus, which stresses social and other support networks. Frey, Greenberg & Fewell (1989) found that appraisals were the single most powerful correlate of parent outcomes such as stress and depression. They emphasised the point that parents differ dramatically in the degree to which they view their child's disability as a negative and stressful occurrence.

Tunali & Power (1993) suggest that an important strategy that parents may use when faced with difficult situations that are not conducive to intervention, is to redefine the stressful events and in this way reduce their importance and effect. An example of this might be a family, feeling socially isolated from people outside the family, coping by emphasizing family-related values and engaging in recreational activities as a family. This appears to reflect Lazarus' emotion focussed coping response. Tunali & Power stress the value of examining family needs and coping independently taking account of the different perspectives of each family member and recognising that these may, in fact, be conflicting.

Sloper & Knussen (1991) proposed that coping resources act as resistance towards, and risk factors for, stress. That is, lack of a particular resource may lay the parent open to stress, they are vulnerable, whereas possession of such a resource may strengthen them against it. For example, one important coping resource is physical energy. Parents of sons or daughters with learning disability are often disturbed at night, as a consequence they may lack energy. This in turn may lead to an inability to tolerate the usual level of stress experienced in the course of their daily activities and may further deplete coping resources and increase vulnerability.

Caring for a person with learning disability does not of itself mean that the carer will inevitably suffer stress related problems but that they may be more vulnerable to the risk of developing such problems.

By the same token one might argue that where a parent is dealing with incidents of challenging behaviour, in addition to sleep problems, the effect would be an even greater increase in vulnerability. Apart from physical resources, ideological or spiritual resources, personality variables are also felt to be important factors in resistance to stress (Sloper & Knussen, 1991). Previous coping experiences and parenting skills have also been found to be important resources (eg Koch-Hattem 1987; Quine & Pahl 1991). These resources, along with social support of various types and structure, including spouse and agency support, have been found to increase resistance to stress (e.g. Dunst et al, 1986). The interplay of these different facets of the experience of and response to a stressful event may be characterised as shown in the diagram shown overleaf (Fig 1).

Stress and parental well being

In light of the variability in the experience of stress depending on the characteristics and experiences of the person in question, one might conclude that any measure of stress that relies on a checklist of items as an indication of degree of stress being experienced would be of no value at all. However, many studies have used checklists which either list psychosomatic symptoms, greater numbers of which are said to indicate higher levels of stress experiences (eg Malaise Inventory; Rutter et al 1970b), or lists of major life events with an associated rating of 'strain' experienced in relation to the events (eg Life Events Checklist; Cheang & Cooper, 1984). These instruments, although relatively crude, have proved useful when

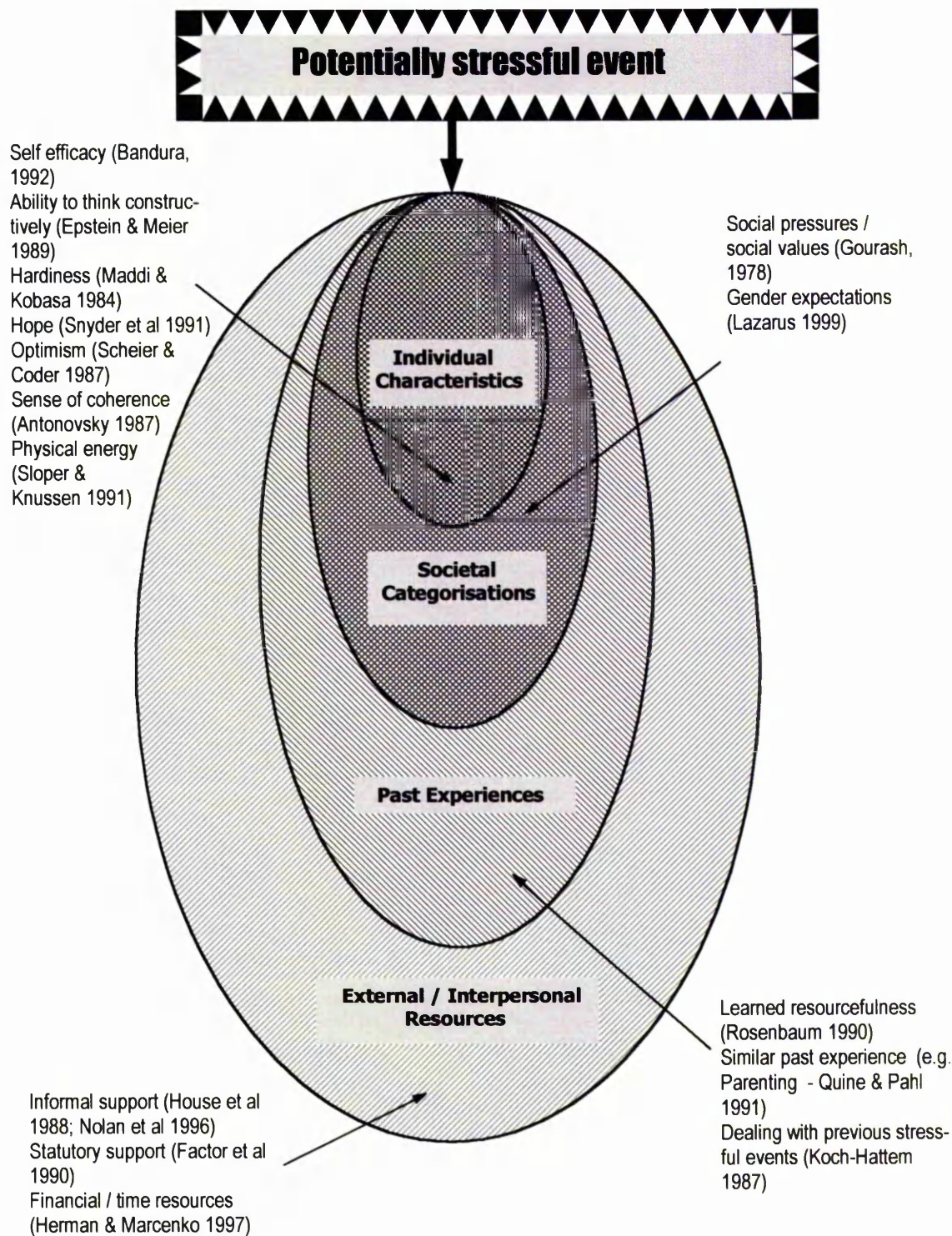


Figure 1: Influences on perception of, and responses to, potentially stressful events

conducting research on the correlates of stress level and have provided a useful glimpse into the effects of caring on the individual.

Hayden & Goldman (1996) in their study of stress levels in families of people with learning disability and their need for services, found that single mothers were more likely to have an higher stress score. Characteristics of the person with learning disability, including severe or profound learning disability, poor health and a large number of challenging behaviours, along with a greater unmet need for services and higher levels of personal care and supervision required, were all related to higher stress scores.

In other work on carers of elderly dependants it has been noted that caring is related to a risk of poor health, depression and social isolation (Zarit, Todd & Zarit, 1986). In their more recent study using methods similar to those employed in the Labour Force survey (HMSO 1990), McGrother et al (1996) found that carers reported 40% more ill health than the general population. The reporting of depression/bad nerves was nearly four times that for the population as a whole. They conclude that current policies and increasing life spans of people with learning disability may mean life-long caregiving for parents which in turn may limit their ability to achieve their own aspirations, possibly resulting in health deficits.

Herman & Marcenko (1997) suggest a model whereby perceptions of services and resources act as mediators to level of depression amongst mothers caring for children (aged 18 or under) with developmental disabilities. They cite evidence that external resources, such as respite or monetary assistance have been found to reduce personal and family stress (Factor, Perry & Freeman, 1990; Agosta, 1989). In addition intra-family resources, such as time, money and informal support (Agosta, 1989) also provided a buffer to parental stress.

They emphasise that aspects of the child's physical condition and behaviour might also be expected to have an effect on parental distress (Bromley & Blacher, 1991) and finally that parents' perceptions of the adequacy of available resources might well also influence parental outcomes in this regard (Minnes, 1988). Herman & Mercenko note that the cumulative effects of physical care and changes in behaviour by the child as s/he grows older have been associated with increased stress and parental problems (Bristol & Schopler, 1984). Studies have also found that the number of adjustments to daily life required to accommodate a son or daughter with learning disability increases with the age of the child (Gallimore et al, 1996). The studies suggest, therefore, that carers of adults with learning disability and challenging behaviour could be expected to have an increased risk of high stress levels and other health problems.

Coping, as described above, appears entirely bound up in the stress process as it interacts with both the event and perceptions of the event. Nolan et al (1996) stressed that coping based on passive acceptance of a situation and dealing with its consequences may be entirely adaptive when nothing can be done about the event itself. They point out that a person usually accesses more than one strategy in an attempt to cope. Coping is described as 'processual' in nature and involves 'strategic thinking' which is shaped and constrained by the values, predispositions and inner resources of the individual (Dill & Feld 1982). Sloper & Turner (1994) in a longitudinal study of adaptation and well-being in families with a son or daughter with Down's syndrome, found that, for mothers, high levels of distress were associated with use of 'Wishful thinking' as a coping strategy, for example, wishing that the event had never happened. Nolan et al (1996) also make the point that coping may involve economic or social costs as well as benefits, that coping may be liberating but it may also be inherently stressful.

Antonovsky (1987) proposed that coping involves striving for 'coherence'. That is, that events remain structured, predictable and explicable; that resources are available to meet the demands of the event; and that the event is worthy of the 'effort' invested in coping with it. To this latter end, the event has to be meaningful to the individual. Nolan et al point out that coping in these terms is influenced by socio-economic grouping and particularly by access to social resources. They suggest that there may be cultural differences in what may be perceived as an appropriate coping response and quote the example that in China a strategy such as praying to the ancestors would be seen as entirely appropriate. However, cultural appropriacy does not equate with response effectiveness. Lazarus (1999) concludes that cultural variables are factors with no more than a 'potential for shaping emotions'. For an event to be experienced as stressful the cultural values and meaning attached to that event must be adopted and internalized by the individual and become part of their 'goals and beliefs'. Similarly, one might expect culturally typical coping strategies to have effect only where they are appraised/experienced as effective by the individual, otherwise the strategy would amount to no more than conformity to societal expectations.

The effectiveness of coping strategies has also received attention in the literature. Lazarus (1993) described coping as both a trait, that is an aspect of personality, and a state, an action adopted to ameliorate a stress provoking situation. He suggested that different strategies will be more or less appropriate depending on the nature of the stressor. For example, it is not adaptive to try to solve a problem that is not solvable. In this situation, as indicated above, it may be more effective to reappraise the situation and/or deal with its consequences. Lazarus (1993) contends that all strategies are potentially useful if matched to a stressor. However, individuals appear to have dominant coping modes (traits). Brown (1993) described 'positive illusions' where high self esteem, strong personality, a belief in self efficacy and optimistic

attitude may lead to active coping which may be sustained despite initial obstacles. This visualization of successful coping aids goal achievement. Nolan et al (1996) point out, however, that it is possible that such 'illusions' may lead to 'delusions' in certain circumstances, manifested as unrealistic expectations and taking risks in achieving a goal.

House et al (1988) described social resources as comprising existence and quality; formal structure; and functional content. Bulmer (1987) and Forrester-Jones & Grant (1995) emphasise that functional content is the most important aspect of this model as the other two areas merely described the opportunity to access support. Nolan et al (1996) also pointed out that social support may not be entirely beneficial and may bring problems of its own. If such help is counterproductive or irrelevant its product is likely to be increased demands on the person seeking help. Accessing social support, they conclude, requires adequate negotiating skills, organisational and planning skills and possibly an amount of reciprocity from the person seeking help. This may well be time consuming and stressful in its own right.

Several studies have also found relationships between supportive or helpful social networks and decreased stress and depression (eg Frey, Greenberg & Fewell 1989). Respite care, the formal service response to allow parents relief from the daily care giving routine, has also been reported to be a critical coping resource (eg Factor et al 1990). In their model, Herman & Marcenko (1997) propose that the perceived adequacy of available resources may also be a factor in determining the amount of stress experienced. This model takes into account four different resources, namely adequacy of financial resources, time to pursue their own interests, baby sitting, and quality of respite services. They found that characteristics such as age of the child had no effect on the outcome measure of parental depression and that amount of care needed by the child was only related to distress by way of its impact on time resources.

Similarly, work recently undertaken in this country on young adults with learning disability and challenging behaviour also found that parents who reported restrictions on leisure pursuits were more likely to show symptoms of psychological distress (Kiernan et al, 1997a).

As noted, Herman & Marchenko (1997) concluded that time parents had for themselves mediated the relationship between depression and care required by the child. They suggested that respite care could affect parental stress levels by enabling them to have time for themselves but that the parents perception of the quality of the service will affect their appreciation of this time and, as a consequence, their well-being. They suggested that the parent's level of need as well as the child's needs should be taken into consideration when allocating respite services. Their study found that informal support did not negate the need for formal services but that such support may be effective in enhancing the benefits to be gained from such provision.

A review of literature concerning children with learning disability and family coping (Scorgie, Wilgosh & McDonald, 1998) concludes that families who cope effectively tend to rate highly on measures of family cohesion and hardiness. These families perceived themselves capable of meeting family needs and used creative problem solving techniques. In addition, families who cope well tended to report a healthy marital relationship, an internal locus of control, especially in mothers, and positive appraisal of their circumstances, particularly by fathers. These families, also displayed acceptance of their child's disability and had realistic expectations of their abilities. They were committed to creating an environment which facilitated the growth and development of all family members. The review concluded that those who cope successfully are also able to access resources from the immediate family, the extended family and others, which helps to ease management of both the child with disability

and the family as a whole, whilst at the same time mediating stress (Scorgie, Wilgosh & McDonald, 1998).

Coping and respite care

Respite services, as mentioned above, are one means by which agencies provide support to many parents which may help to provide time resources. Time resources enable carers to pursue their own interests, or perform tasks they are not able to do at any other time. Work in the United States by Lutzer & Brubaker (1988) suggests that the quantity of respite care desired by parents of sons or daughters with learning disability does not vary with the age of the parents. However, they did find a difference in the type of care acceptable to parents in that older parents favoured an out-of-home service, whereas younger parents were more interested in co-operative sitting arrangements where parents trade sitting arrangements with each other. One may speculate that the reasons behind these differences lie in the initial requirement for respite. Older parents in need of a break from caring in order to 'recharge their batteries' may not feel able to increase their work load at another time to compensate. Younger parents, however, may be able to make use of small amounts of free time and still have the resources, particularly physical energy, to return the favour.

Nolan et al (1996) propose that, in terms of service delivery, carer's sources of satisfaction indicate the importance of the cared for person's needs being met, their dignity maintained, and having a good quality of life. Research has found that carers find it difficult to ask for help and that services often appear inappropriate and unsympathetic (Lewis & Meredith 1989). Similarly, help may be hard to accept unless the providers are perceived to know as much about the cared for person as the carer (Tarabrerelli 1993). In terms of use of respite care, Montgomery (1995) stated that the criteria for service uptake were that the family should be

in need of help and the service they wanted was available. While this might be sufficient for many, it is arguable that carers would appreciate a respite service which offers benefits to their dependant that they are not able to provide.

The effects of service support on carer well-being has been a subject of investigation in its own right. For example, Botuck & Winsberg (1991) reported improvements in carer well-being following receipt of support services. However, there is some evidence that such improvements diminish over time (Rimmerman, 1989). Carers of adults with learning disability who lived at home found that support services did provide a very useful function in providing a break from what would otherwise have been a continuous, and potentially overwhelming, cycle of care. However, Todd & Shearn (1996) found that the support received from services was perceived as unhelpful to parents who wished to develop a 'lifestyle of significance and meaning to them'. Support services offered parents a glimpse of a non-parental lifestyle but was unable to help them achieve it. In this way services relieved parents of some of the burden of caring but at the same time highlighted the fact that they were restricted in their lifestyle.

Other work in the UK looked at the experiences of people with sons or daughters with learning disability and challenging behaviour (Kiernan et al, 1997a). This research showed that parents who felt that their social and leisure time was restricted by caring had greater problems of adjustment to their son or daughter. These parents also showed deficits on measures of mental health and stress. This would suggest that respite needs were not being met for this group.

Planning future residential care

A British study (Grant, 1989) looking into placement preferences amongst families of people with learning disability, found that a predisposition towards continuing care by family members tended to be favoured by carers who had more relatives, though fewer friends or neighbours, in their social network. These carers' families were more likely to be in manual occupations and were found to be less lonely than those who expressed a preference for placement via an agency.

In a study based on parents with a son or daughter with learning disability and challenging behaviour, including some of those who form the basis of this thesis, Qureshi (1993) found that the majority of parents (73%) expected that their son or daughter would need an alternative residential placement at some time. The largest percentage of these anticipated a need for a placement eventually, but not until they themselves were no longer able to provide care. Some of the parents interviewed stated that what they really needed was help to care for their son or daughter at home. Others commented that even if they did wish to give up caring they did not feel that there were any suitable residential facilities available for their son or daughter.

Qureshi (1993) found that the desire to find an alternative placement in the near future was not linked to the amount of distress suffered by the mother but to factors such as the mother's wish for employment and the extent to which social and leisure activities were affected. In addition, she found that a son or daughter's tendency towards uncooperative behaviour when performing personal care and domestic tasks was related to the expressed wish to give up care. The presence of self injurious behaviour was also found to be associated with a desire for alternative residential care.

In terms of service receipt, it appeared that greater amounts of respite care were related to a wish to give up caring for a son or daughter at home. Qureshi (1993) argues that such a result suggests that short term care has a 'precipitative effect' in that the break from caring that it provides allows parents to experience a life without caring responsibilities. This she proposed may be exacerbated by the situation which these parents found themselves in, of limited availability of such breaks. Indeed some parents had been asked to take their son or daughter home earlier than planned because staff had difficulties coping with their behaviour.

In a follow up to this study (Kiernan & Alborz, 1995), the factors relating to wish to give up caring in the Qureshi (1993) study were investigated in relation to actual moves. However, the factors described above were not found to be predictive. It is possible that, as in other studies described below, factors relating to planning are different to those affecting actual placement. Kiernan & Alborz (1995) found that people who were at the younger end of the age range studied (24 to 37 years), who had injured a parent, and/or whose parents perceived supervision to be a problem, were more likely to have moved.

Richardson & Ritchie (1989) suggest that there are two stages to the parental decision to seek alternative care. The first involves the recognition that the time is right for their son or daughter to move from home. The second, more practical stage, concerns seeking an acceptable placement and arranging a smooth transition. They comment that where moves occurred quickly the parents felt themselves fortunate, though there was a period of disorientation. However, they suggest that where there are a number of short respite visits to the residence the transition may be eased.

Essex et al (1997) analysed families' explanations of their decision to place their son or daughter in alternative care and found three distinct profiles. The first they describe as a 'normative launching process'. The types of reasons for placement given by families categorised in this way, emphasised the move as a means to achieve greater independence for the son or daughter. Some of these explanations also stressed greater independence for the parents themselves. These moves occurred around the same chronological age for the person with learning disability as would be the case in the general population. For example, one might take this as between 18 and 29 years. The second set of reasons indicated a 'stress process model'. For these parents the decision to use a waiting list or to place their son or daughter arose through parental ill health or age related changes in their son or daughter which meant that parents were no longer able to cope. For some families the death of the mother was the impetus. The last type of planning or placement reasoning they suggest displays anticipatory planning, a kind of 'postponed launching pattern'. For these families although the son or daughter was past the normative age for this transition, mothers were behaving proactively in seeking to secure residential provision against the time when they would no longer be able to continue caring.

The majority of Essex et al's (1997) sample avoided planning altogether, expressing a preference for keeping the son or daughter at home as long as possible and suggesting that residential planning was something for the future. In relation to the predictors found in the main analysis, they found that, consistent with the stress process model, those people with a higher number of unmet service needs and poorer health, and whose mothers had small social support networks, were more likely to have their names placed on a waiting list for residential placement. They also found some support for the 'normative launching model' as families with higher incomes in which the mother was in better health were also more likely to add

their son or daughter's name to the waiting list. However, they suggested that an alternative explanation of these findings may be proposed in that, within the 'postponed launching pattern', mothers in good health might use the waiting list as a means of proactive planning against any caregiving crisis occasioned by their own aging. They suggest that families with higher incomes may benefit from being able to access more expensive private facilities.

Bigby (1996) undertook a qualitative study of the nature and effectiveness of planning for the future for 62 older adults with learning disability in Australia. This was a retrospective study involving people who were and were not in touch with services prior to their move to alternative residential care. She found that parents involved with learning disability services were more likely to have a comprehensive plan. In families where there was a clear successor to the parent as carer, usually a sibling, more reliance was placed on implicit plans. Where there was no clear successor to the parent, they tended either not to have made any plans at all, or to have an explicit plan. The latter refers to actions such as discussions with a relative regarding the future care of the individual concerned which may have been formalised, for example, by statements in the parent's will.

For these people, in the majority of cases, the reason for moving was parental death or incapacity (55%). Nevertheless the move had been gradual for most people rather than a sudden event (49%) and had been managed informally for the majority (79%). Bigby (1996) found only five people to have experienced a sudden move and only one of these had involved emergency contact with services.

Where there was a key person to succeed the parent, and the parent was unable to manage the move, the key person stepped in and took responsibility. In many cases they foresaw the need

for a move, made arrangements and in this way averted a crisis or the need for a short term inappropriate placement. In the longer term, Bigby reported that half the sample experienced more than one residential move, with six people being moved more than four times. She concludes that, though few parents had made concrete plans, the existence of a key person who was less emotionally involved than the parents relieved them of the difficulties involved in making detailed transitional arrangements. In addition, the existence of such a person provided the security of an advocate to negotiate service provision and ensure that the interests of the person with learning disability were foremost in any decisions taken which would affect their life. This was particularly important in the light of the lack of stability of residential placements initially achieved.

Kaufman, Adams & Campbell (1991) conducted a survey in the United States to identify how many parents had made efforts to plan for their son or daughter's future residential care needs. They found that just over half of respondents had made no plans whatsoever, and that those who had plans had, for the most part, not fully formed or developed them. The family characteristics which related to lack of planning were higher frequencies of contact with extended family and friends and a lower family income. This finding mirrors that of Grant (1989) mentioned above which indicated that families from manual occupational groups, who had greater numbers of people in their support network, expressed a preference for their son or daughter to continue to be cared for by a family member.

Bromley and Blacher (1989) in a study of factors which delayed parents' decisions to seek alternative residential care for their children found that feelings of attachment and guilt about relinquishing care was most widely cited as the reason for the delay in seeking alternative care, particularly for the parents of the older children. Placement was often viewed as an admission

that the parent could not cope with the child at home and therefore must have failed at child rearing. They found that many parents acknowledged that supportive services were helpful in relieving stress or burden of child care but it was not widely considered to substitute for the need of an alternative residential placement.

Factors relating to placement

Current policy supports the position that children with learning disability should spend their lives in the family home. However their continuing development and changing needs through early childhood towards adolescence can put considerable strain on the family (e.g. Krauss & Seltzer 1993). Research findings have suggested that being older and having a more severe learning disability were predictive of placement (Meyers, Borthwick & Eyman 1985). Other studies, using samples ranging widely in terms of age, have suggested that characteristics such as behaviour problems, age, ethnicity, medical problems, mobility, continence, or speech were considerations in the decision to place a person outside home (Borthwick-Duffy, Eyman & White 1987).

Investigators have found placement more likely if parents are elderly or report poor health (e.g. Suelzle & Keenan 1981). However, Hanneman & Blacher (1998) in a longitudinal study of actual placement of a group of children, studied a range of factors that might be considered to be influential in consideration of, and actual placement in, alternative residential care. These factors included characteristics of the child, such as age and gender; socio-demographic characteristics of the parents; quality of the home environment; family and child adaptation; the degree of perceived stress on the family and caregiver; and social and financial support.

Hanneman & Blacher found that actively considering placement, though an important influence on actual placement, was not related to placement in any straightforwardly predictable way. Placement bore little systematic relationship to support received or to child characteristics. More serious consideration of placement was evident where a parent perceived that the child was directly or indirectly having a negative impact on the family. In addition, more serious consideration was given to placement where there were additional children in the family or where the mother had greater socioeconomic resources.

Freedman, Krauss & Seltzer (1997) reported that having a residential plan for an adult son or daughter resulted in a higher probability of placement but did not guarantee that placement would occur. Indeed placements were found to occur even in the absence of a plan. They reported that parents of adults with a severe or profound level of learning disability were less likely to plan for the future than those whose son or daughter had a less severe learning disability.

In a longitudinal study of residential planning and placement in the United States, Essex, Seltzer & Krauss (1997) emphasise that planning is a process and not a discrete event. This process they believe is subject to change especially in the light of the stages of the family life cycle (Blacher & Hanneman, 1993; Tausig, 1985). Essex et al (1997) found that a greater number of unmet service needs and poor health of the son or daughter with learning disability was predictive of joining a waiting list for residential placement. In addition, a small social network and better maternal health were also predictive of waiting list use.

However, for actual residential placement the main predictors were firstly having the son or daughter's name on the waiting list, but also poorer maternal health at Time 1 and having a

son or daughter who was older. In their examination of the relationship of challenging behaviour to residential placement the number of challenging behaviours was not predictive of being on a waiting list nor living away from home.

A study of carers who had placed an elderly relative into nursing home care in either the US or UK, found a significant number of carers felt that decisions about placement had been left until they could no longer cope with the situation. In both countries carers had not had sufficient time to discuss events thoroughly or to feel that they had fully participated in the placement process. There was a lack of information about types of placement and what constituted a 'quality' facility (Dellasega & Nolan, 1997).

The literature reviewed in this chapter identified a wide ranging sweep of factors which may be influential in making a decision to place a son or daughter with learning disability into alternative care. The aspects covered reveal the complexity and intricacy of the relations not only between carer and 'cared for', in this case a person with learning disability who also has challenging behaviour, but between members of the nuclear and extended family, as well as previous generations and contemporary societal values. This web of interactions affects and is affected by each person it connects. A full understanding of the influence of each factor on the individuals involved is likely to be advanced by adopting a multidisciplinary approach to human research questions.

4 *Synthesis and Discussion*

There is general agreement in the growing research into the nature of caregiving. Recent work by Nolan et al (1996) extends a five stage model proposed by Bowers (1987, 1988) which proposed that anticipatory, preventative, supervisory, instrumental and protective/ preservative

care describe the wide range of tasks undertaken by carers. The Nolan et al model concurs with this proposal except in the chronicity of the stages. Their model proposes that, in particular, anticipatory care will be in evidence throughout the caregiving period, though the subject may change over time, as opposed to the Bowers' conceptualisation of a short-term, preliminary stage, occurring before the caring relationship has begun. Nolan et al also extend Bowers' model by adding the concept of (re)constructive care, where the carer enables their dependant to continue to use previous skills / abilities and, where these have declined, promotes the adoption of new challenges. A strength of the Nolan et al model is that it appears more comprehensive and may generalise more widely to different carer groups.

Many researchers stress the importance of taking the positive aspects of caring for a relative into consideration when researching the carer / cared for relationship (e.g. Grant et al, 1998; Turnbull et al, 1986; Heller et al 1997). Many more have researched the benefits that carers' derive from such a relationship in terms of personal development and sense of satisfaction (Davies, 1980; Pearlin et al 1990; Clifford, 1990; Beresford, 1994). Satisfactions derived from caring are said to include those which stem from acts which are intended to benefit the dependant person, and those conducted as an 'expression of love' (Abrams, 1985; Nolan et al 1996). Several researchers emphasise the 'hypothetical exchange' of benefits derived from the belief that, were roles reversed, the dependant would provide the same kind of care for their carer (Bulmer, 1987; Hirschfield, 1981, 1983; Finch & Mason 1993; Nolan et al, 1996).

However it appears that caring for a person with low levels of functioning may have differential effects on the carer. Heller et al (1997) report that caring for a person with lower levels of functioning was associated with higher levels of carer satisfaction. Hayden & Goldman (1996), however, report that lower levels of functioning was related to higher levels

of stress in mothers. These studies appear contradictory but one may speculate that positive and negative outcomes may occur concurrently as, for example, in sport, where the satisfaction of running a race well may also be accompanied by the effects of the bodily stresses the race itself inflicts. The carers of people with lower levels of functioning may indeed suffer greater levels of stress related to the physical and mental demands of their relative's care. However, as discussed in some of the literature above, this stress may be dissipated to an extent by the satisfaction experienced by the carer through personal development and provision of 'high quality' care.

The pattern of relationships within a family may be influenced by past and present family composition and experiences, as well as those from the wider community. The literature reviewed above gives a picture of family life evolving through its own 'life cycle' (Olson et al, 1984) but throughout being influenced by family history (Bowen, 1966; Lieberman, 1979) as well as interactions between family members themselves (Bowen, 1966; Minuchin & Fishman, 1981; Turnbull et al 1986). Research has suggested that stress may be experienced when families negotiate the transition between stages in the family 'life cycle' (Olson et al, 1984); especially when such changes are 'non-normative' (McCubbin et al, 1980); occur 'off-time' (Neugarten, 1976); and, for families with an adult son or daughter with learning disability, there is a lack of the usual 'markers' of adult independence (Turnbull et al 1986).

Research has also centred on the factors that influence families, or more particularly the main carer, to continue to care rather than seek an alternative placement. As mentioned above, one of the influences may be the personal satisfaction derived by the carer from the act of caring (eg Heller & Factor, 1993). Townsend et al (1989) suggested that long term care results in better adjustment to the caregiving role. This may be viewed as an acceptance of the situation

and adaptation to a different way of life (Kiernan & Alborz, 1995). Other researchers suggest that over time the stresses associated with caring deplete the physical and psychological resources of the carer (Johnson & Catalano, 1981). Again, although these outcomes appear contradictory they are not necessarily mutually exclusive. It would appear possible to fully adjust to the caregiving role, but nevertheless experience negative physical and / or mental effects associated with the demands of caregiving. However it has been suggested that high levels of stress over time do affect the carer's ability to continue in that role (Parker, 1990). Motivations to continue, such as keeping the person 'out of an institution' or rejecting other forms of residential care because it falls below the carer's own standards, have been suggested (Nolan et al, 1996) and are likely to be a factor in such considerations.

Models of stress and coping have developed over time from basic stimulus-response models (Holmes & Rago, 1967; Robinson, 1983) through more complex stimulus-response models with associated temporal dimensions (Dohrenwend & Dohrenwend, 1974). However, these are largely seen as too simplistic to reflect the interplay of factors associated with the experience of stress and related attempts to restore equilibrium (Antonovsky, 1987; Nolan et al, 1996; Lazarus, 1999). Transactional models of stress and coping have sought to address this more complex interplay of factors involved in the experience of stress and acts of coping (McCubbin & Patterson, 1983; Folkman & Lazarus, 1984). Major tenets of the transactional model of stress and coping are the roles played by both subjective cognitions related to the potentially stressful event and the personal resources available to facilitate effective coping. There is a growing body of literature on the nature of the correlates of stress and of resources which act to buffer against its effect. Sloper & Knussen (1991) suggest that resources act as both resistance to as well as risk factors for stress. That is, possession of a resource provides

strength through which one may cope effectively, whilst lack of that resource acts as a weakness laying the person open to stress related deficits due to an inability to cope.

There has been wide acceptance of the transactional model as a basis to investigate levels of stress experienced and effective coping in caring relationships (eg Sloper & Knussen, 1991; Sloper & Turner, 1994; Kiernan & Alborz, 1995; Nolan et al, 1996). Coping resources have variously been described as *intra-personal*, that is physical, ideological and spiritual (eg Sloper & Knussen, 1991), and based on past experience (Koch-Hattem, 1987; Quine & Pahl, 1991); *inter-personal*, that is involving spouse, network or agency support (eg Dunst et al 1986); and *material*, that is financial and temporal (eg Agosta, 1989).

Several researchers emphasised the importance of time resources (eg Agosta, 1989; Factor et al 1990) manifested in the ability of carers to deal with matters outside those generated by the caring role, and to have enough time to follow leisure pursuits (Todd & Shearn, 1996; Kiernan & Alborz, 1995). Other correlates of high stress levels have been found to be lone parenthood, higher levels of disability requiring greater levels of personal care and supervision (Hayden & Goldman, 1996; Factor et al, 1990; Agosta 1989; Bristol & Schopler, 1984), poor carer health (Hayden & Goldman, 1996; Zarit et al, 1986; McGrother et al, 1996), greater number of behaviour problems, and greater unmet need for services (Hayden & Goldman, 1996). Conversely, higher levels of respite care, financial assistance, and support from a social network (Factor et al, 1990; Agosta, 1989; Frey et al 1989) were found to relate to decreased stress levels. Some researchers point to increasing demands made by caring for a child growing towards adulthood as contributing to higher stress (Bristol & Schopler, 1984). These studies are largely complementary, however it would appear that there is some way to go in establishing how these resources relate to each other and / or to particular groups in society.

There is already some evidence of difference based on socio-economic status, as discussed below.

Coping as a process has been widely studied in its own right. Lazarus (1993) described coping as both a trait and state and much of the research reviewed here appears to fall under these two headings. Although viewing predominant use of a particular coping style as a trait is widespread in the literature, Lazarus (1999) prefers to view coping as a process, changing with the nature of each stressor. He admits however that taking this approach in isolation would possibly be too situation specific.

'Strategic thinking' is said to be constrained by the values, predispositions, and inner resources of the individual (Dill & Feld, 1982). Coping as a state, or coping attempt, has been described as being emotion focussed, that is, taking effect within the individual at the cognitive level, and / or problem focussed, that is external to the person and aimed at physically changing the environmental stimulus which is the source of the stress (Lazarus, 1993). Beresford (1994) provides a slightly different interpretation of these terms. She describes emotion focussed coping as being directed only at the somatic/feelings level within the individual, in an attempt to ease physical symptoms of distress. Problem focussed coping she describes as relating to both internal and external action by the individual to alter the person-environment relationship causing distress, this includes reappraisal of the stressful event. Lazarus (1999), states that emotion focussed coping strives to 'regulate the emotions' (which one might characterise as to 'calm down') by changing the *meaning* of the person-environment relationship or avoiding it. Both definitions emphasise the intra-personal nature of emotion focussed coping, but the Beresford definition centres on acceptance of the event and alleviation of symptoms, whereas Lazarus' definition emphasises cognitively 'changing' the event such that it is rendered non

(or less) threatening. As stated above, this coping strategy is defined as 'problem focussed' by Beresford. The distinction is subtle and this strategy may be seen as equally attributable to either coping type where emotional control is seen as the means and target of the coping attempts.

Coping traits have been related to a variety of outcomes. In particular, practical coping has been associated with satisfaction with life, and wishful thinking with poor mental and physical health (Sloper & Knussen, 1991). Other studies concentrate on the use of coping strategies. For example the use of passive acceptance which appears adaptive when a problem cannot be resolved, or the use of culturally appropriate strategies (Nolan et al 1996). However, there would appear to be an issue regarding whether an 'appropriate' response is necessarily an 'effective' one. Lazarus (1999) comments that cultural values may only be considered an influence on coping when they have been adopted by the individual and become part of their own goals and beliefs. Other researchers have found effective coping related to family cohesion and hardiness, perceived adequacy of resources, acceptance of disability and realistic expectations, as well as access to social support (Heller & Factor, 1993; Scorgie et al 1998). However, it appears that information on potentially useful strategies per se only provides a starting point for individuals from which they may develop their own successful coping attempts. Many factors appear to influence effective coping, as described above, and therefore it would not appear possible to be prescriptive in such matters. Nevertheless, two resources were examined in greater detail because of their significance and reported usefulness in the literature. Social support and respite care have both been cited as useful buffers to stress and consequently they are important factors in enabling carers to continue to cope successfully with their caregiving role.

Social support

Social support has been widely investigated both as a buffer between the experience of stress generated from the caring relationship, and as a backdrop against which norms and values are established (Gourash, 1978). The number of people who may be counted as within a network is said to be potentially limitless. Studies, therefore, tend to investigate 'active' network members (Glendinning 1983; Grant, 1986). Membership of social support networks are said to be rarely static, decreasing over time with some replacement of members lost at the outer edges. Formal support has been found to replace some such members but more usually in families with a dependant who has severe physical limitations. However, formal assistance was found to be no more likely in families where there were higher care demands occasioned by challenging behaviour than in other families with a member with learning disability (Grant, 1993). Research has shown that only about one fifth of the people in support networks provide support on a day to day basis (Wellman, 1981). However, several studies of the experience of carers of sons or daughters with learning disability have found that support to the main carer, usually the mother, is extremely limited. Some support tends to be provided by a spouse but very little by siblings, even where they live in the same household (Prosser & Moss, 1996; Grant, 1993, Qureshi, 1990).

On the whole, support provided by members of the wider network of family and friends is seen as beneficial and associated with carer well-being and positive attitude (Gourash, 1978; Dunst et al, 1986), but Grant (1993) points out that such help may not be universally reliable, effective, helpful or long term. As the evidence suggests that significant support to carers of people with learning disability is rare (Qureshi, 1990; Prosser & Moss, 1996), the related benefits or costs of such support may be of marginal relevance to this study group.

Respite care

Respite care has been found to be beneficial due to its effect on time resources for carers and consequent opportunity to develop a lifestyle of significance and meaning to them (Todd & Shearn, 1996). The literature emphasises the carers' concern for the quality of care provided by respite services and the level of interest displayed by staff for their relatives well-being (Lewis & Meredith, 1989; Taraberrilli, 1993). Indeed the take up of such services has been shown to relate not only to need, but to the availability of provision which is perceived as acceptable (Montgomery, 1995).

Several studies have focussed on the relationship between respite care and the subsequent decision to place a son or daughter with learning disability in long term alternative provision. Contrary to expectations higher levels of respite care have been found to relate to a desire to place the person with learning disability into alternative care sooner rather than later (Qureshi, 1993), or to be helpful but irrelevant to the need for placement (Bromley & Blacher, 1989).

Moves to alternative residential care

In terms of studies relating to moving from the family home, there appears to be a limited amount of research available. Richardson & Richie (1989) proposed that achieving a move from the family home to alternative care is a two stage process. The first stage involves recognition that the time is right to consider a move, and the second an active search for a suitable placement. However, the research reviewed above suggests that the factors involved in the decision to plan a move, or to place a son or daughter's name on a waiting list, are different to those which are involved in actual placement. The evidence appears to suggest that those from manual occupations or with lower incomes are less likely to plan and, for the most part, more likely to rely on a larger network of family members for continuing care of

their son or daughter within the family (Grant, 1989; Essex et al, 1997; Kaufman, Adams & Campbell, 1991). For families with higher status occupations, mothers who wished to work and/ or smaller social networks, there was greater expectation that a placement would happen sooner and that care would be provided by an agency (Grant, 1989; Qureshi, 1993; Essex et al, 1997). Overall, however, there appeared to be avoidance of planning, with the majority of those surveyed having no plan (Qureshi, 1993; Kaufman et al, 1991), or plans that were not fully formed (Kaufman et al, 1991; Bigby, 1996). As indicated above however, planning has not been found to relate to placement in any direct way (Freedman et al, 1997; Hanneman & Blacher, 1998; Kiernan & Alborz, 1995).

In terms of actual placement there appeared to be general agreement that moving from home was likely to be occasioned by the poor health or death of the main carer (Essex et al, 1997; Bigby, 1996; Suelzle & Keenan, 1981). Other researchers found that older sons or daughters with learning disability were more likely to be placed (Meyers et al, 1985; Essex et al, 1997), as well as those with more severe learning disability (Meyers et al, 1985; Borthwick-Duffy et al, 1987). The number of challenging behaviours exhibited was not found predictive of a move by Essex et al (1997) or Kiernan & Alborz (1995) in a study based on people identified as showing challenging behaviour in service settings. However, contrary to many studies the latter researchers found that younger members of the group studied were more likely to have moved. Studies of children with learning disability suggest that increasing strain is put on family life in coping with the demands as a child grows towards adolescence. As a group the number of people with learning disability who show challenging behaviour is small, representing only about ten to fifteen percent of the population as a whole (Emerson et al, 1997) and issues affecting them may therefore be masked in population research. One may speculate that, for some families, it may be difficult to cope with a persistent behaviour

problem when it is displayed by a young adult. It is possible that for some in the Kiernan & Alborz group, who were all in early to middle adulthood, challenging behaviour may have a particular influence on family life and placement in alternative residential care in early adulthood reflects this. The study found placement related to injury to a parent and to problems in supervision of the person with learning disability. These may be characteristics peculiar to groups of people with learning disability and challenging behaviour that are associated with early placement in alternative care.

Essex et al (1997) proposed a model for the process of placement in which they described three distinct profiles. These included 'normative launching', where the person moves from home at about the same time, and for similar reasons as most members of society; a 'stress-process model' of placement, where placement is precipitated by a crisis within the family; and a 'postponed launching' where, although placement occurs later than for most members of society, it is used as a precautionary strategy against the time when the carer may no longer be able to cope. One of the aims of this thesis is to examine the applicability of these categories to families with sons and daughters with learning disability and challenging behaviour.

The complex interplay of personal, social and material influences outlined above is conducted within a wider political context regarding individual rights, and access to and availability of resources through which family care may be maintained and alternative care achieved both in the short and long term. Chapter two, addresses these 'macro' influences on family decisions regarding care and placement.

Chapter 2

Service provision and policy developments affecting people with learning disability and their carers

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Chapter 2

Service provision and policy developments affecting people with learning disability and their carers

Growing recognition of the importance of carers as a group in the UK, USA, and other countries with 'developed economies', has led to the development of policies to acknowledge their value and input, and to provide support. At the same time there have been developments in legislation on the rights of people with 'mental incapacity', their rights as citizens and, in particular, the importance of obtaining informed consent in matters concerning them wherever possible. This chapter describes these developments in the UK and examines the effects these issues may have on carers now and potentially in the future.

1 Carers and the service system

As described in Chapter One research into caring over the past fifteen years has provided a comparatively clear picture of the type of support carers give and an indication of the support they require. Twigg & Atkin (1994) suggest that carers need to be seen in the wider context of service provision, however they emphasise that caring arises as part of a deep relationship such as marriage, parenthood or kinship. In such circumstances the carer feels responsible and obliged to give care and therefore this is not a strictly voluntary relationship. As the caring role is one aspect of a much deeper relationship, they argue that carers carry on caring even when it is against their own interests to do so and because of this agencies have a moral, rather than straightforwardly instrumental, duty to them. Sentiments of this kind have now been acknowledged in the recommendations of the National Carer's Strategy (Caring about Carers, 1999 - see below).

One service seen as providing benefit to carers in a direct manner, as mentioned above, is respite care. The most common form of such care in the past has involved the person with learning disability staying away from home overnight. However, Twigg & Atkin (1994) found that respite received by carers was often a by-product of provision aimed at enhancing the life of the person with learning disability. Respite for the carer was not an openly recognized aim of the service. Rather, they were seen as part of the 'taken-for-granted' background to provision. Twigg & Atkin (1994) state that carers accepted this and recognized the benefits gained by the person with learning disability, however they also acknowledged the benefits to themselves in terms of relief from the responsibility of caring.

The Twigg & Atkin (1994) study also found that direct social work input was rare and that there was little evidence that social workers acted as a link to other services or provided a sounding board reflecting the views of carer and person with learning disability. Their main role was in obtaining placements in day or overnight care facilities and, once this duty was fulfilled, contact ceased.

Interviews with service providers revealed that it was carers who were assertive who obtained help. Resources for service delivery were short and aims of the service 'vague and unachievable' with few guidelines on priorities. Twigg & Atkin (1994) found that service providers tended not to seek out cases, responding, in general, only to those who 'made themselves visible'. This was not seen as an ideal situation but was nevertheless accepted as a fact of life in the way services respond. A more assertive attitude was something that service providers wished to encourage in carers. However only some were able to achieve this. Generally the limits on resources available meant that they could not afford to do so.

On the whole, service providers avoided case-seeking and did not actively promote use of their service. The requirement was for carers to continually reassert their needs or services would be withdrawn. However, services did respond to distress in the carer where this became known to them. This role was one that services were happy to adopt as a guiding principle but it was not pursued to the extent that any kind of monitoring of the family situation took place. One of the services with more global approval was that of provision of respite care so that the carer could have an occasional holiday. Responding to one-off special needs was something agencies were able to do, unlike the provision of services that required continual input (Twigg & Atkin, 1994).

Twigg and Atkin (1994) comment that carers have arrived late on the scene of service delivery and consequently, where their needs have been met, it has tended to be through use of 'marginal' resources. They quote the example of overnight respite care, which is often provided out of spare resources in residential homes or in hospitals, and carers groups which similarly arise out of marginal resources and the good will of particular practitioners. Such marginal provision can be problematic, however, when for example respite care is provided in places which are not adapted to the needs of users or provision is erratic and unreliable.

More recently the government has published a Charter for long term care (Better Care, Higher Standards, 1999) in which they specify the standards that people with long term needs, including those with learning disability and their carers, should expect in terms of care or support from their local housing, health, and social services. The Charter promotes target setting by local service providers for informing users and carers about provision; for understanding and responding to their needs; for provision of a suitable place to live; for helping the disabled person to stay, or in the case of a person with learning disability become

independent; for provision of the right health care; and for helping 'carers to care'. Charters are seen as a way of trying to ensure consistency in service delivery across the UK. They also aim to promote user and carer involvement in decisions about the services they receive, to encourage service providers to act in a more coordinated fashion, and to make availability clear.

The emphasis on providing people with disabilities and their carers with clear information about what is available, who can obtain a service, and involvement in decisions about provision of services is to be welcomed. The Charter addresses the lack of clarity in aims and the responsive, rather than proactive nature of service provision in the past, highlighted by Twigg and Atkin (1994). It gives service providers a clear signal that it is part of their role to make sure that their target client group is made aware of, and helped to use, the resources available. However, the Charter does not guarantee that better or more abundant provision will be provided.

2 Legal status of Carers

The legal status of carers has become an important issue because of a major shift in policy and practice in the care of people with learning disability which has taken place over the past twenty five years. Since the 1971 White Paper 'Better Services for the Mentally Handicapped' was published there has been an increasing move towards care for people with learning disability away from large institutions and towards smaller residential homes. An underlying tenet of this policy was the continuing support of people with learning disability within the family home providing 'this does not impose an undue burden on them or him and he and his family should receive advice and support' (HMSO 1971, Cmnd, para 40). Subsequently, the NHS and Community Care Act (HMSO, 1990) formalised the aims of prior policy directions

to provide suitable care in the community and gave carers the right to be involved in the process of planning care.

This Act acknowledged that carers play an important role in the provision of care and that successful implementation of the Act would depend on statutory service providing assistance and support to carers through advice and practical services. Subsequently, in recognition of the importance of their role, The Carers (Recognition and Services) Act 1995 came into force in April 1996.

The Act gave legal recognition to all carers, including those looking after a person with learning disability, and brought them formally into the local authority assessment processes for community care services. This means that local authorities have to assess a carer's needs alongside those of the person they care for. The term 'carer' for these purposes does not include a person paid to care, or one who does so in a voluntary capacity. It does require that care should be 'substantial' and 'regular'. However, the exact definition of these terms was left to each local authority to decide. Carer and cared-for assessments have to take place at the same time to ensure that both are taken into account in the allocation of services. These assessments are meant to be reviewed on a regular basis and whenever a significant change takes place. Such a change might, for example, be in a carer's ability to continue caring, which constitutes a change in circumstances warranting reassessment (Community Living 1996).

'Caring about Carers' (Feb 1999)

In recognition of the fact that one in eight people in Britain is a carer, and that without this massive informal care support system many people would need the support of statutory

services, possibly to the detriment of the quality of life of the cared for person and at considerable cost to the taxpayer, the government has introduced a national strategy to support informal carers. Their document 'Caring about Carers' (1999) states that the government values carers and will support them in this role.

They emphasise that those who provide the wide range of benefits and services available should not neglect the carer and their needs whilst meeting the needs of the cared for person. They go on to state that they recognise that caring is founded on close relationships and is often undertaken through choice. Their stated objective is '*to support people who choose to be carers*' (p13, para 10 - italics added). This phrase appears to overstate the voluntary nature of caring for dependant relatives for a large number of families. For example, parents whose child is born with a disability are not presented with a choice whether to care or not, but few would reject their son or daughter because they were born with exceptional needs. One assumes that use of this ambiguous phrase is unintentional as the text does refer to parents caring for a son or daughter with a disability. However it remains that such a phrase might be used to prioritise assistance, for example, to those who care for an elderly relative (i.e. where care is not strictly duty but more a 'noble deed', no obligation involved) over those who care for a son or daughter who has a disability (i.e. where care may be seen as 'same as' in any other family and to be expected, obliged). This interpretation would have the added benefit of being a comparatively short term commitment to a carer as an elderly infirm relative is unlikely to live as long as a healthy but learning disabled 20 year old.

The Government's strategy has three key aims. Firstly to provide

'information for carers, so that they become real partners in the provision of the care to the person they are looking after, with the means to provide that care as well as

they all wish to, and with wider and better sources of information about the help and services which are available to them'.

Secondly, to

'support carers, from the communities in which they live, in the planning and provision of the services that they and the person they are caring for use, and in the development of policies in the workplace which will help them to combine employment with caring.'

This appears to preclude development of entirely new forms of support for carers in terms of services and only to enhance or improve what is currently available.

Thirdly, they aim to

'care for carers so that they can make real choices about the way they run their lives, so that they can maintain their health, exercise independence, and so that their role can be recognised by policy makers and the statutory services.'

The main tool to achieve the latter appears to be an array of 'respite' services to enable carers to take the time to fulfill their own needs. The government report states that this will be addressed by empowering carers to make more choices for themselves and have more control over their lives. However they also point out that the needs and wishes of one of the parties in the caring relationship should '*not be prioritised*' (p14, para 13 - italics added) over the other. One can envisage that this may lead to serious situations in which stalemate prevails (see below).

The report acknowledges that the caring relationship develops out of pre-existing bonds of affection, a wish to reciprocate, and duty. It acknowledges that there may be pleasures as well as burdens associated with caring. However it also acknowledges that motivation to continue caring may be influenced by a lack of good quality alternatives to living in the family home, as well as social pressures.

The document describes the end of informal care, which may occur for a wide variety of reasons, and suggests that there is a role for professionals in facilitating the end of the caring role. One way in which the strategy hopes to 'rebuild' carers' lives when that role is ended, is by assisting them to return to work, via training if necessary, however they also quote the peak age for caring as between the ages of 45 and 60. It is difficult to see a person over the age of 60 having a decent chance of employment in competition with younger unemployed people, despite many years working hard as a carer. They may, in fact, consider themselves unemployable or 'burnt out'. Future entitlement to additional pension payments to carers, to be introduced by 2050, is announced in the document, but will, it appears, be of no use at all to any carer currently over the age of 15.

The strategy document encourages statutory services to collect information about carers and their needs in their locality, so that they may respond with relevant and targeted information. It calls for a partnership to be developed between carers and services based on 'respect and recognition of carers in their own right'. However, it might be appropriate that this 'partnership' should encompass respect and recognition between services, carer, and *cared for person*, to the extent that the latter are able to participate in decision making. The report also states that carers' needs, including their health and ability to continue caring, should be assessed and met with regard to their wishes. However it also points out that although

assessment by social services is a formal process laid down in legislation, this is not the case for the health services. It is only '*recommended*' that health professionals locally should be aware of the carers' health needs and how they can be helped.

The document reasserts the recommendations of the Carers (Recognition and Services) Act 1995 which gives people who provide 'substantial care on a regular basis' the right to request an assessment in their own right from social services. It reports that implementation of this Act is patchy, though carers report satisfaction with the assessment and results where these have taken place (Carers' National Association, 1996). As mentioned above, Caring about Carers states that carers should be entitled to a discussion of their needs. These discussions should take place at least yearly and should focus on the services they are receiving as well as those generally available. It concludes that informing carers involves provision of the right (general and individualised) information, in the right form and at the right time. One hopes that implementation of the latter requisite will mean that such information will be updated regularly and emphasise the importance of provision of general information. It is only with access to such information that a carer may identify assistance appropriate to their circumstances. That is, if they do not recognise that they have a need which can be remedied they will not seek assistance for it.

Caring about Carers emphasises that carers should be involved in service planning or provision but that this should achieve something for them also. More specifically it was proposed that local and health authorities follow a series of steps . . .

- identify carers in the area and their needs
- establish which services are already available and the extent to which they are used
- involve carers in assessments, or ask them to *assess their own needs* (italics added)

- ensure carers are fully briefed about meetings they are being invited to attend
- communicate regularly and routinely with carers and their organisations
- make sure that the times and locations of meetings suit carers

The steps show a willingness to allow for the limitations placed on carers by the act of caring. The government acknowledges that some carers may not wish to be fully involved in planning and/or provision of services, but suggests that they may respond to strategies such as the use of comment cards for evaluation of services that are home based. However suggestions that carers might assess themselves, though probably cost effective in terms of staff time, travel, and speed at which assessments may be undertaken, seems to underestimate the extent to which carers may need guidance or assistance with the process. This could lead to under reporting of types of need the carer may consider cannot be remedied or, indeed, may not identify. It would seem inappropriate to adopt this approach except under extremely unusual circumstances.

The strategy aims to support carers in terms of their own health needs. The report states that more than half of carers suffer, or have suffered, some kind of physical injury or stress-related illness (Henwood, 1998). However it goes on to state that the evidence on whether carers have more or fewer health problems than other people of the same age is not conclusive, older people being particularly prone to physical injuries in general. The document suggests that, as the majority of carers are in touch with a GP and significant numbers are in contact with other community health professionals, the opportunity should be taken to review the carer's health. It suggests that these health professionals should assess the carer's ability to undertake the kinds of task which their role demands both in terms of physical capacity and emotional or mental health needs.

The report admits that the way current legislation is laid out prevents carers from obtaining help in their own right from the NHS, and as such they are undervalued. The Government intends to legislate so that carer's needs are addressed more directly when Parliamentary time allows. However, this may mean that such legislation is some way off and that there will be no change in the foreseeable future.

One of the key services through which the government believes that carers may live a healthier and more fulfilling life is that which gives them the opportunity to 'take a break' when needed. They suggest getting away from the term '*respite*' and emphasise '*breaks*' which are positive and fulfilling experiences for both the person needing care and the carer. Specifically, they emphasise that, for example, sitting in so that a carer may attend the dentist should not be defined as 'a break'. There is also encouragement for statutory authorities to act *proactively* in the provision of breaks, and in doing so, to assess the requirements of both carer and cared for in this regard. Feedback about the success of the break is also encouraged, and is suggested as a contractual requirement.

In recognition of the fact that caring for another person may result in the carer becoming isolated because they do not have the opportunity to leave the house, the report suggests that *outreach strategies*, through a variety of means should be implemented, or extended, to provide the types of information, training or support that carers may need. This would be a major shift for service providers who, on the whole, previously tended to act only in response to a request, or crisis in the family. Although the document announces the allocation of a 'ringfenced' grant for the development of these services over a three year period, it is of concern that, due to longer term resource constraints, the aims of the strategy may be undermined. Suggestions for the implementation of support schemes for carers put a heavy

emphasis on the use of volunteers to provide a workforce in the provision of services. This may lead to schemes of varying quality, quantity and effectiveness, as the number and availability of volunteers, as well as their personal qualities and commitment may vary. If this is the case it is questionable whether this would be fair on any of the people involved.

The Government recognises that the initiatives outlined in the report are only a start but states that carers' needs are to be taken into account in all policies, and promises to follow up with the action required to implement the new initiatives.

Residential care provision

One of the key services underpinning the above strategy is the provision of 'breaks' for carers. However, for families with a son or daughter with learning disability there is often a need for a more permanent arrangement in the long run. The availability of such provision is, inevitably, a major issue. Advances in health care and the ageing of the baby boom generation have coincided to produce an increasing number of people with learning disability surviving into adulthood (e.g. Parrott et al, 1997). As stated above, parents are faced with a continuing parental role past the time when their son or daughter would have achieved independence had they not had a learning disability. In addition, adulthood is achieved at a time when parents themselves may be beginning to experience age-related problems with their own health.

Prevalence of learning disability in the general population is given as approximately 3 or 4 per thousand. Of these about 52% are male (e.g. Katusic et al, 1995). However the incidence of severe learning disability has been shown to be greater in females. A population study by Katusic and colleagues (1995) found the incidence to be more than twice that for males. Level of intellectual ability necessarily has implications for the level of care required, and possibly

the type of challenges the person's behaviour presents. Studies have found an incidence of challenging behaviour in between 10 to 15 percent of the population of people with learning disability (Emerson et al 1997). In addition, studies such as the 1988 and 1995 surveys by the Hester Adrian Research Centre provided data which showed that almost twice as many males were likely to be identified as showing challenging behaviour as opposed to females (1988 N=695 64% male; 1995 N=297 66% male). Any population of people with learning disability and challenging behaviour will therefore be predominantly male and this may make the characteristics of the group different to that of the general population of people with learning disability.

The majority of parents can now expect to be survived by their son or daughter with learning disability (Janicki & Wisniewski, 1985). Consequently two issues are of great concern to them, that is, providing adequate care for as long as possible, and making plans for the care of their son or daughter when they are no longer able to do so (e.g. Heller & Factor, 1993). From a services perspective, the current policy of encouraging informal carers to continue caring for their sons and daughters into adulthood has probably averted the need for extra residential provision in recent times (McGrother et al, 1996).

In an epidemiological study of residential demand for people with learning disability, Parrott, Emerson, Hatton & Wolstenholme (1997) described the potential demand for services based on information derived from the Sheffield Case Register. This register, established in 1974, gathers information every two years for children and every five years for adults. In addition, it collects returns from services yearly, or monthly in some cases, on all people identified from a variety of sources, including clinical and service based, as having a learning disability.

This register revealed an overall prevalence of 4.5 cases of learning disability per 1,000 of the population. The register also provided information on the age on uptake of residential provision for people with learning disability by level of disability. Similarly, it also provided figures on ages of carers. Level of disability was defined as *severe disability* (i.e. severe incontinence, severe behaviour problems, partial mobility with severe incontinence and severe behaviour problems, or non-ambulance alone), *moderate disability* (i.e. as before except that difficulties were mild in nature, or partial mobility alone) and *most able* (i.e. there were no incapacities of the types listed).

Parrott et al (1997) found that the median age for entrance to residential accommodation over a ten year period (1985-1995) for people with severe disability was 21, whereas for people with a moderate level of disability it was 37, and for the most able 35. The corresponding median ages of carers were 52 for those with a son or daughter with a severe disability, 69 for those with a son or daughter with a moderate disability, and 68 for those of the most able. These findings show that placement into residential care tended to occur at a younger age for parents and sons and daughters who had severe learning disability and associated problems. The median ages for the moderate and able groups being very similar.

It is estimated that there is a shortfall in available places for people with learning disability of approximately 25,000 in the UK (Emerson et al, 1996). In the context of likely general increased demand outlined above, this is likely to mean that, in many areas of the country, statutory services may give low priority to proactive residential planning with families. Lack in provision of this nature would make a nonsense of assessing parents' ability to continue caring because there may be no alternative for the foreseeable future.

3 Legislation on Mental Incapacity

On another plane, it has become widely recognised that there needs to be some clarification in law around the issue of who makes decisions for people who may not be able to decide for themselves. Historically, parents have cared for their son or daughter with learning disability into adulthood on the assumption (and on the whole quite rightly) that, as a parent, they knew the person best, had their best interests at heart and, therefore, made good and reasonable decisions about their welfare. However there is no legal basis to this state of affairs.

The Law Commission (1995) in their report on this matter state that although there is some legislation about making decisions regarding people who are 'mentally disordered' within the Mental Health Act (1983) the scope of such decisions is limited and, in terms of a guardian to oversee the care and treatment of people unable to care for themselves, constrained to people who show serious levels of aggressive or irresponsible behaviour. Under this legislation the ways in which they may act in support of such people, is only to require them to live and or work in specific places and to attend treatment. The Mental Health Act (1983) includes provision for dealing with the property and financial affairs of such a person and has short term protective powers, through the Court of Protection, to remove a person to a place of safety. However, the Law Commission see these as too centralised and too restrictive. They were also concerned that the types of decisions that could be made on behalf of another person were only business or finance related, there being no reference to issues of personal welfare or health. They found the provision too inflexible, either the person with mental disorder could decide on all issues or on none. For people who would not come within the definition of 'mentally disordered' there is provision for Enduring Power of Attorney but this has similar shortcomings to the above. It is 'all or nothing' in nature, and once registered, it can only be revoked by a court.

The Law Commission report points out that the United Kingdom signed up to a resolution which asserted that

'the mentally retarded person has a right to a qualified guardian when this is required to protect his person well-being and interests' (United Nations resolution 2856, 1971).

However, this intent was never formalised under English Law and to do so has been considered too intrusive, and that such control over people receiving care should not often be necessary (Report of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency 1957 Cmnd 169 para 832). The Mental Health Act (1959) provided for compulsory measures which were only to operate where absolutely necessary, that is, when coercion was required. This granted the 'guardian' powers of the parent of a child under 14. This Act was reviewed in the early eighties to become the 1983 Act mentioned above. The main task of this Act was to cut back on the categories of people who could be put into guardianship.

The Law Commission felt that the legislation to date had not recognised the benign side of guardianship, that is, something more akin to advocacy. In terms of these Acts 'guardianship' was viewed as restrictive rather than a means of enhancing civil rights and liberties.

More recently the high courts have made declarations on individual matters, for example, regarding sterilization or withdrawal of artificial feeding. However these declarations only confirmed or refuted the lawfulness of a decision, the court is unable to grant authority to anyone to decide for a person in the future, nor is it able to decide what steps should be taken next in any particular matter.

In addition to the United Nations declaration stated above, it was declared that a

'mentally retarded person has a right to protection from exploitation, abuse and degrading treatment' (Declaration on the Rights of Mentally Retarded Persons, 1971

UN General Assembly 26th Session, Resolution 2856, para 6).

In the United Kingdom some powers do exist to assist a person who may be being abused. The Mental Health Act (1983) provides the framework within which a suitably authorised person may enter and inspect the premises in which a 'mentally disordered person' lives. It also allows for a warrant to be gained to enter premises and remove such a person to a place of safety on the grounds of 'seriously irresponsibly conduct' which may result in harm to themselves or others. Similarly, the National Assistance Act 1948 and the National Assistance (Amendment) Act 1951 provide similar protection to people suffering

'grave chronic illness or who are aged, infirm, physically incapacitated and living in insanitary conditions'.

Unlike the 1983 Act, there is no need to show mental incompetence, however this means that it may be applied to people who are not mentally incompetent but who chose to live in what others regard as insanitary conditions. On the other hand, it does not apply to vulnerable people who are at risk of abuse or exploitation but who live in sanitary conditions.

Therefore, though the existing legislation provides some protection to vulnerable people it has proved insufficient to back up the civil rights and liberties of people with learning disability and other vulnerable adults. Consequently, the Law Commission has proposed a new Act which would

- define 'capacity'
- establish a single criterion for taking decisions on behalf of a person who lacks capacity to do so.
- clarify the law where action is possible without resorting to formal procedures.
- extend and improve laws for power of attorney to 'outlast incapacity'.
- provide for a decision or decision-maker to be made or appointed by court.

These laws would apply to people aged 16 and over and codes of practice are to be produced to assist in implementation.

The scheme proposed allows for people to *'make decisions on behalf of and in the best interests of'* a person who lacks capacity. The assumption in law would be, as now, that an adult has capacity, lack of capacity would have to be proved. This proof requires some type of test and three types were considered - status, outcome, and function. The status test which, for example might classify someone as mentally disordered because they are labelled such within a particular service, was considered too rigid because it is at odds with a policy of adopting the least restrictive form of intervention. An outcome measure would have limitations in that should the assessor disagree with the person's decision, that person may be classed as incompetent. Such an option was seen to penalise individuality and force conformity. The functional approach was seen to fit in with other tests in English Law, focussing on the person's *'ability to decide at the time a decision needs to be made'*. This approach emphasises the person's capacity to understand the nature of the matter in hand and the likely effects of any decision made. It was seen as the most flexible of the options and provisionally a 'test' has been established focussing on the inability to understand information

relating to the decision to be taken, or alternatively, an inability to choose amongst alternatives.

The Law Commission have adopted the term 'mental disability' to describe individuals affected by this proposed Act. The term is defined as

'any disability or disorder of the mind or brain (temporary or permanent) which results in impairment or disturbance of mental functioning'.

In addition, they have specifically included people who have mental capacity but who are unable to communicate their decisions at the time they need to be made, for example, some stroke victims. A person is defined as being without capacity if, at the time the matter needs to be resolved, they are unable to make a decision due to mental disability or because

'they are unable to communicate a decision because they are unconscious or for any other reason'.

Making a decision in their terms involves the ability both to understand relevant information and to use that information. The Law Commission propose that a person is unable to make a decision if, at that time, they are

'unable to understand or retain relevant information, including relevant information about the foreseeable consequences of the alternatives or of making no decision at all'.

A person would also be regarded as 'unable to make a decision' by reason of mental disability if *at the time* they were unable to make a decision based on relevant information presented in broad terms and simple language. The Law Commission stress that a person would not be

regarded as 'unable to make a decision' because they do not make what others would consider the 'prudent' choice. For persons unable to communicate a decision, all reasonable steps should have been taken to enable such communication to take place.

As stated above, the decisions made on behalf of another person should be in their 'best interest'. The Law Commission state that this term should take account of the person's past *and present* wishes and feelings, as well as '*factors that the person would have taken into consideration if they were able to do so*'. They re-emphasised the need to permit, encourage and enhance the person's ability to participate as fully as possible. They underline the importance of obtaining the views of 'appropriate' others, such as family members, friends, care workers or managers, where practicable, in order to ascertain what the wishes and feelings of the person are and what is in their best interest. They also indicate that the outcome of the decision should be the least restrictive alternative with respect to the person's freedom of action and that this should be achieved in the least restrictive manner.

Where a person has never had capacity, as in the case of a person with profound learning disability, their preferences and personality will be largely unknown and in these circumstances it is proposed that an assumption is made that they would have been a

'normal decent person acting in accordance with contemporary standards of morality'.

In consultation with others, before the publication of the Report, family carers had expressed a concern that consideration of the 'best interest' of the person without capacity might exclude the interests of others within the household. However the Law Commission state that they believe that the interests of family members or other cohabiters would count amongst factors

the person would have considered if they were able to do so and therefore would be taken into account. As stated previously, it would be appropriate to consult those concerned with the welfare of the individual to provide information and interpretation of the persons wishes and feelings, *as well as their own view on the matter.*

One of the purposes of the proposed Act is to give a 'general authority to act reasonably' to persons with daily care responsibilities for a person with mental disability. This would make it lawful to do things for a person believed to be incapacitated, in particular circumstances, if it is reasonable and for their personal welfare or benefit. The obligation, as before, would be to act in the person's 'best interest'. This authority would also enable a carer to deal with day to day financial matters relating to the person without capacity, both in terms of making purchases of goods and services, and in using the person's savings accounts to provide money for such goods and services up to a proposed maximum of £2,000 per year. Agreements with institutions for such a facility would have to be renewed every 2 years.

The Law Commission Report also details exceptions to the 'general authority' to act on behalf of another person and this is in relation to . . .

- consent to marry
- consent to sexual relations
- consent to divorce (based on 2 years separation)
- agreement to adoption or consent to freeing a child for adoption.
- voting in elections
- acting as a parent except in relation to a child's property

In dealing with the person with mental incapacity the Commission state that they should not be confined or coerced, except where this is to protect themselves or others from serious harm. The Law Commission propose that this 'general authority' does not include the use of, or threat of, force to make the person with mental disability do something they object to. The carer would have no authority to detain or confine the person whether or not they object to this treatment. However, this statement would not preclude taking steps necessary to avert substantial risk of serious harm. 'General authority' to act may not override the authority of an attorney or appointed manager acting within their remit, however, it would allow them to challenge such representatives in court. However, this does not preclude a person with 'general authority' from acting to prevent death or serious deterioration in the condition of a person while a court order is being sought.

The Law Commission propose a new offence to ill treat or wilfully neglect a person over whom the carer has powers. An important part of the new Act is to protect vulnerable people who are at risk. In their definition of 'vulnerable' is included

'any person aged 16 or over in need of community services because of their disability, age or illness and who is unable to care for themselves or protect themselves from significant harm or exploitation'.

Harm in this instance is defined as

'ill treatment, including sexual and mental abuse and/or impairment, or avoidable deterioration, in physical, mental and/or emotional condition and/or behavioural development'.

The government's report 'Making Decisions' (October 1999) sets out their proposals to reform the law in regard to people with mental incapacity. The report accepts the Law Commission's recommendations on the presumption of capacity and functional test for incapacity. This test adopts a flexible approach in which the extent to which a person may be enabled to make their own choice is to be determined within each particular set of circumstances. The government accepts the Law Commission's definition of 'capacity' and 'best interests'. In addition, they agree with the factors put forward that should be taken into account when making a decision on behalf of another person. That is, past and present wishes, views of appropriate others, and adoption of the least restrictive alternative in terms of the person's freedom to act. However they add that any expectation of the person recovering capacity in the 'reasonably foreseeable future' should be taken into account, as well as whether the expressed wish of the person without capacity were the result of '*undue influence*'. The government also accepts the Law Commission's recommendations regarding provision of a 'general authority to act reasonably'. However, they emphasise that action under this authority should not only be reasonable in the circumstances, but also '*reasonably believed by the decision-maker to be in the person's best interests*'. However, in regard to a new offence of ill treatment or wilful neglect of a person without capacity, the government is not persuaded that legislation is appropriate although they do not rule out such legislation in the future.

In general, however, although the changes listed above are welcomed, as McHale (1998) points out, such wide ranging powers would require a considerable amount of Parliamentary time to implement. She points out that the parliamentary agenda is already overcrowded and that this may result in parts rather than the whole of the proposed changes being enacted. This may prove unsatisfactory to many.

Although it is right and proper that, wherever possible, a person with learning disability should be able to make their own decision about matters that affect them this may lead to unforeseen difficulties. For example, when considering moving away from the family home relatively able people with learning disability may be able, or assisted, to look at the issues involved in moving from home, and grasp the consequences of various alternatives, but may still not be persuaded that their carer's need for 'permanent' respite may outweigh their own wish to remain in the family home. Service personnel are instructed not to prioritise one of the parties' needs or wishes above the other's (Caring about Carers, 1999). This may result in stalemate. Alternatively, a victim of abuse made aware of all the possible alternatives and related consequences of a move may still request that they stay within an abusive relationship although this may not reflect their own best interest. In either case the law would instruct that the person may not be considered 'incapacitated' in relation to this particular decision and therefore may not be over ruled because their decision does not appear 'prudent'. There are no easy answers to this dilemma.

4 Discussion and Summary

In recent years there have been substantial developments in policy regarding rights of individuals and changes in service priorities to reflect more equitable delivery. However, the backing in law to ensure the attainment of the many worthy aims of policy initiatives is scant.

Thus far, carers have the right to have their needs assessed by social services alongside those of their dependant relative, however, such assessment cannot ensure appropriate service delivery. One of the major shortfalls in the approach is the lack of any statutory requirement for carer health to be monitored. Caring about Carers (1999) suggests that GPs and other community health professionals are ideally placed to assess health of carers, in that they are

more likely to have contact with carers than other service providers, yet there is only 'encouragement' that they should take opportunities to assess well-being. There is no information at the present time on the extent to which GPs are aware of the numbers of carers in their locality or the identities of these people.

Initiatives / intentions such as those described in the government document 'Making Decisions' (1999) signal an intent to formalise the civil rights of people who 'lack capacity'. Although overdue, such rights may lead to some serious situations where the needs of 'carer' and 'cared for' clash.

It has been proposed that those responsible for the provision of services have a moral duty to support carers. The situation in the past, where respite was a by-product of services aimed at the person with learning disability and supplied out of marginal resources, should be changed. In addition, the environment of provision primarily to those who are particularly assertive or in crisis, needed to be addressed (Twigg & Atkin, 1994). This state of affairs has been recognised and targeted by recent strategy documents issued by the government (Caring about Carers, 1999; Better care, Higher standards, 1999). These documents describe changes in process which aim to establish consistency in service provision across the country, ensure that service providers become aware of the numbers and needs of carers in their locality, and that relevant general and individualised information about services that are available are provided to carers, as well as encouraging carer involvement in planning decisions. There is also encouragement for service providers to act in a more coordinated way across departments and to provide more respite and support services to carers.

Recognition of the value of carers increased steadily from the time when changes were made in policy which recommended that people with learning disability should be cared for in the community and not in large mental handicap hospitals (Better services for the mentally handicapped, 1971). However it was many years before government formally acknowledged the need to consult carers in the process of planning care for the person with learning disability (NHS & Community Care Act, 1990). The NHS & Community Care Act, although recognising the need for carer involvement in decision making about their dependant, did not take into account any consequent needs the carers themselves may have.

The Carers (Recognition and Services) Act 1995 finally addressed this deficit, although implementation to date has been found to be patchy (National Carers Association, 1996). The strategy document Caring about Carers (1999) provides targets so that provision to carers may become consistent across the UK. This document describes an intent to support those who 'choose to care' through partnership with service providers, information, and assistance. The aim is to enable carers to make choices about the way they live, to maintain their own health and independence, and give them the recognition and respect they deserve from those who provide services. Although this document goes further than any other in the assistance it promises to carers in their own right, there are a few areas of concern.

Firstly, the document appears to overstate the extent to which carers may 'choose to care' and throws up issues in interpretation as regards the voluntary nature of the relationship which may have a bearing on prioritisation of services. Where priorities must be set, providers may interpret the directive as means to prioritise assistance to those who do not have a 'normative' duty to provide such care, for example, carers of elderly relatives. That is, the concept of a son or daughter caring for a parent may be conceived as less of a 'duty' and more a 'noble deed'

as opposed to a parent fulfilling a 'normative' role vis a vis their child. It is a small point but in a climate of resource limitation and substantial demand some decisions on the prioritisation of recipients would have to be made and this may be one of them.

Secondly, although social services are formally required to assess carer needs, it has been shown that GPs and other community health professionals have greatest level of contact with carers (Henwood, M, 1998). However, it is only 'recommended' that they use such opportunities to make assessments of carer health and capacity to provide care, there is no statutory requirement that this should occur.

Finally, although a 'ringfenced' grant for the development of support services is announced (Caring about Carers, 1999) there is a question over the resources needed in the longer term to facilitate the aims of this strategy. Most of the proposed changes appear to require more effective use, or redistribution, of existing resources and reliance on volunteers to supplement the work of paid staff. This brings concerns of its own regarding the means by which quality, quantity and effectiveness of support services may be ensured.

A major theme in the strategy document is the provision of 'breaks' so that carers may have more control over their lives, however, there is no commitment to provide extra resources in the longer term to enable providers to ensure provision of the array of services recommended. Without such resources it is difficult to see how the strategy will achieve its aims in the longer term. An element of good practice in provision of breaks, promoted by the Government, is a 'transparent and equitable charging system within a national framework'. This may be a primary source of funding in the future but raises questions about the realisation of 'equity' in provision, hinted at in the aim. A policy of this type would need to be sensitively balanced

to ensure that all carers and their dependants who wish to have a break or access to a particular service may do so regardless of their ability to pay. In addition while there is no statutory requirement for health assessment, carers may still be at risk of sacrificing their own well-being for the sake of their dependant.

Other concerns become apparent when considering the needs and rights of carers alongside those of the person they care for. The recent Law Commission Report (Mental Incapacity 1995) proposes legislative changes which have been largely accepted by the government (Making Decisions, 1999). The proposals aim to recognise the civil rights of people with 'mental disability' including people with learning disability. The proposed legislation recognises that individuals should be allowed to make their own decisions in matters regarding their welfare, as far as possible, and that every attempt should be made to make information regarding a particular issue intelligible to them so that they may make an informed choice. The proposed changes also aim to give carers a 'general authority' to act reasonably in matters concerning the welfare of a person with 'mental disability'.

There are, however, potential areas of conflict between this proposal and the Carers strategy. For example, in matters such as a move to alternative residential care, the needs and expressed wishes of carer and dependent may conflict. The strategy document Caring for Carers (1999) specifically states that service providers should not place the needs and wishes of one party above those of the other. As described above, a condition of stalemate may ensue. It seems appropriate, therefore, that there should be a point at which one person's needs should be prioritised, and reasonable that this should happen before a crisis occurs.

Caring about Carers (1999) promotes recognition and respect for carers as partners with service providers in provision of help to the person needing care. However, although respect for the views of the cared for person is emphasised, there is a tendency to marginalise their status. Compliance with the sentiments of 'Making Decisions' (1999) would suggest a three-way partnership with recognition and respect for the dependent person who would also provide an input to the extent their disability allows. In the case of people with learning disability who are not able to express their views, the current system of service provision already allows that a care manager may act as advocate and argue on behalf of their client (NHS and Community Care Act, 1990). If the proposed legislation on 'mental incapacity' is passed there may also be an 'appointed manager' to make decisions in matters affecting the person. The inclusion of 'advocates' of any description would bring an independent voice to promote the interests of the person with learning disability. The data collection for the studies reported in this thesis occurred prior to the Carers (Recognition and Services) Act 1995. However, though in place, it appears that the legislation has not yet taken full effect and useful lessons may be drawn from the experiences of parents interviewed in this thesis.

Reprise

The aim of this thesis is to examine some of the theories outlined in chapter one and issues in chapter two, in the light of actual placements for people with learning disability and challenging behaviour. This is done at three levels. Firstly, the differences between people living in residential care and in the family home are explored. This cross sectional analysis uses quantitative techniques on an epidemiological database of people with learning disability and challenging behaviour which was generated in the late 1980's in the North West of England. This analysis examines the findings in the literature regarding the influence of personal characteristics in placement.

Secondly, in an extension to the related work carried out by Kiernan & Alborz (1995), the group of people who moved from home in the years between parental interviews following the epidemiological survey and a follow-up study of these families in 1993 are matched by age and gender with people who did not move. Matching is undertaken to control for extraneous effects of gender, males being more prevalent in the group than females, and age, to ensure that differences do not merely repeat an earlier finding. This study addresses the extent to which families of those who moved reflect findings in the literature regarding a range of individual, dependant and family characteristics, and resources.

Finally, a qualitative analysis is undertaken of responses to a semi-structured interview by parents of sons and daughters who had moved. This analysis seeks to track the process of decision making for the families involved and examine how these relate to Richardson and Ritchie's (1989) model of decision making, and Essex et al's (1997) models of placement types. Comparisons will then be made between the experience of the transition process for these families and those studied by Bigby (1996).

Chapter 3

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Chapter 3

Methodology

1 Introduction

The following studies involve secondary analyses of data sets generated by the Hester Adrian Research Centre over a period of approximately eight years. The data sets comprise two large scale population surveys, two related smaller data sets and a qualitative data set (see Fig. 2, p115). The large surveys identified people with learning disability who showed challenging behaviour in service settings. The two small data sets comprise data from rounds of semi-structured interviewing. One round of interviews was conducted with a number of families of people with learning disability identified at the time of the survey in 1988, the other was a follow up of these families in 1993, but incorporates data from additional interviews with parents of people identified in the original study but not approached until 1995. Transcripts of interviews, which were available for the majority of parents whose son or daughter had moved to alternative residential care, formed the qualitative data set. These three types of data set formed the basis of the analysis undertaken in this study and, by their nature, suggested a mixed method approach to analysis.

Mixed method approaches

During the past three decades there have been numerous debates over the superiority of one or the other of the two leading paradigms in social and behavioural science research (Datta, 1994; Guba & Lincoln, 1994; House, 1994). These paradigms, known as the positivist/empiricist and constructivist/phenomenological approaches (Guba & Lincoln, 1994), underlie quantitative and qualitative methods respectively. The initial position

taken in this debate was that the two approaches were incompatible. The positivist, and particularly the post-positivist approach embodied the conceptualization that reality is constructed by the individual and that research is influenced by the investigators theories and preconceptions, but that time and context free generalizations are possible and that there are real causes that precede or are simultaneous with effects (Lincoln & Guba, 1985; Reichardt & Rallis, 1994). Constructivists, on the other hand advocated an approach which conceptualized multiple, constructed realities, which suggested that investigators are influenced by their own set of values, that time and context free generalizations are not possible and that it is impossible to distinguish causes from effects (Lincoln & Guba, 1985).

Datta (1994) pointed out however that the two approaches are compatible at some level because they have both been used successfully for years, and have both contributed to knowledge and influenced policy. In an attempt to reconcile the two approaches a group of researchers who became known as 'pragmatists', took the position that it was important to adopt an approach to design and analysis which best suits the research question (Brewer & Hunter, 1989). Other researchers went further and contended that there is enough similarity between the basic beliefs underlying the two positions for quantitative and qualitative research to form 'an enduring partnership' (Reichardt & Rallis, 1994). The similarities include that they both conceptualize reality as constructed, both recognise the effect of the investigator in the research process, both believe theories are never 'proved' but may be disproved, and that many theories may be used to explain a given set of data.

Tashakkori & Teddlie (1998) describe mixed method studies as ones which combine qualitative and quantitative approaches into the research of a single or multi phased study,

all of which use triangulation techniques (Denzin, 1978) to look for confirmation of findings from a variety of sources. Creswell (1995) distinguished four mixed method designs; sequential studies, where a qualitative phase of study is followed by a quantitative one or vice versa; parallel/simultaneous studies, where qualitative and quantitative phases are conducted at the same time; equivalent status designs, where both approaches contribute equally to an understanding of the subject of study; and dominant - less dominant studies where a major portion of the research is conducted using one or other of the approaches which is then supplemented by a small scale study using the remaining mode.

This type of design is distinguished from a mixed *model* design which reflects the pragmatist paradigm and combines qualitative and quantitative elements *within* different phases of the study (Tshakkori & Teddlie, 1998). The approach also embodies the technique of collecting qualitative data, elements of which are then 'quantitized' (Miles & Huberman, 1994) and analysed quantitatively.

The original study, for which the data analysed here was collected, adopted a dominant - less dominant approach with the main emphasis being given to the quantitative data set. A smaller scale mixed model study was then added to provide information on the experience of challenging behaviour in the family home. In this thesis a mixed-method approach is used overall and, in the predominantly qualitative part of the study, data is analysed qualitatively and then 'quantitized' to a small extent to provide the reader with an indication of the prevalence of a particular view or experience amongst other group members. This pragmatist approach to data analysis puts the importance of the research questions above considerations of methodology and the philosophies underlying them

(Tashakkori & Teddlie, 1998). A mixed method approach has the advantage of using methods with non-overlapping weaknesses and complementary strengths (Brewer & Hunter, 1989). Quantitative studies are often criticised for placing too much emphasis on the statistical significance of any findings, whilst qualitative studies may be criticised for reflecting the researcher's view to a greater extent than that of the participants (Tashakkori & Teddlie, 1998). However, one of the strengths of using large databases is that any findings are likely to be sound, in that the probability of making type I errors is much reduced. In addition, one may be far more confident about generalising any findings to the wider population from which the sample is drawn. Where the coverage includes all the target group in specified representative regions there is additional confidence that any findings may be representative of the wider population.

Sampling and related issues

In this thesis, although initially identified from a comprehensive population sample, bias may have been introduced by focussing on selected individuals (i.e. those in a particular age group) or by reliance on the representativeness of those who could be traced and agreed to take part in the study. However use of 'convenience samples' is often the only feasible way to conduct a study of this type, and provided the sample is used with reasonable knowledge and care, particularly in the interpretation of findings, they are an accepted means of research (Kerlinger, 1973). In this study, outcomes from quantitative analysis will be used to guide the analysis of the smaller quantitative and qualitative data sets. The qualitative element of the study provides confidence in the strength of the validity of any findings in relation to the topic under investigation.

The use of small data sets restricts the applicability of findings to the general population so that any findings from this data may not be confidently used as predictors, in this case of placement, beyond the study group. However, it was considered that the information provided by the small data sets could be used to look for confirmation from findings of other research in the area, within the study group, and to provide direction for the qualitative analysis and for future research.

Qualitative data from interviews with eighteen parents whose son or daughter had moved from the family home since initial data collection in 1988 are analysed. A sample of eighteen in a qualitative study constitutes a relatively large group on which to base this type of analysis and provides an opportunity to document a wide range of experience related to the transition from home to alternative care. In addition, this analysis provides an opportunity to establish how quantitative findings from the earlier analysis relate to the reality of moves to residential care.

As stated above, additional interviews were obtained with a number of families who had not previously taken part. These interviews mirrored those conducted with the original group so that data from two groups could be merged. This placed a limitation on the study in terms of 'grounded' data generation (Glaser & Strauss, 1967), however analysis of the qualitative data was handled in a manner consistent with methodological aspects of the approach, including generating 'low level categories' to describe relevant features of the data; creating definitions of and linkages between categories; and making constant comparisons between cases to fully explore the complexities of the data (Glaser & Strauss, 1967).

Overall, therefore use of mixed methods in this research provides width and depth to the topic under investigation.

Variables in the analyses

As noted above one of the limitations of secondary analyses is the restriction imposed by the use of variables designed to collect data for other purposes. This results in a corresponding deficit of variables one might have wished to have pursued. In relation to this study there are various influences on the decision to place a son or daughter in alternative residential care identified in the literature review that will not be pursued in the following analyses because the data is not available, and a further set a variables that will be examined, but because the sample for whom the information is available is small, must be treated with extreme caution.

The areas that cannot be pursued include:

- the caring relationship, that is the satisfaction and reciprocity apparent in the relationships prior to the circumstances which occasioned the move.
- the influence of the family systems framework, specifically values and sensitivities passed down through the family, definition of structures such as 'dyads', coalitions and triangles, and the functions of and interactions between family members (Bowen, 1966; Minuchin & Fishman, 1981; Turnbull et al, 1986).
- coping strategies (Folkman & Lazarus, 1984), health (Ware & Sherbourne, 1992), family environment (Holahan & Moos, 1983), severe life events (Cheang & Cooper, 1984). Although investigated as part of the follow up study in 1993, data was only collected for the study participants *after* their son or daughter had left home and therefore may not reflect their situation prior to the moves (see below).

- race/ethnicity. Almost all the families involved were white British and there was only one Asian family amongst movers, therefore analysis is not viable.

The interview schedule for parents evolved over a six year period and additional measures were used at follow up in 1993 and in 1995 interviews. However, these measures (involving coping, life events, family environment and health) were not completed by parents prior to the moves. This being the case, it was considered that inclusion of the data would add nothing to our understanding of the factors involved in placement. As argued in the literature, transitions in the family life cycle are said to be times when there is a marked shift in family interaction. Roles may be redefined and relationships renegotiated (Olsen et al, 1984). If this is the case coping strategies, life events, family environment and so on may well have altered once the person with learning disability moved away from home, and so this information would only be useful for a cross sectional comparison of parents lives before and after a son or daughter left home. This being the case, regretfully, analysis of this information was not considered useful.

On the other hand a number of possible influences on parental decision making identified in the literature may be investigated via the large survey databases. These largely reflect the personal characteristics of the individuals involved, particularly intellectual and physical ability and extent of behavioural challenge all of which have been discussed in the literature reviewed in chapter one. Analysis of these variables should provide an opportunity to clarify and / or extend earlier findings by other researchers and with data set whose size is less likely to reflect chance effects.

Variables which could be examined to some extent using the small database in the second study reflect, stress level, stage of the family life cycle, and demographic data, including income, and socio-economic status. However the limitations imposed by size of the group for whom this data is available precludes investigative work but provides an opportunity to establish whether findings reflected in the literature are apparent in the group under study.

Aims of the research

The aims of this research follow three strands of investigation.

- 1) Are there differences between those people with learning disability and challenging behaviour who continue to reside in the family home and those who are placed in alternative residential care?
- 2)
 - a) Are any differences apparent in service settings in 1988 between those people with learning disability who had and had not moved away from home over the subsequent seven years?
 - b) Did those who moved out of home have different effects on their families, or have different family circumstances, from those who did not?
- 3) What are the processes involved in the decision to seek alternative care and how does a move affect the people involved?

Description of participants and instruments used in of each of these studies will be dealt with separately.

2 *Participants*

Study 1a and Study 1b

This investigation involved secondary analysis of data collected in 1988 and 1995 in seven and two District Health Authorities in the North West of England respectively which were selected to reflect demographic variations in the population at large. These studies were designed to identify those people with learning disability who also exhibited challenging behaviour (Kiernan, Qureshi & Alborz 1989, Emerson et al 1997). The surveys aimed to screen the administratively defined populations of people with learning disability in the districts covered. That is, a person was considered to have a learning disability if they received assistance from a learning disability service. There was one notable exception to this strategy in the 1988 survey. In this survey schools for children with a moderate learning disability were not screened. The reason for this was that there was a degree of uncertainty about whether some of the children who attended such schools actually had a learning disability. It was felt that it may be difficult for staff to determine who was covered by the survey and who was not, particularly for borderline cases.

The 1988 study identified 695 people over the age of 5 years who had learning disability and had also been challenging to staff in service settings during the previous month, or who would have been so were it not for specific measures introduced to prevent the occurrence of such behaviours, for example, through use of reinforced glass or restricted access to some part of the building. Some of these people were identified as showing challenging behaviour in more than one setting, for example in a day centre and in respite care facility. Where this was the case, the amount of time the person spent in the setting was taken into consideration and the questionnaire completed by staff in the setting where

the person spent the most time was designated the 'main' schedule. This 'main' schedule was used primarily in subsequent analyses.

The 1988 cohort comprised 447 (69%) men and 248 (31%) women aged between 5 and 87 years (median 27 years, mean 29 years, SD 14 years). This thesis looked specifically at factors which differentiated the group of people who lived in the family home (N=237) from those in alternative residential care (N=458).

The 1995 study adopted the same method of identification used in 1988. This study identified 286 people who had learning disability and challenging behaviour. The sample comprised 189 males (66%) and 97 females (34%) between the ages of 3 and 87 years (median 25 years, mean 27 years, SD 16 years). Of these 144 were resident at home and a further 142 lived in alternative residential care.

Study 2a and Study 2b

2a) This study involved 36 people with learning disability and challenging behaviour who were identified in the large scale survey described above and whose parents took part in the interview studies discussed below.

In 1989 an interview study was conducted which involved the families of 59 people aged between 19 and 34 years (median 22 years, mean 23 years, SD 3 years) 35 (59%) of whom were male, who were part of the cohort described above and were living in the family home (Qureshi 1990). The study used a semi structured interview to examine areas of family life which might be affected by the presence of a son or daughter with learning disability who was known to be a challenge to services. Forty four of these families were

reinterviewed in 1993 to examine any changes in family circumstances or experiences that had taken place since the original interviews. The study investigated the effect of the introduction of specialist challenging behaviour teams with a brief to provide support and therapy in community settings where an individual showed incidents of challenging behaviour (Kiernan & Alborz 1995). Ten of these people, 8 of whom were male, had experienced a move from home to residential placement in the intervening years and their interviews were examined in respect of factors found related to desire for alternative care in 1989 (Qureshi 1990).

In 1995 a follow up study on members of the original cohort who were classified as severely challenging in 1988 was conducted, along with a parallel study which repeated the identification process but in only two of the original seven districts (Kiernan et al, 1997b; Emerson, et al 1997). In addition to this work interviews with parents was sought.

Identification of additional families for interview in 1995

Identification of these parents involved examining the original database to identify individuals who were living at home in 1988. Families already contacted were then excluded. Social service departments were contacted to establish the current address of the families, as well as to ascertain whether there was any reason why families should not be contacted. Such reasons might include, for example, illness or bereavement in the family and also, very occasionally, the death of the person with learning disability.

After obtaining current addresses and as much pertinent information as possible, parents were sent a letter describing the earlier parent project and asking for their help to extend this work (Appendix 1). They were sent a summary which described the issues involved

and a slip to return if they did not wish to take part. Seventy nine families were identified and letters sent out. Of these 50 sent back refusal slips or declined to take part when contacted by telephone.

This represents a 37% response rate which was disappointing compared with initial approaches to families in 1989 which achieved a 70% response rate. The 1989 study made initial approaches to parents through a social worker, community nurse or day care worker and, at that time, concern was expressed about the role of these professionals as 'gate keepers' (Qureshi 1990, personal communication). There were some circumstances in which the professional involved had refused to approach a target family because they felt it inappropriate. It was felt that this excluded the possibility of gaining the experience of families who may have been willing to participate but were not given the chance to decide.

In light of these concerns it was decided to limit the involvement of professional workers and, after consultation, approach the families directly. However, in light of the significantly greater refusal rate when using the more impersonal approach by letter it may be fair to suggest that approaches to families by known individuals may in the long run be more productive despite the loss of some families due to the judgement of a third party.

Of the twenty nine interviews obtained, 21 were with families where the person involved still lived at home and eight were with families where the person had moved out of home since 1988. The latter group comprised five males and three females whose ages ranged from 13 to 37 years (mean 25, median 25, SD 7). Their families, together with the ten families interviewed in 1993 whose son or daughter had moved at that time, made a sample of eighteen families who had experienced a move between 1989 and 1995. The

group, therefore, comprised thirteen males (72%) and five females (28%). Comparison of the group of people who agreed with those who refused to be interviewed revealed no significant differences in level of intellectual ability or physical problems. There were also no differences in age or extent of challenging behaviour as perceived by staff in service settings. The group of parents who refused interview, however, were more likely to have a daughter than a son. More than three quarters of the parents of daughters (78%) refused interview compared to just over half (51%) the parents of sons.

Sample Selection

The follow up parent study conducted in 1993 had concluded that the main variables associated with a move from home were serious injury being inflicted on a parent, being in a younger age group (the people involved were aged between 24 and 37 years) and supervision of the person having been seen as a problem in 1988 (Kiernan and Alborz 1995). In the 1995 study it was considered necessary to look in more detail at other characteristics or processes that might account for moves from home. In other words, was there anything that distinguished this group of young people who had left home from another of the same age who had not. For this reason it was deemed necessary to identify a group of individuals who were of the same age but who had not moved (see Fig.2). There is also some controversy in the literature around the differences in the type and extent of disability that affect males and females (e.g. Vandenberg 1987). This uncertainty coupled with the unwillingness, in 1995 at least, on the part of parents of daughters to take part was considered a potential influence on any findings. Therefore, to exclude the possibility that results might be obtained solely due to the preponderance of one gender over the other in one of the groups, the people who had moved were matched with others who had not taking age and gender into account.

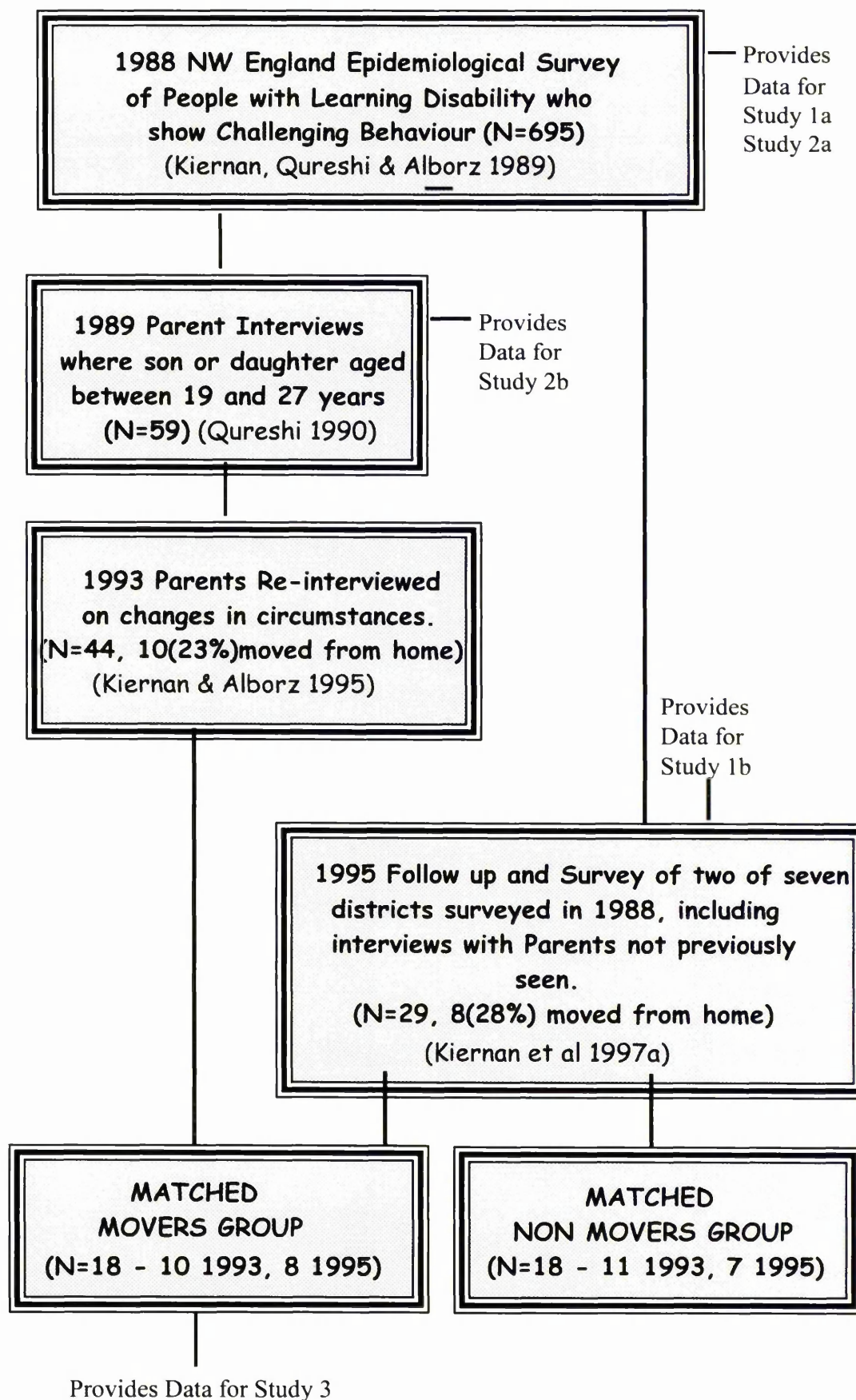


Figure 2: Derivation of the Study Groups and Data Sets

Matching

It was possible to exactly match ten of the eighteen people who had moved on age and gender with a person who still lived at home. Where more than one person of the same age and gender as the mover were identified the match was randomly selected from the group by allocating a number to each person and then rolling a die.

A further six were matched with people of the same gender but were either one year older or younger than the person who had moved from home. In the remaining two cases the people involved had to be matched to someone three or four years older. This last matching was the best available and considered acceptable in order to maximise the numbers. The participants comprised 26 (72%) men and 10 (28%) women aged between 13 and 37 years at the time of parental interview.

2b) A subsample of these matched groups was investigated to establish any differences apparent in the experiences and views of parents prior to a move. This sample required analysis of data from parent interviews from 1989. As such it was only possible to use those matched pairs who were part of the first parent interviews. These parents were all re-interviewed in 1993. There were ten pairs of individuals for whom this data was available. That is, a total of twenty people in all. Of these sixteen (80%) are male and four (20%) female, similar proportions to the group as a whole, their ages ranging from 18 to 30 years.

Study 3

This study involved qualitative analysis of the responses of families to open ended questions about their experiences of their son or daughter moving from home. Interviews with the parents were semi structured, allowing the quantitative analysis of much of the

information obtained, but retained many open ended questions. Prior to interviews parents were assured of the confidentiality of their responses and asked if they were happy for the interview to be recorded. They were told that the recordings would be used to check the information noted on interview schedules where this was ambiguous as well as to provide any additional information not covered by the questions. The majority of parents agreed to the interview being taped and as a result this part of study involved fifteen taped interviews, ten completed in 1993 and a further five in 1995, as well as three interviews which were not recorded. The 'taped' group concerned twelve men and three women with learning disability aged between thirteen and thirty-seven years. As such the transcripts are representative of the group in total. Written notes from interviews with the three families who declined a taped interview were included where appropriate.

The majority of interviews were carried out by the author (N=10), two additional female interviewers carried out interviews in 1995. These interviewers were given training on the background to the Interview as well as in carrying out the interviews. They were given a taped interview to listen to and a copy of the Interview schedule completed at the time of the recording. They then completed role play interviews with the author acting as 'parent'. This enabled the author to give directions or answer questions about how responses should be written on the Interview schedule. The interviewers each completed a practice interview with parents not involved in the present study. For taped interviews the author was able to listen and transcribe relevant sections for analysis. For the interviews where no tape was available the interviewers provided written notes and verbal feedback on the session. It was considered that the background and availability of interviews carried out by the author for training purposes lead to interviewing styles that were compatible.

Interviews were carried out in a conversational style, the interviewer providing some direction in the flow of the conversation but allowing parents the opportunity to talk about the issues that were important to them as they occurred in the process of the interview.

3 *Instruments*

Study 1a, 1b, and 2a

These two studies both used data from a large scale epidemiological survey of people with learning disability who were challenging to their carers in service settings. The instrument used to collect information on the people identified was the 'Individual Schedule' (see Appendix 2). This was a self completion questionnaire designed to be completed by a member of staff who knew the individual well (Kiernan & Qureshi 1993).

The Individual Schedule (1988 version) - service settings

The questionnaire collected wide ranging data about the individuals including 8 background items and 21 items on intellectual and physical disability and their effects on the person. There were 4 questions relating to the type of challenge the person represented in that setting and, where there was a serious challenge or where the challenge would have been serious were it not for the use of specific procedures designed to control the behaviour, further information on the behaviour was sought (10 - 12 items in each section). This information included a brief description of the behaviour, its consequences and specific treatment and/or response employed. Staff were also asked nine summary questions about the extent of any disruption caused in the setting by the person's behaviour and its affect on staff. One final question investigated medication. The questionnaire used a multiple choice format such that staff were instructed to ring the answer they felt applied to that particular person. Where the options did not 'fit' there was a place to write in an alternative.

The 'Individual Schedule' was extended and updated in 1994 to provide a more comprehensive analysis of the types of behaviour exhibited by the person, their service history, any orders under the Mental Health Act (1983), as well as more detailed information on treatment procedures and training needs of staff dealing with people whose behaviour was a challenge (Alborz, Bromley, Emerson, Kiernan & Qureshi 1994).

Study 2b

This study is based on data collected using a parent interview schedule designed by Qureshi (1988). It was designed as a semi-structured interview which collected some information on the skills and abilities of the son or daughter in a structured way so that it might be compared to data collected from service settings, but also employed open questions designed to explore the day to day experiences of the families involved (see Appendix 3).

The Parent Interview (1988 version) - family home

The interview asked about household composition and the material circumstances of the families (3 items). Information was sought on the cause of their son or daughter's disability, any physical limitations they had, their ability to communicate and to care for themselves (11 items). It also asked about sociability, ability to occupy themselves constructively and the extent of any supervision required (3 items).

Questions on challenging behaviours were presented in an open format with particular emphasis on discovering how families dealt with incidents when they occurred and whether they could prevent occurrences. They were also asked about their expectations for the future, whether any difficult behaviours were expected to improve and whether the sons or daughters were changing in their outlook as they matured (16 open ended

questions). They were then asked specifically about incidents of physical attacks on others, self injury and destructive behaviour (4 - 8 items in each section).

Parents were also asked about their perceptions of how strangers viewed them and their son or daughter when outside the home, and the extent of contact with, and help from, family members (4 items). Questions were put about the specific effects of having a family member with these difficulties for the parents themselves, in terms of social activities, employment, physical labour, expense and other resources (16 items). They were also asked whether they felt there had been any effects on their own health (3 items).

Finally details of service provision were discussed. The quantity, reliability, sufficiency, suitability and helpfulness of any day and respite care was discussed, as well as other service inputs (11 items). Open questions on services that parents found helpful were put and comparisons between adult and child services sought (7 open ended questions). The interview concluded with thoughts on living arrangements in the future. Specifically whether the son or daughter had long periods away from home in the past or if there had been an attempt to settle him or her elsewhere. Any ideas for an ideal service were sought, as well as any specific plans that had been made (8 open ended questions).

Study 3

Study 3 stems from a project undertaken in 1993 to follow-up the parents interviewed in 1989. For this work it was deemed necessary to revise the original interview to provide a way of collecting information provided by open ended questioning in the earlier work in a more structured fashion, as well as to extend the areas of questioning.

The Parent Interview (1993 version) - family home

Typed transcripts from the earlier interviews were read and themes emerging from them marked. Using software developed for analysing qualitative data (Reeves 1989) quotations relating to various subject areas were extracted. The original open ended question was retained but the range of responses generated was then used to provide a coding frame. In relation to parental health, for example, the questionnaire had posed the question . . .

Do you feel that looking after (name)
all these years has affected **your** health, physically, or in
a mental or emotional sense?

The answer was then coded . . .

No reported effect on health	1
Physical health only	2
Mental / emotional health only	3
Physical and mental / emotional health	4

An instruction was given to transcribe detail if given.

Analysis of the transcripts provided a range of complaints mentioned by parents which they felt were due at least in part to caring for a son or daughter with learning disability. However, there was no similar information about health conditions from parents who did not believe that their health had been affected by their caring role. This information was needed to establish whether those problems mentioned by parents who felt that their health had been affected by caring, were specific to them and thereby possibly a direct effect of caring.

As a result, in the 1993 version of the parental interview, in addition to the original question parents were asked specifically whether they had suffered any of the problems noted from transcripts. If they had suffered in this way they were then asked whether they felt that this was due in any way to their caring role. As follows . . .

When we have spoken to parents in the past they mentioned a range of different health problems that they suffered from at the moment or in the past. Have you or your husband / wife suffered any of these?
(Show card)

If yes, Do you think it was due to caring for?

They were then presented with a card listing the various health complaints (see Appendix 4) and their answers noted.

Other questions were similarly amended or extended on the basis of parental responses to the first set of interviews.

The Parent Interview (1995 version) - family home

For parents interviewed in 1995 the questionnaire was updated once more, again taking into account parental responses. In particular, a version of the questionnaire was developed solely for parents whose son or daughter had left home (See Appendix 5). This questionnaire excluded items only relevant where the person lived at home and expanded and quantified information on the move from home. For example, interviews in 1993 had described the process of moving to new accommodation and from the information given it was possible to generate a coding frame as shown below.

How was the move done?

Gradually - plenty of short stays first to get used to the place	1
More rapidly - a few short stays before the final move	2
Sudden move - no time for preparation. Crisis or other reason.	3

Some information from these questionnaires was used as a background to the qualitative analysis of transcripts from parents whose son or daughter had left home.

Additional Measures

Studies 2b and 3

The questionnaires and parental interview schedules provided descriptions of the person with learning disability and their behaviour, family circumstances, extent and ratings of support from services, as well as descriptions of attempts to handle episodes of challenging behaviour. There was also information given on the events surrounding the decision to place the person with learning disability into alternative residential care along with the process of achieving this. However, none of this provided any independent indication of the effect of caring on the parents involved.

Qureshi (1990) included the Malaise Inventory as a measure of possible psychological distress. *The Malaise Inventory* (Rutter, Graham & Yule 1970a) is one of the most widely employed measures of psychosomatic symptoms and has been used as an outcome measure in many studies of families with a disabled member (e.g. Sloper, Cunningham, Knussen & Turner 1988; Bradshaw & Lawton, 1978; Burden 1980).

The Inventory was adapted by Rutter & Graham from the Cornell Medical Index (Rutter, Tizard & Whitmore 1970b) and comprises 24 forced choice items relating to minor physical and emotional health problems. Rutter suggested that a score of five or six was outside the normal range and indicative of stress. The measure has been shown to have reasonably good test-retest reliability. Quine & Pahl (1985), for example, reported a correlation of .94 between scores from 20 mothers who completed the inventory on two occasions. In various studies concerning family adaptation to a child with Down's syndrome Malaise scores have been found to be significantly correlated to a range of outcomes including child behaviour problems and other measures of mother-child and marital relationships (e.g. Cunningham, Sloper, Rangelcroft & Knussen 1986).

The Malaise Inventory was one of five measures that parents were asked to complete in 1993/5. However this was the only measure on which there was comparable information for a parents before their son or daughter left home. Scores on this Inventory were available for all but one of the mothers in the study group who were interviewed in 1989. This mother had a son or daughter who had left home. Additional measures (as referred to on p107) were left with parents to complete after the interview. Parents were given a stamped addressed envelope for their return.

Chapter 4

Results

Study One: Are there differences between those people with learning disability and challenging behaviour who continue to reside in the family home and those in alternative residential care?

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Study 1a: Characteristics of people with learning disability and challenging behaviour who live in the family home and in residential care in 1988.

1 Preliminary Exploration of the Variables

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Degree of Learning Disability

Personal Characteristics

Data reduction

Indices

Distribution of scores on indices

Disability Groupings

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Scale reliability analysis

Disability grouping for the subgroup

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2 Residency

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Comparisons on personal characteristics of children based on residency

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4 Summary

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Study 1b: Characteristics of people with learning disability and challenging behaviour who lived in the family home and in residential care in 1995.

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 - Diagnoses
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Chapter 4

Results

Study One: Are there differences between those people with learning disability and challenging behaviour who continue to reside in the family home and those in alternative residential care?

Introduction

The aim of Study One was to investigate any apparent differences between the populations of people who lived at home with a family and those in alternative residential accommodation. This was achieved through an examination of the data provided by service staff on people with learning disability who were exhibiting some form of challenge in service settings in 1988 or 1995. These two data sets are analysed separately and their outcomes compared. This was done because although many questions were the same at each time point there had been changes to others. In addition, the service context in which the surveys were conducted had changed from one with a large NHS hospital based contribution to a greater reliance on provision from Social Service Departments and Voluntary Organisations. It was considered that this difference in physical characteristics of the settings in which the people with learning disability received a service may well produce fundamental differences in the way behaviour was perceived and the extent to which behaviours were considered challenging within specific settings. This may have an effect on the identification of individuals in the survey.

Section one of each analysis (1988 and 1995) comprises an exploration of variables from the questionnaires completed by staff. Data reduction techniques are used to distil a succinct range of variables through which to compare the groups. As leaving home is fundamentally age related the issues presented by this are also tackled in this section.

The second part of the analysis focuses on key variables and uses analysis of variance (ANOVA) and discriminant analysis to explore group differences based on residency. ANOVA provides a way of comparing group means and highlighting variables found to differ significantly between groups. These variables are then entered into a discriminant function analysis in order to determine their utility in identifying individuals living at home or in residential care. The ability to provide such information or make predictions would assist in prioritising help in decision making and future planning towards the families most likely to require alternative provision at that point in their family life cycle.

The third section of the analysis deals with residency comparisons between groups of children with learning disability and challenging behaviour. This analysis follows the same format as that outlined above. However, as fewer numbers were involved it was not possible to use the same degree of sophistication. In 1995, 115 children were identified as showing challenging behaviour, however, only 9 children were living away from home. Such a small number of children away from home made exploration of the factors associated with a move impracticable. For 1995 therefore, no analysis of data on children is attempted.

Study 1a: Characteristics of people with learning disability and challenging behaviour who live in the family home and in residential care in 1988.

1 Preliminary Exploration of the Variables

Diagnoses

In order to investigate the personal characteristics of the people identified in the 1988 survey (N=695) variables from the 1988 Individual Schedule were explored. The Individual Schedule contained many variables which described the person's level of functioning, including items on degree of handicap and presence of conditions such as Down's syndrome. However, the numbers of people known to have a recognised condition were small. Only nine percent of the sample were known to have Down's syndrome (n=61), four percent had Cerebral Palsy (n=27) and five percent had a diagnosis of Autism (n=33). Between 56% and 64% of each of these small groups were living away from the family home.

There was also an item on psychiatric diagnosis, however presence of such a diagnosis was unknown for the majority of people identified in the survey (60%). Twenty nine percent of the sample were said not to have any psychiatric diagnosis, leaving only 11% known to have mental health problems (n=81). The psychiatric diagnoses recorded were, depression (n=10), affective disorder (n=9), schizophrenia (n=27), psychotic condition (n=13), neurosis (n=2) and other psychiatric diagnosis (n=20).

All the people with a diagnosis of schizophrenia were living away from home, as were 92% of those with a psychotic condition. Eighty five percent of those with an 'other' type of psychiatric diagnosis and eighty percent of those who suffered with depression, lived away from home. The number of people with diagnoses of the remaining conditions were very small, however five of the nine people who suffered an affective disorder and one of the two

with neuroses also lived away from home. The usefulness of this data is questionable due to the very large number of people for whom presence or absence of a diagnosis of a psychiatric condition was not known. However it would suggest that a known diagnosis is more likely for people living away from home, though this may be partly age related in that psychiatric diagnoses are relatively uncommon in children who, by and large, live at home.

Degree of Learning Disability

The Individual Schedule also included a question on the degree of learning disability suffered by the person. Once again there was a large amount of missing data where staff had recorded that the extent of the disability was unknown (n=103). Staff were asked to record the degree of handicap in the categories - Borderline : Moderate : Severe/Profound - where 'severe' was understood to mean an IQ of 50 or less. This produced a categorisation of the sample as being - 8% Borderline, 22% Moderate and 70% Severe/Profound in terms of intellectual disability. However, due to the large number of people for whom a rating was missing and the lack of information on how decisions were made to place individuals in each category it was felt that, in terms of description, it might be more fruitful to examine items describing observable behaviour or characteristics.

Personal Characteristics

As mentioned in the introduction, the aim of this study was to compare the characteristics of two groups of people with learning disability and challenging behaviour based on where they lived. The Individual Schedule contained eighteen items related to personal characteristics which staff might observe (see Methodology section and Appendix 2). Initial investigations revealed a large number of missing cases on the two variables associated with performance of domestic skills. This was largely due to the fact that the opportunity to observe such skills

was not available at a significant number of sites. These variables were therefore excluded. There were also a large number of missing cases on the variable relating to incidents of deliberate incontinence. This was due in part to staff being unable to make intentional attributions to incidents of incontinence at specific moments, or in particular places. This variable was therefore also excluded from analysis.

The remaining array of descriptive items was considered unwieldy, however, and potentially confusing as many items were highly correlated. Many of these variables could be seen as relating to level of intellectual or physical functioning. It was also considered that variables relating to behaviour might be a manifestation of intellectual disability, that is, an observable effect of disability. Variables relating to the consequences of challenging behaviour, such as disruption to the setting, were seen as a measure of magnitude. It was considered that such behaviour related variables might load on factors with attributes of disability. For example, presence of self injury might reasonably be expected to load on a factor with variables representing level of intellectual ability.

Data reduction

Factor analysis was used to try to identify any underlying factors which related to personal characteristics and thereby reduce the number of variables in subsequent analyses. This method of analysis was chosen so that no a priori assumptions were made about which variables would be important in describing individuals. Variables relating to abilities, challenging behaviour and its consequence were identified. Variables where few people scored, for example, PSYCHI - psychiatric diagnosis, were excluded. The variables included in the analysis were :

FITS - Presence of Epileptic seizures
 VIS - Sight
 DEAF - Hearing
 MOB - Mobility
 CONTI - Continence
 FEED - Ability to feed themselves
 WASH - Ability to wash themselves
 DRESS - Ability of dress themselves
 WILLSC - Willingness to perform self care tasks that is capable of doing
 OCC - Extent to which is able to be occupied constructively
 MONEY - Ability to use money
 SPEECH - Ability to communicate verbally
 UNDCM - Extent to which understands verbal communication
 UNDSP - Clarity of speech
 STEREO - Presence of stereotypic behaviours
 AGGR - Episodes of aggressive behaviour
 SINJ - Episodes of self injury
 DESTR - Episodes of destructive behaviour
 UNACC - Episodes of socially unacceptable behaviours
 OFTEN - Frequency of episodes of challenging behaviour
 DISRU - Usual extent of disruption caused by episodes of challenging behaviour
 CLEAR - Extent to which challenging behaviour causes work clearing up
 CALM - Extent to which challenging behaviour causes staff to have to calm other clients
 WORK - Extent to which challenging behaviour causes other additional work
 TERM - Frequency with which challenging behaviour causes the termination of an activity

Principal Axis was chosen as the extraction method in preference to Principal Components because the latter assumes that all the variance within the data may be explained by a set of factors which are orthogonal to one another. Principal Axis, on the other hand, holds that variables entered into the analysis will have a certain amount of their variance in common with each other, but that each will also have a part that is unique to that variable. The factors produced may therefore correlate with one another to some extent. This assumption was thought to be more realistic.

The method of rotation chosen was Oblique. Oblique rotation allows for the possibility that the resulting factors may be correlated with each other. A decision was made not to force the analysis to derive a specific number of factors but to allow the eigenvalues to direct factor

creation. The conventional δ value of 0 was adopted which allows for a moderate level of correlation between factors.

Factor analysis initially extracted five factors. In order to clarify the relationships of the variables to the factors the following method for exclusion from further analysis was adopted. Any variables which loaded at less than .40 on any of the factors were excluded. In addition, any variables which loaded at .40 or more on two or more factors were also removed. The factor analysis was then repeated with the reduced number of variables and the exclusion criteria repeated until the remaining variables were all loading at .40, or above, on only one factor (Pedhazur & Pedhazur Schmelkin, 1991). The final analysis produced four factors, as follows:

Factor 1	Loading
OCC - Extent to which is able to be occupied constructively	.49474
MONEY - Ability to use money	.71798
SPEECH - Ability to communicate verbally	.95486
UNDCM - Extent to which understands verbal communication	-.85855
UNDSP - Clarity of speech	.86975
STEREO - Presence of stereotypic behaviours	-.48983
Factor 2	Loading
DESTR - Episodes of destructive behaviour	.54624
CLEAR - Extent to which challenging behaviour causes work clearing up	.64884
TERM - Frequency with which challenging behaviour causes the termination of an activity	.40333
Factor 3	Loading
MOB - Mobility	-.71755
CONTI - Continence	.53355
FEED - Ability to feed themselves	-.61445

Factor 4**Loading**

UNACC - Episodes of socially unacceptable behaviours	.50248
OFTEN - Frequency of episodes of challenging behaviour	.68873

Factor Correlation Matrix

	Factor 1	Factor 2	Factor 3	Factor 4
Factor 1	1.00000			
Factor 2	-.09930	1.00000		
Factor 3	-.48185	-.06160	1.00000	
Factor 4	-.23148	.20200	.02557	1.00000

Factors 2 and 4 clearly relate to challenging behaviour. Episodes of destructive behaviour being related to termination of an activity for the individual involved and extra work clearing up for staff. Unacceptable behaviours, such as non-compliance, verbal abuse, hyperactivity or temper tantrums, were associated with a higher frequency of incidents. This was to be expected as many of these unacceptable behaviours were, by their nature, frequent. Indeed it was the frequency of their occurrence which was their particular challenge (e.g. hyperactivity, pestering).

Factors 1 and 3 define indices of intellectual ability and physical limitations. The correlation matrix above shows there was a substantial correlation between these two factors. This was to be expected as many of the people with the most severe physical limitations also had more severe learning disability. What was interesting, however, was that physical limitation was distinct enough from intellectual disability to produce a separate factor. It was proposed that this might be due to a group of people who, despite physical problems, suffered only a mild or moderate level of learning disability. Conversely, it was also reasoned that there may be a group with few physical limitations who were nonetheless severely intellectually disabled.

Indices

To investigate these characteristics further, index scores were computed for each individual. It was decided to limit the analysis to the two factors relating to intellectual and physical disability (Factors 1 and 3). The factors relating to behaviour were interesting, but indices were not constructed because it was felt that they would not help to illuminate differences between groups of people with learning disability and challenging behaviour who lived at home from those who did not, beyond use of the behavioural variable alone.

In computing index scores the following procedure was undertaken.

Variables with negative loadings were reversed. For each variable loading on the factor if the first level was 1 the following formula was applied to each individual's rating.

$$(Rating\ on\ variable - 1) / (k - 1)$$

Where k is the number of levels on the variable.

This procedure ensured that each variable would have equal weight in the final score.

Next $(Sum\ of\ the\ transformed\ variables / No.\ Variables) \times 100$

The final score on each index had a value ranging between 0 and 100 with a higher score denoting a higher level of disability. Scores on the intellectual ability index correlated with DEGREE (staff rating of degree of handicap) at $r = .34$, $p = .000$ and, when restricted to adults, at $r = .40$, $p = .000$. These relationships though strongly significant are disappointingly weak. However, it was felt that the computed index would provide a more robust measure of intellectual disability as it was based on observable characteristics and behaviour. In addition, it overcame the problem of the large number of missing cases on DEGREE, which may have

had a significant effect on further analyses. The appropriateness of using the same index with differing age groups is dealt with in the section on age and residency below.

Distribution of scores on indices

The distribution of scores on the two indices were then examined.

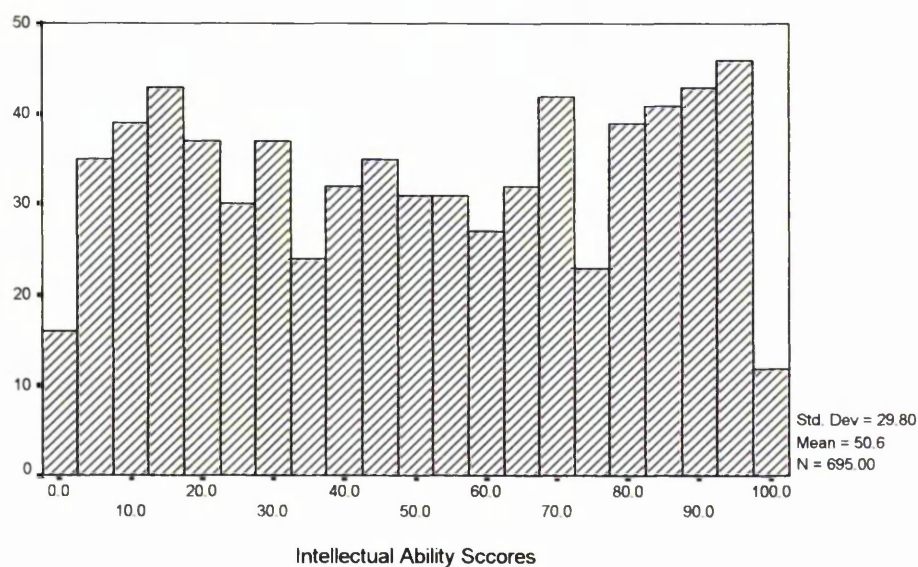


Figure 3: Distribution of scores on Intellectual Ability Index
(Low score = High level of ability)

Figure 3 shows the distribution of scores on the Intellectual Ability Index to be fairly flat but with perhaps slightly more people with either a high or low level of ability compared to those in the mid range. The distribution above shows that those identified as having challenging behaviour were drawn across the spectrum of ability levels. The distribution on the Physical Limitation Index is shown below.

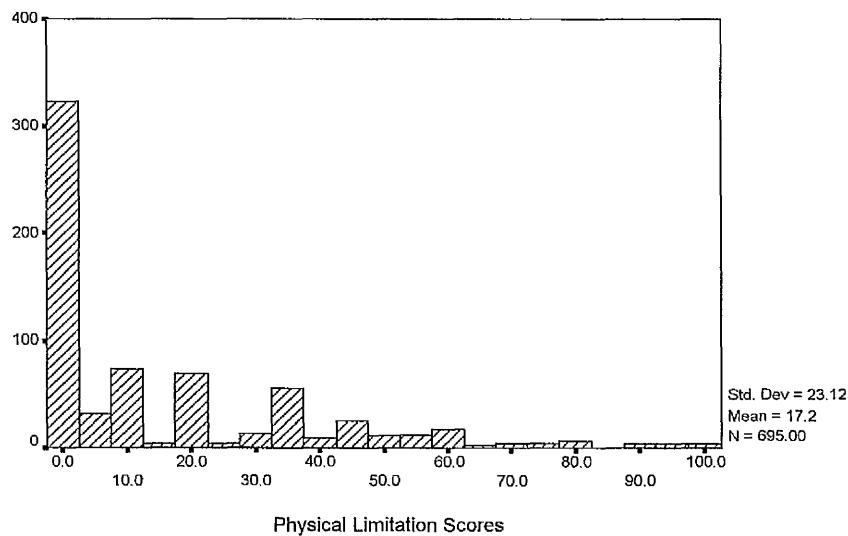


Figure 4: Distribution of scores on Physical Limitation Index
(Low score = fewer limitations)

This figure shows that a large number of the people identified by the 1988 survey had no physical limitation, in terms of incontinence, mobility or the ability to feed themselves. Unlike the distribution of scores on the Intellectual Ability Index the distribution is skewed. Taken together these distributions suggest that those identified as having challenging behaviour include a large proportion who had a more severe learning disability but no physical problems in terms of mobility, continence and feeding independently. Analysis of the characteristics of the individuals in the two types of residence will use the indices generated above as descriptors.

Disability Groupings

On further consideration of factors which may affect residential placement, it was reasoned that those factors operating, for example, in the decision to place a person with mild intellectual disability who is physically able into residential care, may differ significantly from those operating when the person is physically able but has a severe intellectual disability and so on. The fact that intellectual and physical disability produced separate factor loadings in

the Factor Analysis described above also supports the contention that intellectual and physical problems may have distinct effects.

Grouping the individuals concerned might be achieved in three different ways. That is, to group either by intellectual level, extent of physical limitation, or a combination of these two. Combining the two disability types, however, produced small groups for some combinations of intellectual and physical disability and was considered unsatisfactory. Similar effects could be obtained by splitting the group either by intellectual level or extent of physical limitation and then looking for relationships between significant variables and the remaining disability type for each subgroup. It was considered that, as the focus of this study was on a sample of people all diagnosed as having a learning disability, intellectual ability should be the grouping variable and not the extent of their physical limitation.

In order to examine groupings of people with similar levels of intellectual ability, quartiles were used to provide cut off points. The wider more flattened spread of scores on intellectual ability provided four groups with similar numbers of individuals in each. That is, those with a good level of intellectual ability (scores 0 to 24, N=172), a fair level of ability (scores 25 to 50, N=176), a group with poor intellectual ability (scores 51 to 78, N=175) and one whose intellectual ability was low (scores 79 and over, N=172).

The skewed distribution of the index of physical limitation did not allow an even split into four groups. The second highest quartile group was particularly small (N=32) and was therefore combined with the third group (N=168) to produce a group with moderate levels of physical limitation (scores 1 to 29, N=200). The collapsing was done in this way as it was considered that the small group may well have more in common with people whose level of

physical limitation was somewhat greater than a group who had no physical limitations of this type at all. The groups formed were as follows. One group with no physical limitations at all, as mentioned above (scores 0, N=324), one with moderate levels of limitation (scores 1 to 29, N=200), and one with a severe level of physical limitation (scores 30 and over, N=171). The groupings of people by level of intellectual ability and physical limitation is shown below.

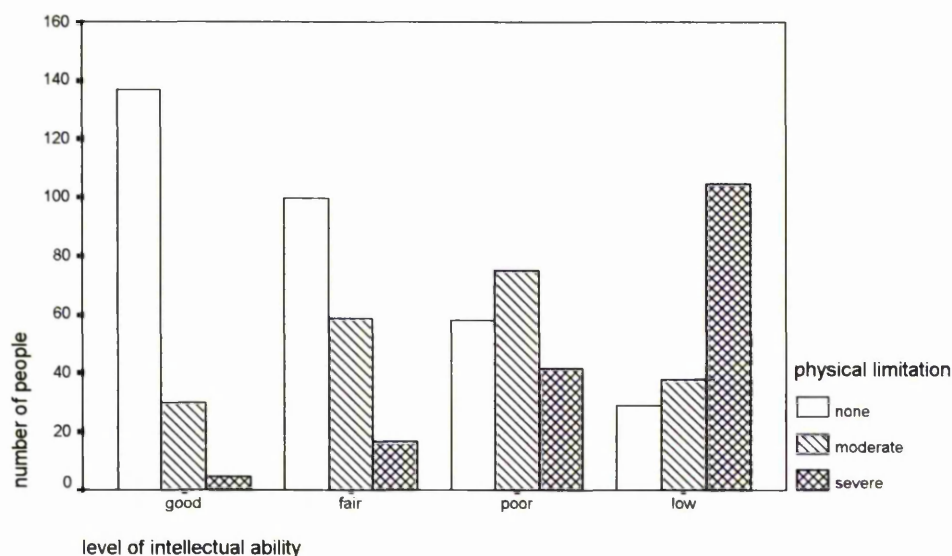


Figure 5: Intellectual and physical disability of people with learning disability and challenging behaviour aged 5 to 87 years (N=695)

As can be seen above, levels of intellectual and physical problems interact such that those with the highest level of intellectual ability were also more likely to have no physical limitations. Conversely, the number of people with severe levels of physical limitation increases with diminishing levels of intellectual ability. These are entirely in the expected directions. Those with a moderate level of physical problems are spread across the four levels of intellectual ability more evenly but are shown to be more likely to occur in the groups of people in the mid ranges of the ability. It was felt that the distributions between the two indices were in the expected directions and would be useful indicators of the intellectual and physical capabilities of participants.

Residency and Age

Given the strong relationship between residency and age, exploratory analyses were performed to establish how the main analysis should proceed. Ages were grouped in bands - 5 to 10; 11 to 19; 20 to 25 roughly representing primary, secondary and tertiary levels of education and then in 10 year bands to age 65, then 66 and over. The distribution of people in the different age groups who were identified in the survey as showing challenging behaviour in service settings is shown below.

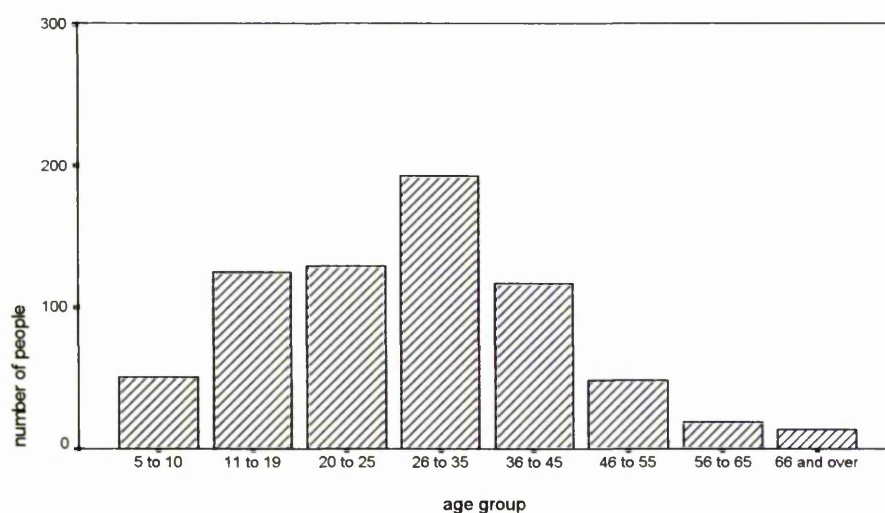


Figure 6: Age distribution of people with learning disability identified as showing challenging behaviour in service settings in 1988

Figure 6 shows that the majority of people identified as showing challenging behaviour were in early and middle adulthood with a sizable number in their teens. In terms of analysis regarding residential placement, it was necessary to establish the percentage of each age group who lived away from home. The following graph shows the percentage of each age group in alternative residential care.

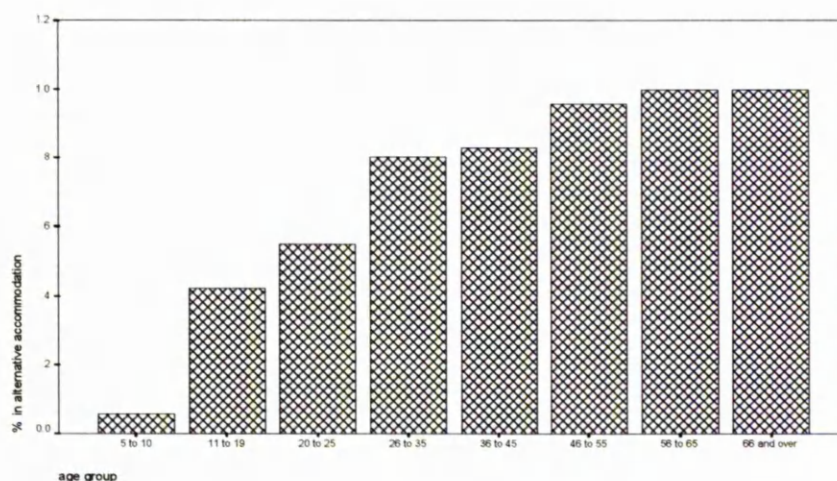


Figure 7: Percentages of people with learning disability and challenging behaviour in alternative residential care

The number of children under the age of 11 in alternative care was extremely small ($N=3$, 6%). The reason for this probably lies in the fact that it is not current policy to place children outside family care. Of the 125 children identified as having challenging behaviour who were between the ages of 10 and 20 years, 42% ($n=53$) were living away from the family home. This was a sizeable proportion of the group but it was felt that the factors influencing placement of older children into residential accommodation may well be different from those operating when a son or daughter has reached adulthood. It seemed appropriate therefore to consider children, defined as anyone under the age of 20, separately from adults.

At the other end of the age range, the number of people over the age of 45 living at home was found to be very small ($N=2$, 3%). When a person is over the age of 45 their parents may well be elderly and/or frail, or without coping resources (such as help from a partner, grandparent, sibling etc) which would have been available in the past. These circumstances may well render them incapable of continuing to care for their son or daughter. A number of parents

may, in fact, be deceased by the time their son or daughter reaches these ages. In consideration of the small number of adults over the age of 45 who lived at home and the feasibility of this as an option for older adults, this group was excluded from further analyses (N=81, 12%).

Scale reliability analysis

In order to establish whether the intellectual ability and physical limitation indices previously derived from analysis of the whole sample remained appropriate in the context of the age subgroups, scale reliability analyses were conducted. The results of the analysis are given in Table 1 below.

Table 1: Results of scale reliability analysis of intellectual ability and physical limitation indices for children, adults aged 20 to 45 and older adults

Intellectual Ability Factor	All (N=659)	5 to 19 (n=163)	20 to 45 (n=421)	46 + (n=75)
Overall Alpha (Cronbach)	.84	.81	.84	.80
Alpha if item deleted OCC	.82	.78	.83	.79
MONEY	.80	.78	.80	.74
SPEECH	.80	.76	.81	.75
UNDCM	.78	.74	.79	.72
UNDSP	.79	.76	.81	.72
STEREO	.89	.87	.89	.88
Physical Limitation Factor	All (N=694)	5 to 19 (n=175)	20 to 45 (n=438)	46 + (n=79)
Overall Alpha (Cronbach)	.71	.73	.70	.56
Alpha if item deleted MOB	.68	.70	.68	.47
CONTI	.60	.63	.59	.38
FEED	.58	.62	.55	.50

The overall alpha on the Intellectual Ability Factor is consistently high for all the subgroups, and the analysis shows that on the whole alpha is stronger when it includes each individual variable. The exception is STEREO without which the alpha improves by approximately .05 in each case. However, a decision was made to retain this variable in the index because during the factor analysis it maintained its loading on the factor despite the quite stringent criteria for remaining in the analysis.

Similarly, the overall alpha on the Physical Limitation Factor achieved .7 or above for the two younger age bands. The alpha for those aged 46 years old or more was not quite as strong and suggests that the index may not be as useful for this particular group. However, as stated above, this age group will not be included in further analyses and so this was not considered problematic. Therefore, with the exception of this last subgroup the consistency and strength of the Alpha values indicate that the intellectual ability and physical limitation indices can be assumed to be appropriate for all age bands.

Disability grouping for the subgroup

It was considered appropriate to examine the levels of disability for the reduced group. There were 125 people with scores of 24 and below (good intellectual ability), 107 with scores between 25 and 50 (fair intellectual ability), 110 scoring between 51 and 78 (poor intellectual ability), and 97 with a score of 79 or more (low intellectual ability).

As mentioned above, the distribution on the physical disability index was such that it was only possible to generate three groups. For the 20 to 45 year olds in the subgroup this yielded a group of 227 with scores of 0, these being the most able with no physical limitation; a group

of 130 who scored between 1 and 29, having a moderate level of physical limitation; and finally a group of 82 scored over 29 and had severe physical limitations.

There were only two people whose level of intellectual ability was good whilst suffering severe physical limitation. From a statistical standpoint a group of two may distort any findings and therefore data on these individuals was examined and it was considered reasonable to incorporate them into the group with moderate levels of physical problems.

The distribution of the sample between groups is shown in Fig. 8 below.

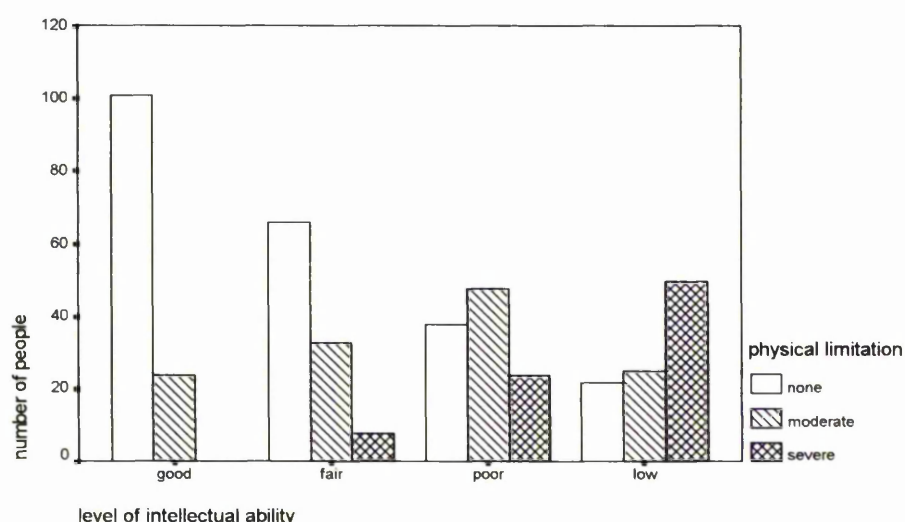


Figure 8: Intellectual and physical disability of people with learning disability and challenging behaviour aged 20 to 45 years (N=439)

Figure 8 shows that this distribution matches that of the whole group very closely. As with the whole group distribution, the number of people with physical limitations in terms of incontinence, mobility and feeding independently, decreases with increasing level of intellectual ability. Conversely, the number of people with severe physical problems increases with lower intellectual ability. The number of people with a moderate level of physical difficulty was more evenly spread across the groups, with the largest number having a poor,

rather than low, level of intellectual ability. This relationship is supported by the factor correlation matrix above. In that analysis there was a significant correlation between intellectual ability and level of physical limitation (Factors 1 and 3, $r = .48$, $p = .000$), and was confirmed by computation of the Pearson's product moment statistic ($r = .53$, $p = .000$).

Section one has provided composite indices of intellectual and physical problems useful for description of the individuals involved in this study. Groupings based on these indices also provide a useful means through which to examine other characteristics of the people concerned, whilst at the same time taking these aspects into account. The examination of age effects established that children and older adults differed from those in their middle years. This was as expected due to the policy context regarding residential placement of children and the feasibility of continuing to reside in the family home for older adults. This led to the establishment of a study group aged 20 to 45 years whose characteristics, in terms of intellectual and physical disability, reflected that of the group as a whole.

Summary of findings

- Indices of intellectual ability and physical limitation were produced to render the large number of descriptive variables more amenable to statistical analysis.
- As current policy does not favour the placement of children outside the family home and because placement decisions regarding children were likely to differ substantially from those affecting adults, children up to age 19 were investigated separately.
- Adults over the age of 45 were far less likely to live at home and it was considered that, as such an arrangement is often not feasible for older adults whose parents may be frail or deceased, analysis would be restricted to those aged 20 to 45 years ($N=439$).

- Scale reliability analyses showed that the indices of intellectual ability and physical limitation could be assumed to be appropriate for each age band.
- The distribution of the selected adult group on the indices of intellectual ability and physical limitation mirrored that of the entire sample (N=695) very closely.

2 *Residency*

Comparisons of personal characteristics across type of residence for the selected group

The indices of intellectual ability and physical limitation and variables describing the presence of challenging behaviour, along with the two variables which were considered to measure the magnitude or impact of such behaviours (frequency and extent), were compared across residence. Two new variables were computed, number of behaviour types reported and number of behaviour types said to be a serious management problem. In the questionnaire completed by staff members the four behaviour types were presented and staff asked to indicate whether the behaviour had presented a management problem in the previous month. There were four response categories, Serious, Lesser, Controlled and No. Number of behaviour types was calculated by a count of the behaviours said to be exhibited (range 1 to 4). Number of behaviours presenting a serious challenge was a count of behaviours rated 'serious' (range 0 to 4).

The number of challenging behaviours present was included at this stage, to provide a comparison with other studies of factors affecting the decision to seek alternative residential care. Research has shown a relationship between maternal stress and number of challenging behaviours (Hayden & Goldman, 1996) but no relationship was found with actual placement in residential care (Freedman, Krauss & Seltzer 1997). It was considered that as in this study all the participants were identified as having challenging behaviour, there was a greater possibility that this may be reflected in maternal stress levels and consequently in the numbers of people in alternative care. The study provided an opportunity to explore whether the number, or severity, of challenging behaviours for a sample of people all with challenging behaviour would have an effect on placement.

One way analysis of variance showed no significant differences between the groups living in family and residential care in terms of intellectual disability ($F = .49$ $p = .49$). However, analysis did show a difference between the groups in terms of physical limitations ($F = 5.20$ $p = .023$). The results of these comparisons are shown in Table 2 below.

Table 2: Comparisons of personal characteristics of people with learning disability and challenging behaviour who live at home and in alternative residential care (N=439)

Variable	df	F Ratio	F Prob. (Two- tailed)	% Variance Explained (E ²)
Intellectual disability	1,437	.49	.485	-
Physical limitation	1,437	5.20	.023	1.18
Age	1,437	25.79	.000	5.57
Sex	1,437	10.53	.001	2.35
Aggressive behaviour	1,437	6.56	.011	1.48
Self injury	1,437	3.54	.060	-
Destructive behaviour	1,437	1.95	.163	-
Socially unacceptable behaviour	1,437	.98	.323	-
Frequency of incidents of challenging behaviour	1,436	7.48	.007	1.69
Extent of disruption caused	1,433	1.49	.223	-
Number of challenging behaviours	1,437	.41	.523	-
Number of challenging behaviour presenting a serious management problem	1,437	.68	.410	-

This table shows that, as expected, the group still living in the family home were more likely to be of a younger age. It also suggests that they were likely to be female and to show more frequent episodes of challenging behaviour in service settings. The extent of any disruption to the setting caused by incidents of challenging behaviour and the number challenging behaviours did not significantly differ between the groups. However, episodes of aggressive

behaviour were more likely in people who lived in the family home. These people also tended to have more physical limitations.

The frequency of incidents was investigated further and it was found that higher frequency of episodes of challenging behaviour were more likely to be reported in day as opposed to residential settings (1,414 df, $F = 10.89$, $p = .001$). Of those who lived in the family home, 103 (92%) were identified as showing challenging behaviour in day setting and only 9 (8%) in respite care. Amongst those living residential care 273 (90%) were identified in their residence and 32 (10%) in day settings. This information was missing for 8 people.

This tendency to report higher frequency of episodes of challenging behaviour in day settings, together with the fact that most people living at home were identified as showing challenging behaviour in day settings, appears to be an area of confounding. It is not possible to determine why episodes of challenging behaviour should be perceived to happen more frequently in day settings. One may speculate that as colleges, day centres and other day services on the whole cater for higher numbers of people than residential or respite facilities, any challenging behaviour may be more difficult to cope with due to attending to the needs of a larger group of people. That is, episodes may become more noticeable or be perceived as presenting a challenge in this environment, whereas if the staff/client ratio is better it may not. Alternatively, staff may be accurately reflecting a real difference in the behaviour of the people who use their service.

It was possible to repeat the analysis shown above (Table 2) using only information provided by day settings for 191 people (100 living at home and 91 away). This was done by including individual schedules for some of the people whose main analysis was based on information

supplied by their residential setting. This analysis confirmed that gender and aggressive behaviour differentiated the groups with those at home more likely to display aggressive behaviour (1,189 df, $F=13.56$, $p=.000$), and those away being more likely to be male (1,189 df, $F=4.17$, $p=.043$). There were no significant differences on any of the other variables.

Using 'main' schedules (day and residential) it was found that more people were identified as showing self injury (1,415 df, $F=7.83$, $p=.003$) and destructive behaviour (1,415 df, $F=8.66$, $p=.005$) in residential settings than day settings. Neither of these variables differed between groups of people living at home or in residential care, although as shown above, self injury approached significance. This finding suggests that there may be an effect due to setting possibly resulting from the perception of behaviours as they interact with other aspects of a particular environment.

Discriminant Analysis

In order to determine whether the variables found to differ between groups could be used as predictors of placement, Discriminant Analysis was performed. The stepwise method of entry was used with F probabilities of .05 to enter and .10 to remove which represented a reasonable amount of flexibility for inclusion in the final solution. The stepwise method was chosen so that each variable was controlled for before the next was entered into the analysis. Prior probabilities given were that the groups would be equal as no assumption about group membership was made. The variables found to differ significantly on the one-way ANOVAs between the group living at home and those living in alternative accommodation were included into the analysis. Level of intellectual disability was also entered because it was thought that this might become significant in placement decisions once other variables were accounted for. All variables remained in the final solution as shown below:

Table 3: Discriminant analysis of variables associated with type of residency in 1988 for adults with learning disability and challenging behaviour.

		Wilks' Lambda	Significance
Step 1	Age	.946	.000
Step 2	Sex	.923	.000
Step 3	Frequency of Challenging Behaviour	.910	.000
Step 4	Intellectual Disability	.899	.000
Step 5	Physical Disability	.881	.000
Step 6	Aggressive Behaviour	.872	.000

Summary Table

Actual Group	No. of cases	Predicted Group 0	Membership 1
Family Home - Group 0	115	78 68%	37 32%
Residential Care - Group 1	323	108 33%	215 67%

These variables together correctly classify 67% of cases overall. That is, for each group the variables in the analysis correctly classified at least two thirds of the people. This result suggests that there were also other, unmeasured, variables influencing placement to consider.

Disability Groupings

As mentioned in the first part of this study, consideration was given to the effect of disability type on residency and the effects of level of intellectual ability explored.

To investigate how level of disability might influence residential placement, discriminant analysis was performed separately for each level of intellectual ability using the same criteria described above. In this way it was hoped to establish which of the variables found to differ significantly between residential groups were instrumental in predicting type of residence for

people with differing levels of ability. The variables entered into the analysis were those found to be related to type of residence in the earlier analyses. That is, sex, age, physical limitation, aggressive behaviour and frequency of incidents of challenging behaviour. The results are shown in Table 4 below.

Table 4: Variables associated with type of residence for adults with different levels of learning disability who show challenging behaviour.

Level of intellectual ability	Variables with predictive power	Wilks' Lambda	Significance
Good (n=125)	Sex	.88972	.001
	Age	.91858	.001
	Physical limitation	.88967	.932
	Aggressive behaviour	.86337	.057
	Frequency of incidents of challenging behaviour	.88775	.605
Fair (n=106)	Sex	.87293	.068
	Age	.89987	.636
	Physical limitation	.89123	.271
	Aggressive behaviour	.89292	.313
	Frequency of incidents of challenging behaviour	.90185	.001
Poor (n=110)	Sex	.86330	.701
	Age	.90333	.001
	Physical limitation	.86450	.000
	Aggressive behaviour	.85887	.407
	Frequency of incidents of challenging behaviour	.83834	.072
Low (n=97)	Sex	.84185	.367
	Age	.92739	.008
	Physical limitation	.84927	.001
	Aggressive behaviour	.84922	.939
	Frequency of incidents of challenging behaviour	.84738	.650

These analyses show increasing age as a predictive factor for three of the four ability levels, for those with a fair level of intellectual ability, however, age was not predictive. For those with a good level of intellectual ability, gender was also a significant predictor with males

more likely to live away from home. Aggressive behaviour approached significance as a predictor for this group. Gender also approached significance for those with a fair level of intellectual ability. There was no significant correlation between age and sex for any of the groups.

For those with a fair level of intellectual ability, only frequency of incidents of challenging behaviour predicted type of residence. In this group, those who lived at home showed a higher frequency of challenging behaviour in service settings. As stated previously, higher reported frequency of episodes of challenging behaviour was associated with being in day as opposed to residential services. The numbers of people identified from each source were examined and the distribution reflected that for the sample as a whole. People with a fair level of intellectual ability were no more likely to be living in the family home than the group as a whole. As frequency did not discriminate any of the other subgroups it was assumed that challenging behaviours were of particularly high frequency for this group compared to others. For those with a fair level of intellectual ability who lived at home, there were 36% more people showing episodes of challenging behaviour at least daily than there were in residential care. For those with good intellectual ability only 5% more of those living at home showed this frequency of challenging behaviour. For the poor and low levels of intellectual ability the difference between residences was 25% and 13% respectively. This analysis showed that the discrepancy was particularly large for those with a fair level of intellectual ability and suggests an actual difference in behaviour between settings rather than a setting effect.

Frequency correlated significantly with the presence of socially unacceptable behaviours ($r = .42$, $p = .000$) such that the more serious the problem managing socially unacceptable behaviours, the more often episodes of challenging behaviour were reported to occur.

For those with the lower levels of intellectual ability (poor and low) physical limitation was a significant predictor of type of residence in addition to age. In both cases those living at home tended to have a higher level of physical limitation, that is they were more likely to have mobility problems, to be incontinent and need help to feed themselves. Of the 20 people with low intellectual ability at home, 80% (n=16) had severe physical limitations. There were 77 people with low intellectual ability in residential care, 44% (n=34) of these had severe physical limitations.

Summary tables, showing the numbers correctly placed using the variables found significant, are shown below.

Table 5: Discriminant Analysis summary tables for residential location of people with good, fair, poor and low levels of intellectual ability

Good Intellectual Ability		
Actual Group	No. of cases	Predicted Group Membership 0 1
Family Home - Group 0	33	22 67% 11 33%
Residential Care - Group 1	92	34 37% 58 63%
Percentage correctly classified 64%		
Fair Intellectual Ability		
Actual Group	No. of cases	Predicted Group Membership 0 1
Family Home - Group 0	31	20 65% 11 36%
Residential Care - Group 1	75	22 29% 53 71%
Percentage correctly classified 69%		

Table 5 (continued)

Poor Intellectual Ability		
Actual Group	No. of cases	Predicted Group Membership 0 1
Family Home - Group 0	31	22 71% 9 29%
Residential Care - Group 1	79	25 32% 54 68%
Percentage correctly classified 69%		
Low Intellectual Ability		
Actual Group	No. of cases	Predicted Group Membership 0 1
Family Home - Group 0	20	14 70% 6 30%
Residential Care - Group 1	77	24 31% 53 69%
Percentage correctly classified 69%		

Taken as a whole, the above analyses suggest that there may well be different factors in operation in the residential placement of individuals, dependent on the type and extent of disability they suffer. The summary tables showed that it may be possible to predict residency for more than two out of three people on the basis of the above variables, an improvement for most groups over the whole group analysis. It remains, however, that there may be factors in operation, relating directly to the families of these individuals, that have explanatory power in whether a person with learning disability and challenging behaviour remains in the family home.

Summary of findings

- Those living away from home tended to be older and male. They were more likely to have fewer physical limitations but were less likely to show aggressive behaviour.
- A finding that those at home tended to show a higher frequency of episodes of challenging behaviour may be related to the setting in which the questionnaires were completed. The majority of questionnaires for those who lived at home were completed in day settings. These settings were significantly more likely to report high frequency of challenging behaviour than residential settings.
- It was not possible to determine whether high frequency of challenging behaviour accurately reflected the behaviour of the people studied or the perceptions of the staff completing questionnaires in the context of day settings. That is, settings where there may be a poorer staff to client ratio.
- There were no significant differences in the number or severity of behaviours exhibited by those living at home compared to those in residential care.
- Discriminant Analysis showed that 67% of people could be correctly classified in terms of residence on the basis of age, sex, frequency of incidents of challenging behaviour, intellectual ability, physical limitation and presence of aggressive behaviour.
- An original finding in this thesis was that discriminating variables differed across levels of intellectual ability. Discriminant Analysis revealed that the following characteristics were associated with residential care . . .

Good intellectual ability Age (older) and sex (male).

Fair intellectual ability Frequency of episodes of challenging behaviour
(lower).

Poor/low intellectual ability Age (older) and physical limitation (less).

- The variables were able to discriminate between residences for 69% of people for all but the group whose intellectual level was good. In the latter case 64% could be correctly classified.
- It was suggested that there were likely to be other, unmeasured, variables in operation in decisions leading to placement in alternative residential care.

3 *Children in Care*

There were 175 children identified as showing challenging behaviour in the 1988 survey. As stated above, 56 of them were living away from home, however only three of these children were aged 10 or less. In looking for possible factors affecting placement decisions similar analyses to those conducted for adults were used.

As a first step age effects were once again considered. There were no significant correlations between age and level of ability or type, number, or severity of behaviour problems. As expected, however, there was a strong correlation between age and type of residence ($r = .36$, $p = .000$) with older children being more likely to live away from home. The fact that only three children under the age of eleven lived away from home suggested that decisions on residential placement for younger and older children may well also vary. For this reason, and as the number of children under the age of 11 was so small, the analysis was restricted to the 11 to 19 years age group ($N=125$).

Comparisons on personal characteristics of children based on residency

A series of one way analysis of variance tests were undertaken on the variables representing personal characteristics and challenging behaviour. The results are displayed in Table 6 below.

Table 6: Comparisons of personal characteristics of children with learning disability and challenging behaviour who live at home and in alternative residential care (N=125)

Variable	df	F Ratio	F Prob.	% Variance Expl. (E ²)
Intellectual disability	1,123	2.32	.131	-
Physical limitation	1,123	.59	.443	-
Age	1,123	1.58	.212	-
Sex	1,123	6.26	.014	4.85
Aggressive behaviour	1,123	.01	.907	-
Self injury	1,123	2.49	.117	-
Destructive behaviour	1,123	.03	.870	-
Socially unacceptable behaviour	1,123	.02	.893	-
Frequency of incidents of challenging behaviour	1,123	3.18	.077	-
Extent of disruption caused	1,123	.01	.934	-
Number of challenging behaviours	1,123	.30	.586	-
Number of challenging behaviour presenting a serious management problem	1,123	.96	.328	-

The table shows that, when limited to older children, age does not vary significantly different between groups. There was no significant difference in behaviour type, number or severity between the two groups. The only variable that differed significantly was gender with 50% of the boys (n=42) living away from home compared to 27% of the girls (n=11). The table shows that one other variable approached significance, that is, frequency of incidents of challenging behaviour.

Discriminant analysis

Discriminant analysis was performed on type of residence and, as with the previous data sets, the stepwise method of entry and probability to enter and remove of .05 and .10 were adopted. Variables included were gender and frequency of incidents of challenging behaviour, because the former discriminated between the groups when the ANOVA was performed and frequency because it was considered that this might reach significance once other effects were controlled. In addition, the intellectual and physical disability indices were included since it was considered that these may be important factors in the placement of children in alternative residential care. The solution is shown in Table 7 below.

Table 7: Discriminant analysis on variables associated with type of residence for children with learning disability and challenging behaviour (n=125)

		Wilks' Lambda	Significance
Step 1	Sex	.952	.014
Step 2	Frequency of Challenging Behaviour	.922	.007
Step 3	Intellectual Ability	.867	.001

Summary Table

Actual Group	No. of cases	Predicted 0	Group Membership 1
Family Home - Group 0	72	40 56%	32 44%
Residential Care - Group 1	56	18 34%	35 66%

Three of the four variables entered remained in the final solution. Only physical limitation was not instrumental in discriminating between groups. The remaining variables together correctly classified 60% of cases. In other words almost two out of three older children can be predicted to be living away from home on the basis of their gender (male), intellectual ability (lower) and frequency of episodes of challenging behaviour in service settings (lower).

72% of children at home were exhibiting some form of challenging behaviour at least daily, as opposed to 45% of those living in alternative residential care. As with the adult sample frequency of incidents of challenging behaviour was significantly different across day and residential settings (1,115 df, $F = 12.56$, $p = .001$). As with adults, the majority of children living in the family home were identified in their day setting (85%), whereas most of those living in residential care were identified in their residence (78%). As with the adults, it is difficult to ascertain whether this difference is in fact based in the behaviour of the children concerned or in the extent to which behaviours present a challenge in particular settings.

Frequency of incidents was associated with the presence of socially unacceptable behaviours ($r = .30$, $p = .011$ home ($n = 72$), $r = .39$, $p = .004$ away ($n = 53$)). As noted previously, this association is as expected because many such behaviours are, by nature, high frequency. In addition, for the group of children living away from home, frequency of incidents was associated with self injury ($r = .42$, $p = .002$, $n = 53$).

In terms of behaviours included under the heading 'socially unacceptable', pica ($r = .37$, $p = .016$, $n = 42$), screaming ($r = .50$, $p = .001$, $n = 42$) and overactivity ($r = .40$, $p = .007$, $n = 45$) were significantly correlated with higher frequency for children in residential care. For those at home frequency was associated with screaming ($r = .39$, $p = .003$, $n = 56$). Frequency was not correlated with any one type of self injury for those in residential care.

On further examination of the types of behaviour shown in service settings, no significant differences were found between the groups. Presence of these types of behaviour cannot be claimed to be an indication of placement decisions because behaviours may be setting specific. However they may indicate behaviours which, if occurring with high frequency, could have

been problematic at home. This analysis suggests that although the group of children living at home had the highest frequency of incidents of challenging behaviour in service settings, this may largely be accounted for by screaming and other unacceptable noises in a classroom situation.

Disability groupings

As with the adult data, groupings of individuals with varying levels of intellectual ability were examined. Figure 9 below shows the grouped distribution of children on the intellectual and physical limitation indices.

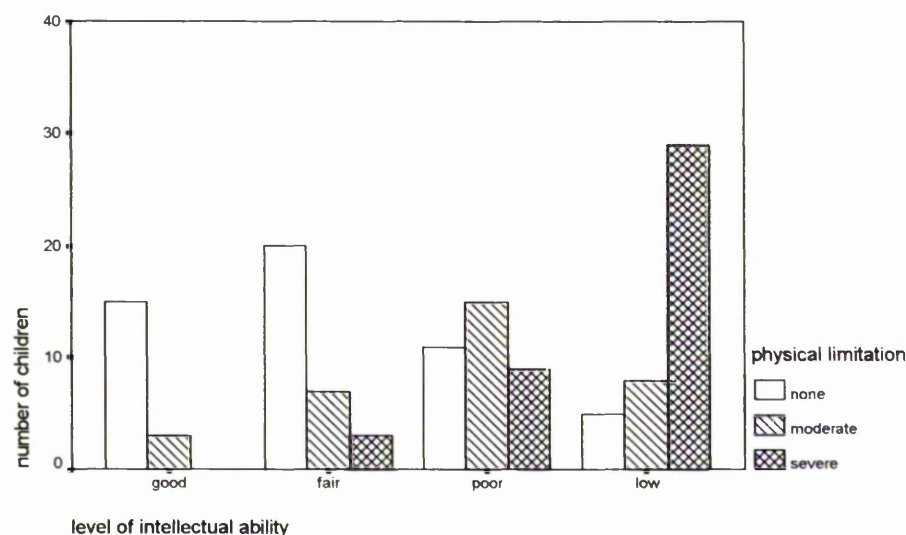


Figure 9: Intellectual and physical disability of children with learning disability and challenging behaviour aged 11 to 19 years (N=125)

There were 18 children (14%) with good intellectual ability and 30 (24%) whose ability was fair. Thirty five children (28%) had a poor intellectual level, whilst for 42 (34%) their level of intellectual ability was low. Groupings on the physical limitation index showed that 51

(41%) had no limitations while 33 (26%) had a moderate level. The remaining 41 children (33%) had severe problems in this regard.

The pattern of distribution for children is different to that for the entire sample and that of the younger/middle adults (20 to 45 years). This is particularly noticeable in the lower level of intellectual ability and greater degree of physical problems. The reasons for this may be twofold. At the most basic level, differences may be accounted for by developmental delay such that, were the same observations made of this group of children when they reach adulthood, they may well show increases in both intellectual and physical functioning on these indices. The second factor may be in the identification process undertaken in the survey in that only schools for children with severe learning disability were approached. Indeed children with mild levels of intellectual disability may not be recognised as such until well into their school years. However, for this sample, age did not correlate with either intellectual or physical disability as measured by the computed indices, though physical limitation did approach significance ($r = -.06$, $p = .06$). This suggests that developmental increments in intellectual ability were not apparent though there appears to be some increase in physical development with advancing age.

The comparatively smaller number of children in the sample meant that it was not possible to conduct Discriminant Analysis for children with differing levels of intellectual ability.

This section has highlighted the possibility that gender (male) and lower levels of intellectual ability may be indicators of placement in residential accommodation. The reason for the lower frequency of episodes of challenging behaviour for children living in residential care is difficult to explain. However, it is possible that high levels of incidents of challenging

behaviour prior to a move may be a contributory factor. Alternatively, where children at home exhibit high frequency behaviours, such as screaming and other unacceptable noises, these may be easier to live with than behaviours such as self injury. The latter did not reach significance in the ANOVAs reported above but was the behaviour on which the largest differentiation occurred. Fourteen children (26%) who lived in alternative accommodation exhibited self injury which was a serious management problem, compared to 12 (17%) of those who still lived at home.

The discriminant analysis suggested that the variables described above correctly classify almost two thirds of children aged 11 to 19 years, in terms of residence. It seems highly likely, however, that as with the adult sample there are factors within the family that have a contributory influence in whether an individual child is placed into alternative care.

Summary of findings

- Analysis was restricted to the 11 to 19 years age group as this comprised 71% of the sample (N=125) and because only three children under this age lived away from home.
- Only gender differed significantly between groups with more boys living away from home.
- Discriminant analysis showed that 60% of the children could be correctly classified on the basis of gender (male), intellectual level (lower) and frequency of behavioural episodes (lower).
- Frequency of incidents of challenging behaviour approached significance ($p = .08$) and as with the adult group those at home were reported to show episodes of challenging behaviour at a higher frequency than those in residential settings. As with adult data there was some confounding due to setting and it was therefore not possible to

determine whether this difference stemmed from the behaviour of the children or the way behaviour was perceived in day as opposed to residential settings.

- High frequency was associated with screaming for both those living in the family home and in residential care but also with eating non food objects and overactivity for the latter.
- Distribution of the entire sample on the index of intellectual ability showed that similar numbers of people had been identified as showing challenging behaviour across the full range of ability.
- Distribution of the sample on the index of physical limitation showed that the majority of people had no difficulties in terms of mobility, continence and ability to feed themselves.
- Distribution of scores on the indices showed that children had lower levels of intellectual ability and greater physical limitations compared with adults. These differences may be accounted for by developmental factors and/or the selection policy adopted in the survey which may well have inflated the numbers of children with more severe disability.

4 *Summary*

Differences between adults aged 20 to 45 years, who had learning disability and challenging behaviour were found, dependent on type of residence. Those who lived at home were more likely to be younger, have greater physical problems and be female. They were also more likely to exhibit a higher frequency of incidents of challenging behaviour in service settings. There was a slight tendency for those living at home to be identified as showing aggressive behaviour.

People who lived in alternative residential care tended to be male, older and have fewer physical problems. These people exhibited a lower frequency of challenging behaviour in service settings.

As discussed above, the fact that those people with learning disability and challenging behaviour who lived at home tended to be younger is to be expected. In the normal course of events one remains at home as a child and moves on to alternative accommodation in early adulthood. This effect of age was investigated using the entire sample and it was found that younger age was correlated with having more severe intellectual disability though this may be partly accounted for by developmental factors. This lower level of intellectual ability might also have arisen due to procedures adopted in the survey. That is, only schools for children with severe learning disability were covered. This strategy would also tend to inflate the numbers of children with more severe learning disability.

Discriminant analysis of adult and child data, based on the variables described above, was able to classify around two thirds of each group correctly. This percentage fell short of the amount at which one would feel confident that the variables were largely influential in determining

residency. It was concluded that there were other, unmeasured, factors that were likely to be having an effect.

A more detailed examination of the groups based on intellectual ability and physical limitation, for adult data, showed some differences in personal characteristics dependent on type of residence. For those with a good level of intellectual ability those who lived away from home tended to be older and male. For those with a fair level of ability frequency of incidents of challenging behaviour (lower) was the only predictor of living away from home. Frequency, in turn, was found to correlate with the presence of socially unacceptable behaviours for this group. For the remaining levels of intellectual ability (poor and low), living in alternative residential care was predicted both by age, that is being older, and having fewer physical limitations. These findings of possible different factors affecting placement associated with different levels of disability has not been reflected in the literature thus far.

For the child data there was little difference between the groups who lived at home and those who lived in residential care. As with the data as a whole, those in residential care tended to be older and for this reason, and the fact that only 3 children aged 10 or under lived away from home, analysis was restricted to the 11 to 19 age group. Those living at home exhibited a higher frequency of challenging behaviours in service settings. For both groups frequency of incidents of challenging behaviour was correlated with exhibiting socially unacceptable behaviour, and for those living in alternative care, with the presence of self injury. The only differences in behaviour listed as 'socially unacceptable' which correlated with higher frequency was screaming and making other unacceptable noises, which correlated with higher frequency for both groups. Eating non food objects and overactivity/constant pacing was associated with high frequency for children who lived away from home. Whether these

differences were due to living away from home, or indicative of problems in coping with such behaviour at home, was not possible to determine from this data. However, it seemed likely that behaviours such as screaming, groaning or making other inappropriate noises in a classroom setting may have greater impact and therefore be perceived to occur more frequently than in other more leisure based contexts.

Study 1b: Characteristics of people with learning disability and challenging behaviour who lived in the family home and in residential care in 1995.

1 Preliminary Exploration of the Variables

As a first step in this extension of the work examining differences between the population of people with learning disability and challenging behaviour who live in the family home and those in alternative residential accommodation, it was considered appropriate once again to examine the personal characteristics of the group (N=297).

Diagnoses

The 1995 version of the Individual Schedule had been amended and extended in various ways as a result of the experience gained in 1988. However, many of the variables remained in their original form. Some variables which had produced little useful information were excluded from this instrument in an attempt to reduce its length. Amongst those variables to go were descriptors such as whether the person had Down's Syndrome or Cerebral Palsy. This was because of the small number of people affected by these conditions amongst those identified as showing challenging behaviour, as well as instances where staff were unaware of such diagnoses. These small groups were unsuitable for inclusion in sophisticated analyses and therefore the usefulness of collecting such data was questioned.

The questions on presence of Autism and Psychiatric diagnosis remained despite similar difficulties with missing data and small affected numbers. As experienced in 1988, however, there were significant amounts of missing data, 12% and 43% of the sample respectively. Of those known to be autistic (n=13, 4%), 77% lived in the family home. This compares with 48% of those said not to be autistic who lived at home and 47% of those for whom a diagnosis of autism was not known.

Of the 13% (n=38) of the sample who were known to have a psychiatric diagnosis, six suffered schizophrenia, two of whom lived at home. A further twelve had unclassified disorders and ten of these were in alternative residential care. Six of the seven people known to be suffering from depression lived in alternative residential care, as did four of the six people with an affective disorder. One person suffered a neurosis and lived away from home, as did five out of six people described as having an 'other' type of psychiatric condition. Where there was known to be no psychiatric diagnosis 48% lived in the family home. Similarly, 62% of those whose psychiatric condition was unknown lived at home.

As with the 1988 data, apart from noting that people who are known to have a psychiatric disorder tend to be living away from home, it was considered that the numbers involved were too small to use in further analysis. The reason why those with diagnoses tend to be living away from home may lie simply in the fact that such conditions are more usually discovered in adults or that staff may have easier access to health services and/or more comprehensive records on people for whom they provide long term residential services. This is emphasised by the lack of information in this respect for those who lived at home (n=75, 52%). From this data it cannot be assumed that having a psychiatric diagnosis has any direct bearing on type of residence.

Personal Characteristics

In Study 1a, a decision was made to construct indices, based on staff observations, to represent personal characteristics. Factor analysis generated two factors which represented intellectual ability and physical limitation. These indices were used in subsequent analyses in preference to a variable from the 1988 version of the Individual Schedule, which described staff knowledge regarding the degree of learning disability suffered by the person. One of the main

problems with this variable was the amount of missing data. The 1995 version of the Individual Schedule abandoned this variable. It was therefore considered appropriate to perform a factor analysis on the personal characteristics of the sample to establish validity of using 1995 versions of the same variables to derive comparable indices.

For the purposes of this analysis any variables that had been changed were recoded to be compatible with the 1988 version. For example, in 1988 the variable involving stereotypic behaviours was concerned only with the frequency of occurrence. The 1995 schedule asked about the occurrence of specific types of behaviour (for example, rocking) without assessing frequency. For the purposes of this analysis a new variable was created which merely noted whether the individual showed *any* stereotypic behaviour.

Two variables which were used in the analysis using 1988 data had been excluded from the schedule in 1995. These were WILLSC (willingness to perform self care tasks that is capable of doing) and OCC (extent to which may be occupied constructively). In the case of WILLSC the loss was not felt to be significant as this variable did not load on any of the factors generated. The second variable OCC, however, remained in the analysis and became part of the final solution. It was used in the calculation of the index of intellectual ability. This loss was unfortunate, but as the remaining variables produced strong loadings on the factor, it was considered that a solution without OCC may provide an acceptable alternative.

Data reduction

To be directly comparable with the 1988 data analysis the same Factor Analysis technique was applied. That is, Principal Axis analysis was employed with oblique rotation ($\delta=0$). The same process for exclusion of variables from further analysis was also adopted. Specifically,

variables loading at less than .40 on any factor, or at .40 or greater, on two or more factors were excluded from further analysis. This process was repeated until each variable loaded at .40 or more on only one factor.

Variables included in the analysis were as follows:

FITSB - Presence of epileptic fits
 VISB - Sight
 DEAFB - Hearing
 MOBB - Mobility
 CONTIB - Continence
 FEEDB - Ability to feed themselves
 WASHB - Ability to wash themselves
 DRESSB - Ability to dress themselves
 MONEYB - Ability to use money
 COMMCN- Ability to communicate verbally
 COMMUND- Extent to which understands verbal communication
 COMMCL - Clarity of speech
 STEREOTY - Presence of stereotypic behaviours
 AGGRB - Episodes of aggressive behaviour
 SINJB - Episodes of self injury
 DESTRB - Episodes of destructive behaviour
 UNACCB - Episodes of socially unacceptable behaviours
 OFTENB - Frequency of episodes of challenging behaviour
 DISEXT - Usual extent of disruption caused by episodes of challenging behaviour
 CLEARB - Extent to which challenging behaviour causes work clearing up
 CALMB - Extent to which challenging behaviour causes staff to have to calm other clients
 TERMB - Frequency with which challenging behaviour causes the termination of an activity

The final analysis produced five factors, as follows:

Factor 1	Loading
MONEYB - Ability to use money	.70666
COMMCN- Ability to communicate verbally	.86423
COMMUND- Extent to which understands verbal communication	.88566
COMMCL - Clarity of speech	.84877
STEREOTY - Presence of stereotypic behaviours	.50986

Factor 2	Loading
UNACCB - Episodes of socially unacceptable behaviours	.48094
OFTENB - Frequency of episodes of challenging behaviour	.42133
DISEXT - Usual extent of disruption caused by episodes of challenging behaviour	.90273
CALMB - Extent to which challenging behaviour causes staff to have to calm other clients	.50306
TERMB - Frequency with which challenging behaviour causes the termination of an activity	.44342
Factor 3	Loading
MOBB - Mobility	.78596
CONTIB - Contenance	.45166
FEEDB - Ability to feed themselves	.60757
Factor 4	Loading
AGGRB - Episodes of aggressive behaviour	-.47730
DESTRB - Episodes of destructive behaviour	-.71826
CLEARB - Extent to which challenging behaviour causes work clearing up	-.63616
Factor 5	Loading
VISB - Sight	.54367
DEAFB - Hearing	.50407

Factor Correlation Matrix

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Factor 1	1.00000				
Factor 2	-.03389	1.00000			
Factor 3	.48792	.11840	1.00000		
Factor 4	.04880	-.48895	-.09515	1.00000	
Factor 5	.32728	.05549	.28882	.11127	1.00000

Several of the loadings on factors which were negative in the 1988 data analysis are positive in the analysis shown above. This is because in the 1995 version of the questionnaire it was ensured that coding categories were consistent in their direction. In the case of personal

descriptors high scores indicated the poorest level of functioning. For behaviour a low score indicated presence and so on.

The factor analysis shown above produced a very similar solution to that derived from the 1988 data. Factor 1 was composed of the same variables as the 1988 solution, with the exception of OCC (extent to which is able to be occupied constructively) which as mentioned above was not included in the 1995 Individual Schedule. The loadings on the factor were also of similar magnitude in both analyses. This finding allows the index of intellectual ability to be used with greater confidence. Factor 3 is also comprised of the same variables with loadings of similar magnitude as its 1988 counterpart. This factor formed the basis of the calculation of an index of physical limitation and, as with intellectual ability, this reaffirmation of an underlying characteristic measured by these variables allows the index to be used with greater confidence.

The factors associated with behaviour were maintained but in an extended form. Factor 2, which mimics factor 4 of the 1988 data analysis, retains the association of the presence of socially unacceptable behaviours with a higher frequency of incidents but introduces further elements. This new version of the factor associates presence of socially unacceptable behaviour with frequent, but short lived incidents, which nevertheless tend to result in the need to calm other service users, and an end to an activity for the individual concerned.

Factor 4, as produced by the above analysis, was similar to factor 2 of the 1988 data analysis where presence of destructive behaviour was associated with work for staff in clearing up. The 1995 data analysis retains this association but also includes the presence of aggressive behaviour. It is possible that individuals who are destructive could also be classified as

aggressive depending on the type of destruction involved. That is, whilst a person who chews, picks or tears their clothes or other materials might be said to be destructive, it would be unusual for this to be seen as aggressive. However, if damage occurred to objects in the immediate environment by, for example, throwing crockery or knocking over furniture, this might be construed as resulting from an aggressive outburst.

As with the 1988 analysis, the two factors associated with behaviour are interesting and make logical sense. However, as mentioned above, it was not considered that construction of indices for these factors would inform this study beyond the effect of the behavioural variable alone and are therefore not investigated further.

In contrast to the analysis of the data from the 1988 study, the present analysis produced a fifth factor. This factor comprised sight and hearing alone. This characteristic clearly represented extent of sensory disability. In the early stages of the factor analysis on 1988 data the variables concerning sight and hearing did load on various factors. However, as the analysis was refined their loadings reduced and they were eventually excluded. The current result should therefore be treated with caution, however sensory disability will be considered amongst other variables when comparing the populations of people who lived at home or in alternative residential care.

The factor correlation matrix shows once again a strong positive association between the intellectual and physical factors, with the sensory factor also showing a relatively high correlation with intellectual ability and somewhat less so with physical limitation. These correlations are all in the expected direction with those with the lowest level of intellectual ability being more likely to have physical limitations and/or sensory disability. The Matrix

also shows a strong negative correlation between the two behaviour factors. This suggests that the two behaviour patterns tend not to occur together.

Sensory disability

The data from the two surveys 1988 and 1995 were examined with regard to the prevalence of sensory disability amongst the two groups of people living at home and in alternative care. The numbers of people who were blind or deaf in either study was small. In 1988, twenty people who were blind were identified as having challenging behaviour, as well as a further fourteen who were deaf. In 1995, the survey identified only four people who were deaf and six who were blind as having challenging behaviour. In 1988 fifteen of the twenty people who were blind lived away from home, as well as nine of the fourteen who were deaf. In 1995 three of the four people who were deaf lived in alternative care, as did two of the six people who were blind.

In 1988, 157 people were identified whose hearing was said to be poor and 62% of these lived away from home. Eighty five people identified in the same survey had poor eyesight and 55% of these lived away from home. In 1995, thirty two people who were identified also had poor hearing and 53% of them lived in alternative residential care. There were fifty three people identified by the survey who also had poor eyesight and 53% of this group lived away from the family home.

In both studies the proportions of people with normal or poor eyesight, or hearing, who lived away from home were very similar. The distribution in 1988 being one third at home to two thirds in residential care. In 1995 the proportions were approximately half and half. People who were blind or deaf, therefore, appeared to be the only ones who were more likely to be

in alternative care. However, the 1995 data on people who were blind contrasts with this, with two thirds living in the family home. The number of people involved is extremely small, however, and no firm conclusions may be drawn.

A sensory index was computed in the same way as the intellectual and physical indices described above. This index correlated positively with age ($r = .12$, $p = .043$) and increased in strength ($r = .14$, $p = .027$) with the exclusion of people who had completely lost one of these sensory modalities ($n = 9$). This suggests that sensory problems marginally increased with advancing age.

However, because those with no problems and those with slight problems do not differ substantially in place of residence and also because those with no sight or hearing ability are too small in number to be reliably studied, blindness and deafness will not be added into the fuller analysis.

Indices

As with the 1988 sample, indices were computed to represent intellectual and physical functioning. The same computation was employed (see p133) producing indices with values ranging between 0 and 100. A higher score on either index represented a lower level of functioning.

There were one hundred and one people identified as having challenging behaviour in 1995 who had also been identified in 1988. With this sub-sample it was possible to do bivariate correlations between the two types of indices at the two time points. The two measures of intellectual ability correlated with $r = .86$, $p = 0.00$, and physical limitations correlated with $r =$

.77, $p = .000$. These were good positive correlations but, particularly in the case of physical limitation, might have been expected to be stronger. It was considered that any disagreement between 1988 and 1995 scores may be accounted for by continuing development, particularly in the case of children and young adults. The analysis was repeated with younger people who were under the age of 25 in 1988, excluded from the group. Age 25 was chosen as the cutoff point because it was considered that rate of development would be considerably slower after young adulthood was reached.

The correlation coefficient strengthened in both cases with intellectual ability increasing to $r = .91$, $p = .000$, and physical limitation to $r = .81$, $p = .000$ ($n = 59$). This result would seem to support the position that some of the variation in scores between 1988 and 1995 may be accounted for by continuing development amongst the younger people identified. The resulting indices were deemed comparable to those generated from 1988 data and satisfactory to include in further analysis.

Distribution of scores on indices

The indices of intellectual ability and physical limitation were computed to produce a score of between 0 and 100 with a high score representing a lower level of functioning. The distributions of scores are shown in Figures 10 and 11 below.

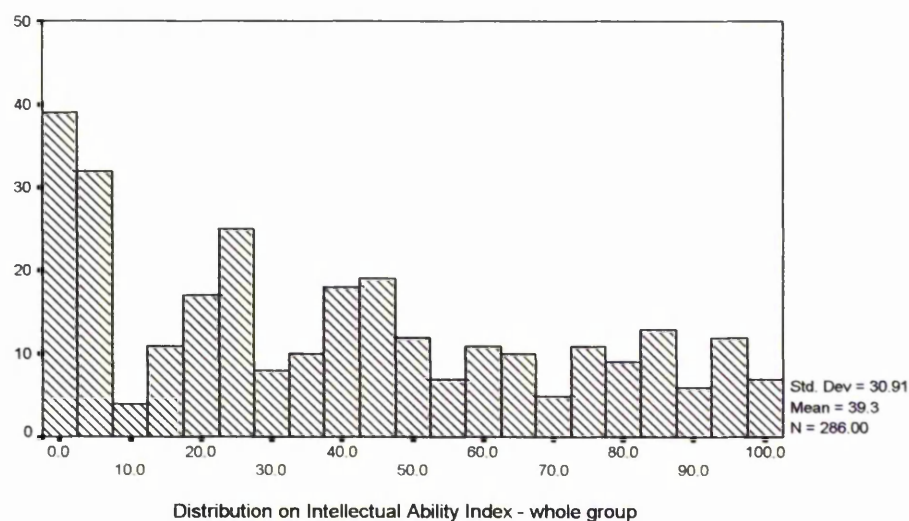


Figure 10: Distribution of scores on Intellectual Ability Index for people identified as showing challenging behaviour in 1995 (N=286)

Unlike the distribution of scores on the 1988 intellectual ability index, the distribution in 1995 shows a greater number of more able people, with numbers reducing as ability becomes lower. The reason for this slightly skewed distribution may lie in the methods adopted in the survey which, like the 1988 survey, used an administratively defined population of people with learning disability. That is, people were covered by the survey if they received a service from learning disability services. However, due to the dispersion of people away from hospitals in the 1990s there were many separate smaller services surveyed and, unlike the 1988 survey, schools for children with moderate learning disability were included. This led to a larger number of people being covered by the survey in 1995 than had been the case in 1988 and a larger number of people with mild levels of learning disability were included. This is likely to have resulted in higher numbers of more able people being identified as having challenging behaviour.

The distribution of scores on the index representing physical limitation is shown below.

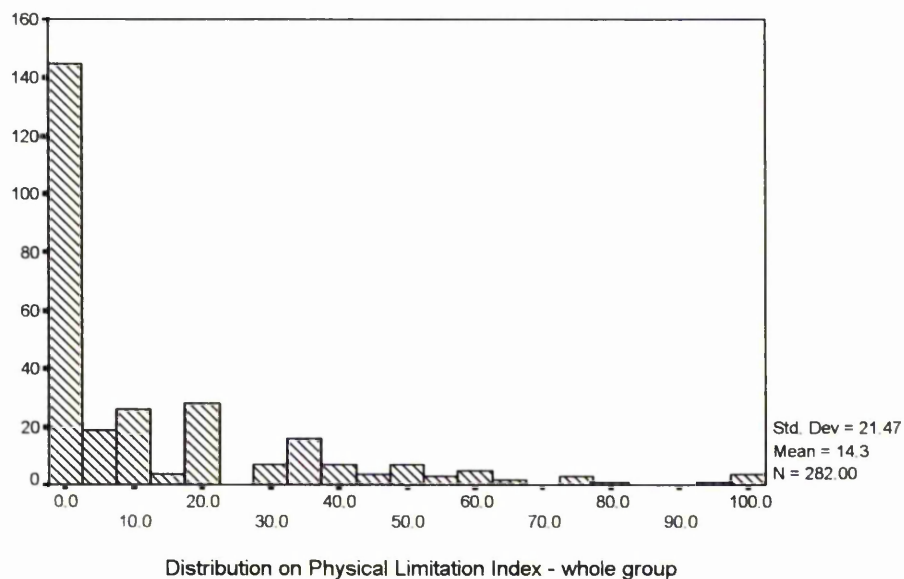


Figure 11: Distribution of Scores on Physical limitation index for people identified as showing challenging behaviour in 1995 (N=282).

Scores on the physical limitation index showed a similar pattern to that of the larger 1988 sample, with the greatest proportion of people suffering no limitations in terms of mobility problems, incontinence and ability to feed themselves. This distribution perhaps under represents those with the most severe levels of physical limitation, suggesting either low levels of challenging behaviour in people with severe physical limitation, or a difference in perception as to what constitutes a challenge from this group.

Disability groupings

Disability level was computed in the same way as for the 1988 data, using quartiles as cut off points to separate the groups. It should be noted that the 1988 and 1995 versions of the intellectual ability index, though highly correlated, were not equivalent. One of the variables that was important in the 1988 index was not available in 1995 and another was not asked about in the same way. In the latter case a new variable had to be computed in compensation which may not have been as sensitive as the 1988 version.

The quartiles on the intellectual ability index fell at different points for the 1995 group but four groups were produced. The scores on the physical limitation index were also divided according the quartile points, however, as with the 1988 data, it was only possible to produce three groups due to the high number of people with no limitation as defined by mobility, continence and feeding ability.

As it was intended to conduct the main analysis on the 20 to 45 year age group as in Study 1a, the disability levels were examined with the smaller numbers in this group in mind. For this age group, when intellectual ability and physical limitation were combined to produce disability groupings, many groups were very small (3 - 8 people). It was felt that this level of discrimination was not viable and, therefore, the scores on both indices were split only at the 50th percentile producing two levels of each type of disability.

For the whole sample there were 139 people with good intellectual ability (49%) and 143 with a poor level of intellectual ability (51%). There were 145 people with no physical limitations and 137 with some problems. Figure 12 below demonstrates group membership.

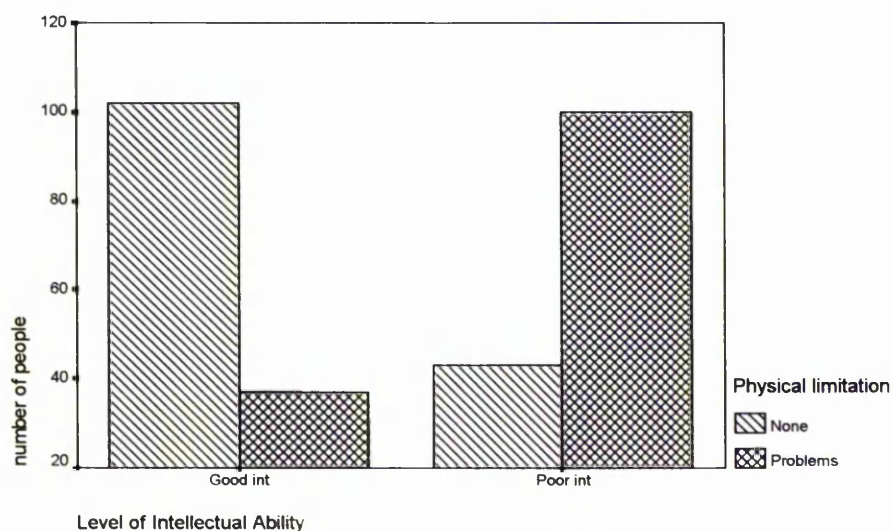


Figure 12: Disability groupings on indices of intellectual ability and physical limitation for the whole sample (N=282)

As with the earlier data the groupings show the expected interaction between intellectual ability and physical limitation, with those who are most intellectual able being less likely to have physical problems.

Residency and age

As there is quite naturally a strong age association with moves from home, consideration was given to the formation of a study group in the same way as with the 1988 data. As categorisation had already been determined from the earlier analysis the same age band categories were adopted for this analysis. The figure below shows the percentage of people in each age group who lived in alternative residential care.

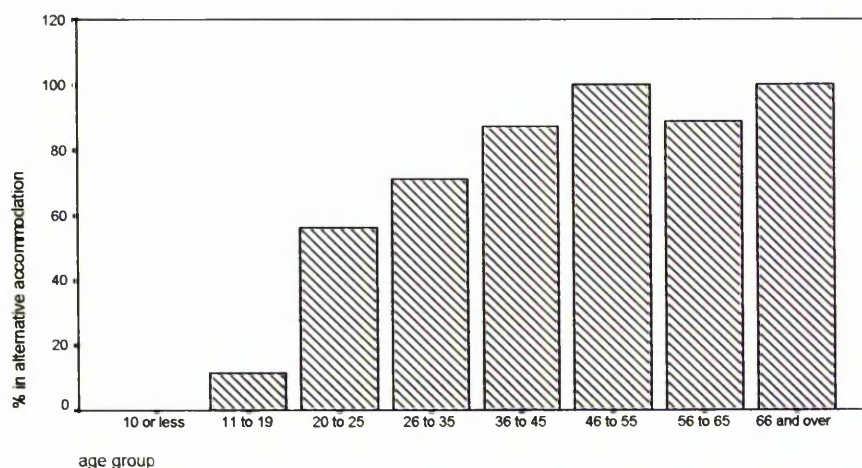


Figure 13: Percentage of people in alternative residential care in 1995 by age band (N=286)

As with the 1988 study there were very few children in residential care and indeed none under the age of 11. Similarly, at the other end of the age range there was only one person living in the family home who was over the age of 45. In the age band 11 to 19, only nine children were living away from the family home. This being the case, children were not included in further analysis. In line with the earlier study and for the same reasons, (i.e. low numbers of

people at home and the feasibility of this as an option for older adults), the main analysis was performed on adults aged 20-45 years.

Scale reliability analysis

Scale reliability analyses were conducted to establish whether the indices based on the variables representing intellectual ability and physical limitation derived from the whole sample remained appropriate for the age subgroups. The results of the analysis are given in Table 8 below.

Table 8: Results of scale reliability analysis on intellectual ability and physical limitation indices for children, adults aged 20 to 45 and older adults.

Intellectual Ability Factor	All (N=278)	19 or under (n=113)	20 to 45 (n=133)	46 + (n=31)
Overall Alpha (Cronbach)	.86	.88	.85	.88
Alpha if item deleted MONEYB	.83	.85	.82	.85
COMMCN	.83	.85	.81	.82
COMMUND	.80	.80	.79	.80
COMMCL	.81	.82	.79	.82
STEREOTY	.88	.89	.87	.92
Physical Limitation Factor	All (N=280)	19 or under (n=115)	20 to 45 (n=134)	46 + (n=31)
Overall Alpha (Cronbach)	.71	.73	.69	.76
Alpha if item deleted MOBB	.64	.66	.58	.79
CONTIB	.64	.78	.59	.62
FEEDB	.58	.54	.60	.66

The overall alpha on the Intellectual Ability Factor is again consistently high for all the subgroups. The analysis shows that on the whole alpha is stronger when it includes the individual variables with the exception of STEREOTY, without which the alpha improves

by between .01 and .04. However, in line with the 1988 analysis, a decision was made to retain this variable in the index because during the factor analysis it maintained its loading on the factor.

Similarly, the overall alpha on the Physical Limitation Factor achieved .7 or above for all age bands. Unlike the 1988 data this index proved to be appropriate for those aged 46 and over. As with the 1988 analysis, the consistency and strength of the alpha values showed that the intellectual and physical indices can be assumed to be appropriate for all age bands.

Disability groupings for the subgroup

As noted above disability level was computed in the same way as for the 1988 data, but due to the smaller number of participants scores on both indices were only split at the 50th percentile producing two levels of each type of disability. There were 47 people who had good intellectual ability with no physical problems, and a further 13 who had good intellectual ability with some physical problems. There were 25 people with poor intellectual ability and no physical problems, and 50 people who had poor intellectual ability and some physical problems. Figure 14 below demonstrates group membership.

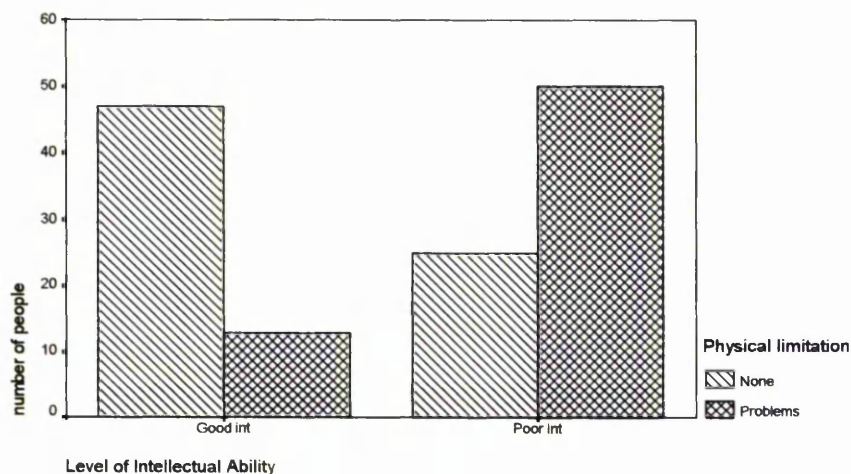


Figure 14: Distribution of intellectual and physical disability groupings for people aged 20 to 45 years who had learning disability and challenging behaviour (N=135).

These groupings reflect the distribution shown in the whole sample and the 1988 data. Specifically, higher levels of intellectual ability are related to fewer physical limitations and vice versa. These groupings, though more crude than their 1988 counterparts, were adopted to provide a more sensitive analysis of the relationship of disability to other factors.

Summary of findings

- Discriminant Analysis confirmed the factor structure produced from the 1988 data with an additional factor related to sensory disability.
- Indices of intellectual ability and physical limitation were produced. These indices correlated strongly with the those derived from the 1988 data set.
- The distribution of the sample on the indices showed a greater number of more able people having been identified by the survey as showing challenging behaviour.
- The 1995 sample showed a similar distribution on the physical limitation index to that of the 1988 sample, with the greatest number of people having no problems associated with mobility, continence or feeding themselves.
- Scale reliability analysis confirmed that it was appropriate to use the indices with the 20 to 45 years age band.

2 Residency

Comparisons of personal characteristics by type of residence for the 20 to 45 year age group

The indices and other variables describing presence and number of challenging behaviours and their consequences were compared across type of residence for the subgroup.

Table 9: Comparisons of personal characteristics of people with learning disability and challenging behaviour who live at home and in alternative residential care (N=139)

Variable	df	F Ratio	F Prob.	% Variance Expl. (E ²)
Intellectual disability	1,138	.19	.660	-
Physical limitation	1,133	.18	.676	-
Age	1,138	16.05	.000	10.49
Sex	1,138	.15	.703	-
Aggressive behaviour	1,138	11.41	.001	7.69
Self injury	1,138	1.16	.283	-
Destructive behaviour	1,138	13.02	.000	8.68
Socially unacceptable behaviour	1,138	.00	.999	-
Frequency of incidents of challenging behaviour	1,130	1.51	.220	-
Extent of disruption caused	1,132	.01	.940	-
Number of challenging behaviours	1,138	16.92	.000	10.99
Number of challenging behaviour presenting a serious management problem	1,138	1.38	.242	-

The table above shows that residency predicted more of the variance in age and number of challenging behaviour than of any other variable. Apart from these, only destructive and aggressive behaviours varied significantly between the groups. From this analysis, it appeared that people who lived in alternative residential care were more likely to be older, have a larger number of challenging behaviour types and to show aggressive or destructive behaviour.

Discriminant analysis

Discriminant analysis was performed based on the variables found significant in the above analysis. Stepwise regression was used with F probabilities set at .05 to enter and .10 to be removed. The analysis produced a classification based on number of behaviour types and age alone.

Table 10: Discriminant analysis of variables associated with type of residency in 1995 for adults with learning disability and challenging behaviour

		Wilk's lambda	Probability
Step 1	Number of types of challenging behaviour	.890	.000
Step 2	Age	.802	.000

Summary Table

Actual Group	No. of Cases	Predicted Group Membership	
		0	1
Family Home - Group 0	37	26 70%	11 30%
Residential Care - Group 1	102	27 26%	75 74%

This analysis was able to correctly classify 73% of the cases. This result provided support for other studies which found the presence of challenging behaviour as a predictor of placement outside the family (e.g. Freedman, Krauss & Seltzer 1997).

Disability Groupings

To establish which, if any, of the variables found to relate to type of residence in the above analysis were important for the differing levels of intellectual ability further discriminant analyses were performed. The variables entered into the analyses were, age, aggressive

behaviour, destructive behaviour and number of behaviour types. Physical limitation was also included because it was considered that this might have an effect once intellectual ability was split into higher and lower functioning groups.

Table 11: Discriminant analysis of variables associated with type of residence for adults with learning disability and challenging behaviour by level of intellectual ability

Level of intellectual ability	Variables with predictive power	Wilks' Lambda	Significance
Good (n=60)	Age	.68310	.331
	Physical limitation	.68547	.858
	Aggressive behaviour	.69463	.000
	Destructive behaviour	.69424	.858
	Number of challenging behaviour types	.67653	.386
Poor (n=75)	Age	.89284	.001
	Physical limitation	.76290	.408
	Aggressive behaviour	.76500	.483
	Destructive behaviour	.85425	.007
	Number of challenging behaviour types	.77003	.863

Summary Tables

1 Good Intellectual Ability

Actual Group	No. of cases	Predicted Group Membership	
		0	1
Family Home - Group 0	18	18 100%	0 0%
Residential Care - Group 1	46	20 44%	26 57%

Percentage correctly classified 69%

2 Poor Intellectual Ability

Actual Group	No. of cases	Predicted Group Membership	
		0	1
Family Home - Group 0	19	14 74%	5 26%
Residential Care - Group 1	56	16 29%	40 71%

Percentage correctly classified 72%

As can be seen in the table above, for those whose intellectual ability was good, aggressive behaviour was the only predictor of residential placement. That is, those who lived away from home were more likely to be exhibiting aggressive behaviour, or more serious levels of such behaviour. Although, on the basis of this variable, it was possible to classify 69% of people according to type of residence, discrimination of the group of people in residential care was weak. Only 57% were correctly classified in this group.

For those with poor intellectual ability, two variables predicted type of residence, age and destructive behaviour. Older people and those showing destructive behaviour, or more serious levels of destructive behaviour, were more likely to be living away from the family home. On the basis of these two variables it was possible to classify 72% of people correctly overall. In this case the performance of the variables in classifying separate residence types reflected the overall result. However, it was considered that as with the earlier analyses, there may be other, unmeasured, variables having an effect. This would seem to be particularly so for those with better levels of intellectual ability.

Summary of findings

- Analysis of variance showed that those who lived in alternative residential care tended to be older have a greater number of behaviour types and show aggressive or destructive behaviour.
- Discriminant Analysis showed that only age and number of challenging behaviour types were predictive of living away from home for the whole group.
- Investigation of significant variables by level of intellectual ability showed that for people with a better level of intellectual ability only presence of aggressive behaviour predicted residence though classification was poor for those living in residential care.

- For people with a poorer level of intellectual ability, both age (older) and destructive behaviour (more) predicted living in alternative care.
- It was confirmed that there appear to be different factors operating in the placement of people with differing levels of intellectual ability.

3 Summary

Although people identified as showing challenging behaviour in the 1995 survey, appeared to have a higher level of intellectual ability than those identified in 1988 (1995 \bar{x} 39.31, *SD* 30.91, *N*=286; 1988 \bar{x} 50.65, *SD* 29.80 *N*=695), the study groups of people aged 20 to 45 years were very similar in intellectual ability (1995 \bar{x} 47.19, *SD* 30.61, *n*=139; 1988 \bar{x} 48.33, *SD* 30.11, *n*=439). There was little difference in level of physical limitation suffered by the groups at the two time points overall (1995 \bar{x} 14.27, *SD* 21.47, *N*=282; 1988 \bar{x} 17.18, *SD* 23.12, *N*=695), or for the study groups (1995 \bar{x} 14.53, *SD* 21.64, *n*=135; 1988 \bar{x} 14.05, *SD* 20.64, *n*=435).

Residing away from the family home appeared to be associated with different variables at the two time points. In both the 1988 and 1995 studies, once the extremes of the age range were controlled and analysis limited to the 20 to 45 year age range, as expected increasing age was still a significant factor. For the 1988 study other discriminating characteristics were fewer physical limitations, being male, having a lower level of aggressive behaviour and lower frequency of incidents of challenging behaviour which were associated with living away from home.

For the 1995 data set, using a smaller sample, gender and physical problems were not significant factors in the analysis. Other influences that emerged from this analysis were, in particular, the presence of aggressive and / or destructive behaviours, and a higher number of different types of challenging behaviour generally.

Discriminant analysis of variables found to differ significantly between groups was undertaken for both 1988 and 1995 data. The resulting classification correctly placed around two thirds of the 1988 group and almost three quarters of the 1995 in terms of residence.

A unique finding in this thesis was a relationship between level of intellectual ability and characteristics indicating people likely to be in residential care. The 1995 data analysis demonstrated that number of challenging behaviours was strongly differentiated by residence when the group was taken as a whole, a finding which appears to support others in the literature (e.g. Freedman, Krauss & Seltzer 1997). However, when level of intellectual ability was taken into consideration, it appeared to provide some clarification of the data indicating that age and destructive behaviour were of significance when considering people with more severe learning disability but not so for the more able, for whom aggressive behaviour was a significant characteristic. The significance of number of challenging behaviour types diminished. This suggests that it may be too simplistic to study groups of people with learning disability without taking level of ability into account.

As mentioned above, closer analysis of the groups was conducted which involved separate analysis of groups of people with differing levels of intellectual ability. Discriminant analyses of 1995 data suggested that the main predictor of residence in alternative care, for those with a good level of intellectual ability was the presence of aggressive behaviour. That is, those living away from home were more likely to exhibit aggressive behaviour. From the 1988 data it was found that those with a good level of intellectual ability who lived away from home tended to be older and male.

Due to small group sizes in the 1995 data set, those with a fair level of intellectual ability were merged with those whose ability was good. However it was possible to study those with this level of intellectual ability separately in the 1988 analysis. For this group, frequency of episodes of challenging behaviours was the only discriminating variable, with those at home presenting a more frequent challenge. However, there appeared to be some confounding of residence with setting type for this variable. Frequency of behavioural challenges may be related as much to staff perceptions of what constitutes a challenge in the context of, for example, a college or day centre environment, as opposed to that of residential or respite facilities. Comparisons were made between the difference in percentage of people presenting daily challenges in day settings over and above those in residential settings, for each intellectual ability level. It appeared that the difference was substantially larger for those with a fair level of intellectual ability compared to other groups. It was considered then, that for these people this was likely to be an actual effect of behaviour, rather than of setting. These differences between settings require further study.

People with a poor level of intellectual ability in 1995 were discriminated by increasing age and the presence of destructive behaviour, older people and those who exhibited greater levels of destructive behaviour were more likely to live away from home. In the 1988 data set, those with either a poor or low level of intellectual ability could be discriminated by increasing age but also by physical limitation, with those who were more able living away from home.

The reasons why different variables related to residential placement in 1988 and 1995 may lie partly in a change in policy regarding residential provision for people with learning disability. In 1988 there were still a number of large mental handicap hospitals in operation in the districts surveyed, though plans were underway to move residents into houses in the

community. By 1995, only one of the five hospitals covered by the initial survey was still in operation and the remaining function of this hospital was the provision of secure accommodation. Hospital closures, though welcomed, may have resulted in potentially fewer residential places being available for people with learning disability outside their family home. Although it is hoped that adequate provision will be available in the community, one might speculate that, at least in the short term, the presence of certain types of challenging behaviour may lead to a prioritisation of provision of this scarce resource for those whose behaviour may be dangerous to themselves or others. The finding from the 1995 data that people who were perceived as more aggressive or destructive were more likely to be living in residential care seems to support this position.

It was only possible to analyse data for children in the 1988 study. For this group of 11 to 19 year olds, gender was the only characteristic which differed significantly between groups, with boys more likely to live away from home. It was not possible to analyse data from children grouped by level of intellectual ability due to the small numbers involved. However, Discriminant Analysis showed that overall around 60% of children could be correctly classified in terms of residence based on gender (male), intellectual level (lower) and frequency of behaviour episodes (lower). This 11 to 19 year old group appeared to have lower levels of ability than the adult group. However this may be due to developmental factors and the strategy adopted in the 1988 study when only schools for children with severe learning disability were screened.

Frequency of episodes of challenging behaviour suffered the same confounding in the child data as it did in the adult data. High frequency (episodes once a day or more) was associated with screaming and making other unacceptable noises for both those in residential care and

those living at home. However one may speculate that such behaviour in a classroom, as opposed to a residential setting, may be very disruptive and might therefore be perceived as challenging more frequently.

Analysis based on staff reports in service settings provided a direction of enquiry. However it cannot inform the process by which families reach a point in their development whereby a move to alternative care for their son or daughter with learning disability becomes necessary or desirable. Such exploration required information from parents directly and studies two and three of this thesis were an attempt to provide such information.

Chapter 5

Results

Study Two: Are there differences between a group of people who had moved into residential accommodation between 1989 and 1995 and a matched group who continued to reside in the family home?

Study 2a: Are any differences apparent in service settings in 1988 between those young people with learning disability who had, and had not moved away from home?

- | | | |
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| 1 | <i>Preliminary Analysis</i>
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Challenging behaviour and gender | <i>page 197</i> |
| 2 | <i>Comparisons Across Residence</i>
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Matched populations
Comparison of personal characteristics for the matched groups | <i>page 200</i> |
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Study 2b: Are differences between the families of people with learning disability and challenging behaviour who remained in, or moved from, the family home apparent while all were still resident at home?

- | | | |
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| 1 | <i>Predictors of moves to alternative care from earlier studies</i> | <i>page 208</i> |
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Chapter 5

Results

Study 2a: Are any differences apparent in service settings in 1988 between those young people with learning disability who had, and had not moved away from home?

Study 2a comprises secondary analysis of staff questionnaire data from 1988 and parent questionnaires and interviews in 1989. The latter are covered more fully in Study 2b.

1 Preliminary Analysis

Parental agreement on presence of challenging behaviour

As a preliminary to further analysis of data from the two groups of parents the extent to which parents agreed that challenging behaviour was present was explored. Of 59 parents interviewed in 1989 all but two mentioned some form of behavioural challenge at home. The parent interview did not ask specifically about socially unacceptable behaviours but there was one question about whether the parent found the person's behaviour difficult or embarrassing when outside the home. Six parents, who did not endorse the presence of aggressive, destructive or self injurious behaviour, did find their son or daughter's behaviour difficult outside the home. One young man had left home between data collection in service settings and parental interview and this data was missing, however, information from service settings showed that he had a range of socially unacceptable behaviours including non-compliance, antisocial behaviour such as bullying, overactivity, smearing faeces and inappropriate sexual behaviour. It would be surprising if all such behaviours were entirely setting specific. Only one parent did not endorse any challenging behaviour. This young woman was non-compliant

in her service setting and this was a serious management problem for staff. Her parent either did not experience this difficulty, or, if it did occur, did not evaluate it as a 'problem'.

The data was then examined to find out the extent to which parents agreed on the presence or absence of the three specific behaviour types mentioned. There was data available for 53 of the 59 parents who were interviewed in 1989. In the case of physical attacks 31 parents (59%) agreed with service staff on the presence or absence of this behaviour. For self injury there was a higher rate of agreement with 38 parents agreeing with staff conclusions (72%). Finally, for destructive behaviour, there were 40 cases of agreement (76%).

It is apparent that in the case of aggressive behaviour / physical attacks, parents were less likely to concur with service staff. It is possible that this type of behaviour may not have been reported to the same extent due to an unwillingness on the part of parents to label their son or daughter's behaviour as 'violent'. Seventeen parents (32%) stated that their son or daughter did not show such behaviour at home though it was reported in service settings. Indeed six (11%) of these presented a serious management problem to staff. It may not be entirely unexpected that behaviour should vary between settings, however it would be puzzling if such great differences were shown to occur. Five parents (9%), on the other hand, reported aggressive behaviour at home where none was said to be present in their service setting. Unfortunately it was not possible to determine from parent interviews the extent of management problems these challenges entailed. In conclusion then, in the majority of cases there was agreement that the person's behaviour was challenging, though the way it was perceived or manifest itself in the two settings may differ.

Challenging behaviour and gender

As noted in the literature review the incidence of learning disability in the population is a little higher for males than females (52% male approx) but severe learning disability may be more prevalent in females (Katusic et al 1995). Level of intellectual ability necessarily has implications for the level of care required and possibly the type of challenges presented. Data from the 1988 survey found 64% of those identified as having challenging behaviour to be male and the later more comprehensive re-survey of two of the original seven districts in 1995, found 66% of those identified as having challenging behaviour to be male. However, for the 1988 survey the proportions of males and females were similar for the four intellectual ability levels with 22% to 27% in each group male and 21% to 28% in each group female. Contrary to the Katusic et al (1995) finding, there was a very slight predominance of males in the poor and low levels of intellectual ability, and of females in the good and fair levels. This difference was significant probably due to the large numbers involved ($N=695$, $r=-.08$, $p=.03$). In the 1995 survey ($N=286$), again the proportions of males and females in each group was very similar (two levels due to the smaller sample size). 51% of males had a poor level of intellectual ability, whereas 49% of females had this level of ability. This result was not statistically significant.

There was no significant difference between males and females on indices of intellectual ability or physical limitation in this study ($N=36$). However, the possibility of other influences related to gender, such as parental worries about possible abuse or pregnancy, could not be ruled out and therefore the decision to match on gender was upheld.

2 Comparisons Across Residence

Age on leaving home

Data from the Sheffield Register (Parrott et al, 1997) gave median ages for carers and person with learning disability on leaving home. For comparison, age on leaving home was calculated for the people with learning disability and challenging behaviour and their mothers, as they were the primary carers for this group. This was done by subtracting the number of years the person had been away from home, from their ages at the time of the interview. The Sheffield Study presents the median ages by level of disability (details given above p 82). This level most closely matches the physical limitation variable computed above. As there were only 18 interviews with parents of people who had left home the subgroups are small and, as a consequence, the figures are only for comparison. It is not possible to generalise from them.

Table 12: A comparison of median ages of parents and their sons or daughters with learning disability and challenging behaviour when leaving the family home, by level of disability, with similar groups from the Sheffield Register (Parrott et al, 1997).

Groups	Sheffield Study [†] Age in yrs		Study group (N=18) Age in yrs	
Most able [†] / No physical limitation (n=11)	Person	35	Person	23 (range 18-35)
	Carer	68	Parent	51
Moderate disability [†] / physical limitation (n=4)	Person	37	Person	24 (range 20-27)
	Carer	69	Parent	49
Severe disability [†] / physical limitation (n=3)	Person	21	Person	26 (range 11-29)
	Carer	52	Parent	47

[†] N not given but based on Register of 2,400 people with learning disability

The table above shows that the parents and son and daughters with learning disability and challenging behaviour in this study were rather younger than the Sheffield group. One reason

why the people in the current study were in the main younger when leaving home may be related to the way decisions were made on who to interview in the original parent study in 1989. That study focussed on young adults between the age of 19 and 27 because this was seen as an age group in which challenging behaviour was more prevalent.

The 1995 study approached parents across the full age range, and of the 29 carers interviewed, seven had a son or daughter over the age of thirty. However, only one of these had left home. It appears that this group of people with learning disability and challenging behaviour left the family home at a younger age than their counterparts who might or might not have challenging behaviour. A larger study would be needed to investigate whether people with challenging behaviour leave home at a younger age than their peers. As acknowledged above, the numbers here are too small to reach firm conclusions.

The remaining analysis in Study Two is concerned with investigating the personal and behavioural characteristics of two groups of young people who were living in the family home in 1988 and were a challenge in service settings. One of these groups went on to alternative residential care during the subsequent seven years, the other continued to reside in the family home.

Matched populations

As described in the Methodology section, a group of people of the same age and gender as those who had moved was identified. There were 13 men and 5 women in each group. The mean age of people in the 'movers' group was 25.67 yrs, median 26. For the 'non-movers' the mean was 25.78 years and the median was 26 years. However, two people, 1 from each

group (both male and aged 26 and 27), were not in receipt of services and as such could not be included in much of the analysis. However, scores on the indices for these people were derived from parent data using the same variables. Correlations between parent versions of the indices and those derived from staff data were strong (intellectual ability, $r = .73$, $p = .001$, $n = 36$; physical limitation, $r = .87$, $p = .000$, $n = 36$). Substitution of parent derived scores for these two people in absence of staff data was therefore deemed acceptable.

Comparison of personal characteristics for the matched groups

A series of Mann-Whitney U tests were conducted to ascertain whether there were differences between the groups in service settings in 1988. The same set of variables investigated in Study 1a were included with the exceptions of age and sex which had been controlled. The results are shown in Table 13 below.

Table 13: Comparisons on personal characteristics of matched groups of people with learning disability and challenging behaviour who did and did not move from home within seven years of data collection (N=36)

Variable	Mann-Whitney U	Probability (Two tailed)
Intellectual disability (n=36)	121.0	.433
Physical limitation (n=36)	68.5	.008
Aggressive behaviour (n=34)	135.0	.760
Self injury (n=34)	141.0	.919
Destructive behaviour (n=34)	116.0	.340
Socially unacceptable behaviour (n=34)	83.0	.034
Frequency of incidents of challenging behaviour (n=33)	102.0	.231
Extent of disruption caused (n=33)	113.0	.249
Number of challenging behaviours (n=34)	117.5	.357
Number of challenging behaviour presenting a serious management problem (n=34)	103.5	.160

This table shows that the only aspects on which the two groups differed significantly was with respect to the extent of physical limitation and presence of socially unacceptable behaviours.

Examination of the data showed that those who had left home had fewer physical limitations than those who had remained and that they were more likely to exhibit socially unacceptable behaviour. The finding that those who left home had fewer physical limitations supports the larger analysis in Study 1a (1988 data) which found that, for those with poor and low levels of intellectual ability in particular, additional physical problems were predictive of remaining in the family home.

Figures 15 and 16 overleaf, show the distribution of scores on the indices of intellectual ability and physical limitation derived using information from service settings in 1988 when all the people concerned were living with their families. This made it possible to compare the distribution of scores for this group with that of the large group.

Although the numbers involved overall are small it is clear that there were more people with severe or moderate levels of physical limitation amongst the group remaining at home who had poor or low levels of intellectual ability. This reflects the large group finding in Study 1a.

As mentioned above, one other difference between the groups was in exhibiting unacceptable social or other behaviours. This finding is different from the findings of the large group study of 1988 data. For the large group, frequency of episodes of challenging behaviour was related to type of residency with those at home showing a higher frequency of challenging behaviour.

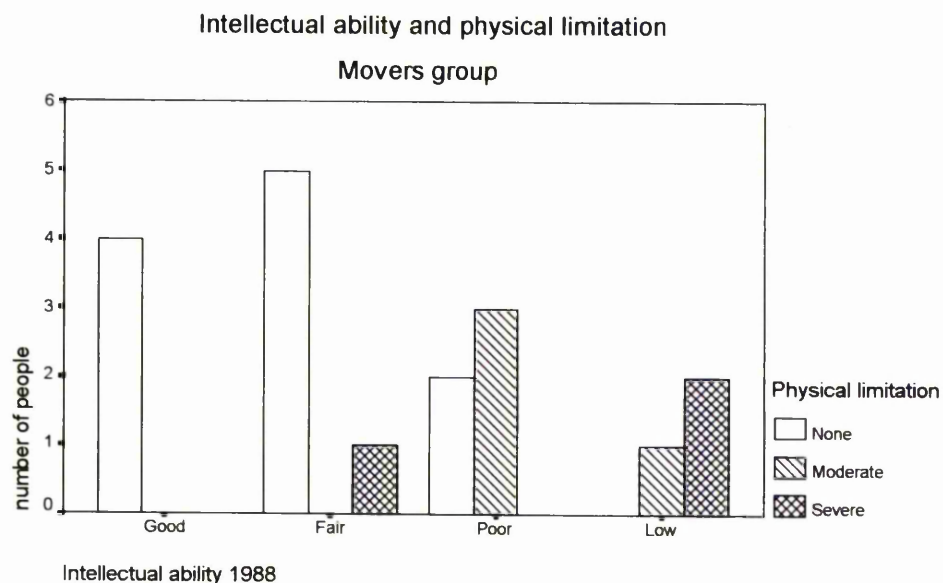


Figure 15: Distribution of scores on indices of intellectual ability and physical limitation for people who had moved away from home between 1989 and 1995 (n=18)

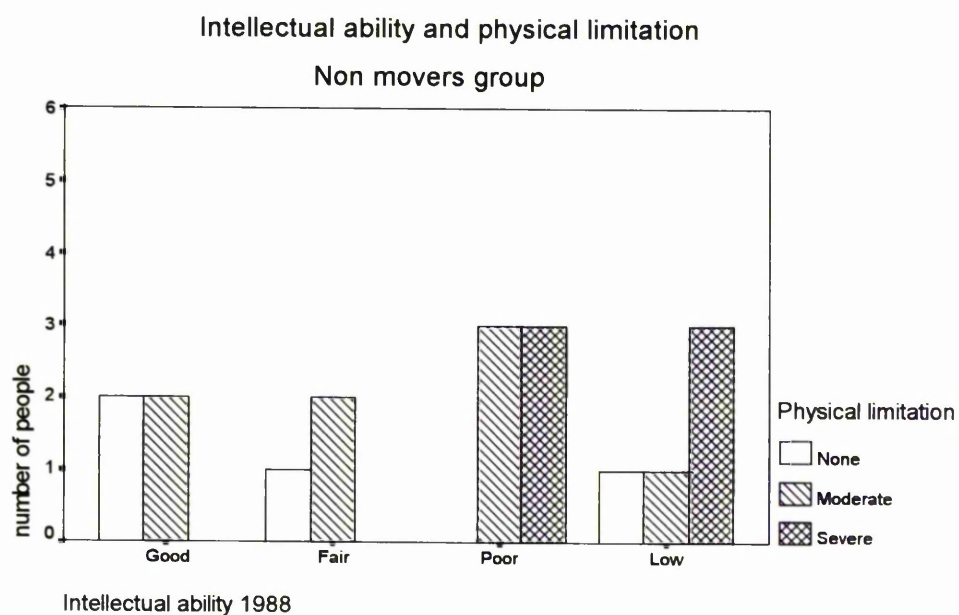


Figure 16: Distribution of scores on indices of intellectual ability for people who remained in the family home between 1989 and 1995 (n=18)

As mentioned in Study 1a, higher frequency of episodes was significantly correlated with the presence of socially unacceptable behaviour. This was entirely to be expected because some of the behaviours described were by their nature high frequency (eg overactivity).

Seventy seven percent (n=13) of people who had moved exhibited unacceptable behaviours in service settings to the point where they were a serious management problem. In comparison only 35 percent (n=6) of the group still at home were described in these terms. Examination of the behaviours which came under this heading (N=13) showed that those who had left home were more likely to show a greater number of behaviour types. One mover and seven non movers showed no such behaviour while three movers and two non movers showed three or fewer of these behaviours. However, thirteen movers as opposed to eight non movers exhibited four or more (n=34, U=76.5, p= .018 two tailed).

3 *Summary of findings*

The outcomes of Study 2a were as follows . . .

- There was general agreement on the presence of challenging behaviour between parents and staff in service settings, though form or extent of the challenge might vary.
- Compared with the Sheffield Register study (Parrott et al, 1997), where ability was good or moderate, both people with learning disability and their carers were younger when the move occurred. This may have been influenced by the recruitment strategy of the original study which focussed on people between the ages of 19 and 27.
- Compared with the Sheffield Register study for people with severe disability/physical limitations, the ages of the three people in the current study differed widely. However,

parent ages were similar to the Sheffield finding, ie Sheffield median 52, this study 44, 47 and 52 years.

- Physical limitations appeared to have an effect on placement with those with more severe problems remaining home longer.
- Socially unacceptable behaviours may also have affected placement. Those who were living away from home had a larger number of behaviours of this type.

Study 2b Are differences between the families of people with learning disability and challenging behaviour who remained in, or moved from, the family home apparent while all were still resident at home?

As with Study 2a, this study involves secondary analysis of data. The data analysed in this section is from parent questionnaires and interviews carried out in 1989. This section is based on data obtained from 20 of the 59 families involved. This sub group comprised 16 men and four women aged between 18 and 30 years. The interviews explored the circumstances and experiences of families whose son or daughter had been identified as showing challenging behaviour in service settings.

In the subsequent five years (1989 - 1994), ten of the people involved had moved to alternative accommodation. The information given to interviewers in 1989 for these parents is compared to that given by parents of sons and daughters of the same age who remained at home to try to ascertain whether there were any differences between the families at that point, prior to the move, which might be a precursor to placement. However, due to the small numbers involved in this section analysis was restricted to variables reflecting issues found to be important in the literature review. Mann Whitney U tests were conducted on ordinal data, and nominal data was dichotomised and Fisher's exact test applied.

1 Predictors of moves to alternative care from earlier studies

Data from the selected subgroup was examined to ascertain the extent to which it reflected the findings of earlier studies using the same data set (Qureshi, 1990; Kiernan & Alborz 1995). The Qureshi (1990) study examined parent interviews from 1989 with regard to their views and experiences in caring for their son or daughter with learning disability and challenging behaviour. As part of this study Qureshi summarised parent comments into a variable reflecting views on future care. This variable had seven categories:

- Avoids/ doesn't think about it
- Hopes for independent living
- Home and family orientation
- Residential alternative eventually
- Alternative care desired soon
- Alternative care wanted now
- Other

It should be noted that there may be difficulties when deriving category codes such as these. Comments may be made throughout an interview which characterise attitude to future care, or other issues. Unless all such comments are carefully noted and used to produce a categorisation in a systematic way, it is difficult to obtain intra-, or inter-, rater reliability. The codings on the variable described above were derived by the same researcher for all participants and it was, therefore, considered that they would have been applied with acceptable consistency.

Using this categorisation Qureshi (1990) showed that the variables which discriminated between parents who stated that they wished to give up caring soon or immediately from those

who were not immediately seeking alternative care were

- mother's wish to take up employment;
- extra financial costs;
- co-operativeness of the son or daughter with learning disability;
- degree of flexibility in caring (ease with which could arrange 'minder' to have short break);
- self injurious behaviour as a serious management problem in service settings.

In that study these variables correctly classified 88% of responses. However, a follow-up study (Kiernan & Alborz, 1995) found the predictive power of these variables disappointing when applied to actual moves ($Kappa=0.16$ whole group, $Kappa=0.44$ most able group only).

The Kiernan & Alborz (1995) study examined parent data to ascertain which variables best predicted an actual move from home. Three variables appeared to be predictive

- serious injury to a parent;
- age of the son or daughter (younger);
- supervision found to be a problem.

These variables correctly predicted the outcome for 39 of the 44 people interviewed for this study (88.6%, $Kappa=.69$).

The present study sought to examine the extent to which the variables from the Qureshi (1990) and Kiernan & Alborz (1995) studies could differentiate between the matched groups. As one of the three discriminating variables from the latter study was controlled by the matching process (age), only the remaining two were analysed.

The only variables to differentiate between the groups were, (i) the perception that supervision of the person was a problem and (ii) injury to a parent. Both these variables were from the Kiernan & Alborz (1995) study. The results of these analyses are shown in Table 14 below.

Table 14: A comparison on variables found to be predictive of wish for residential care in 1989 and of having moved by 1995 between matched groups of people with learning disability and challenging behaviour (N=20)

Variable		Probability (Two tailed)†
<i>Qureshi (1990) variables</i>		
Mother employment affected (n=20)	U = 40.0	.481
Extra financial costs (n=20)	U = 28.5	.105
Cooperativeness (n=19)	U = 44.0	.968
Flexibility in caring (n=18)	U = 37.0	.549
Serious self injury in service setting (n=18)	X ² = 0.41	1.000 (2 tailed)
<i>Kiernan & Alborz (1995) variables</i>		(One tailed)†
Injury to parent (n=20)	X ² = 6.55	.043
Parents found supervision problematic (n=20)	U = 18.5	.015

† Two tailed probability was used for the Qureshi variable because the study did not give the direction of the effects (Qureshi 1990). For the Kiernan & Alborz (1995) variables details were available and it was therefore possible to use one tailed probabilities.

One might expect better differentiation using the variables from the Kiernan & Alborz (1995) study, as the participants involved in the matched group study also formed part of the larger sample investigated in that analysis. The Kiernan & Alborz (1995) sample included 34 as opposed to 10 non-movers. However, as numbers are small the result suggests that the differences between the groups are substantial on these items (see Tables 15 and 16 below for distribution of scores). The Qureshi variable 'extra costs' is likely to have been significant had it been possible to use one tail probability. However, with the numbers involved it was not possible to identify any less robust differences between groups.

The only variables found to differ significantly between the groups, as mentioned above, were the extent to which the person was perceived to present a problem regarding supervision, and

injury to a parent. In answer to a question on whether supervision was a problem, parents of movers were more likely to see it as difficult.

Table 15: Supervision problem by type of residence at follow up (n=20)

Supervision a problem	No	Slight	Definite
Movers (n=10)	2	1	7
Non movers (n=10)	7	2	1

A variable reflecting the amount of supervision given did not differ significantly between the groups. This suggests that it was not necessarily the amount of supervision required which families found difficult, but possibly the reason for the supervision. Such difficulties might arise from a need for supervision outside the family home for more able people (Kiernan & Alborz, 1995), and/or difficulties arranging supervision within the context of the family's organisation.

Table 16: A comparison of number of people with learning disability who had injured a parent as a result of their challenging behaviour and lived at home with those who had moved to residential care.

Person had injured parent as a result of challenging behaviour	Yes	No
Movers (n=10)	4	6
Non movers (n=10)	0	10

Only parents whose son or daughter had moved reported being injured by them in the past. These injuries were perceived as significant and were not minor or incidental. For example, one mother suffered a broken thumb and another reported that at one point her head was full of scabs from objects being thrown or used as weapons. It is understandable that where there

is significant injury to a parent the caring relationship may well be unsustainable in the long term and service providers will perceive the need to act (see Chapter 2).

It was not possible to analyse variables discriminating between parents wish for alternative care for their son or daughter for the group who had not moved in 1995 because only one parent wished for a move in the short term. This parent had a son who was at the younger end of the age range of people in the study, inflicted injury on his parent at some time and parents' rated supervision as a slight problem (Kiernan & Alborz 1995 predictors of a move). His mother wished to work part-time and felt unable to take short breaks from caring. The young man did not injure himself but did cause some extra expenses for clothes, shoes, bedding and furniture. There were some problems regarding his co-operativeness in performing self care tasks and interfering with housework, but these were of a moderate level (Qureshi 1990 predictors of wish for alternative soon).

This person, therefore, met the criteria for someone likely to move (age, injury and supervision problems) and possibly most of the predictors of desire to relinquish care as suggested from the Qureshi (1990) study though this is a matter of speculation because the direction of the effects was not specified.

2 Comparisons based on other findings in the literature

Factors found to be significant in other studies reviewed above which were represented by variables in this series of studies were examined. These included socioeconomic status Hanneman & Blacher (1998); phase of the family life cycle Essex, et al (1997); household type (Baker et al, 1996); severity of learning disability (Meyers, Borthwick & Eyman 1985); extra work (Heller et al, 1997); number of challenging behaviours, support from services (Hayden & Goldman, 1996); mother's age, perception of adequacy of service support (e.g. Hayden & Heller, 1997); mother's stress level (e.g. Parker, 1990); mother's health (Zarit, Todd & Zarit, 1986); restrictions on mother's social activities (e.g. Kiernan et al, 1997a). Other variables relating to behaviour exhibited at home were included because it was felt that they may have an effect specific to this group of people with learning disability and challenging behaviour. The results of these analyses, again using the Mann Whitney U Test or Fisher's Exact, are shown in Table 17 overleaf.

None of these variables discriminated between the groups. Even physical limitation which was shown to be significantly different when using the larger matched group did not reach significance. However, this may be due to the small numbers involved which means that only very large differences are detectable. Nevertheless, it was considered important to examine the data for such evidence.

Table 17: A comparison on variables reflecting findings in the literature on factors associated with planning alternative residential care and actual moves between matched groups of people with learning disability and challenging behaviour (N=20)

Variable		Probability (Two tailed) [†]
<i>Family Characteristics</i>		
Socioeconomic status (based on classification of occupation) (n=19)	U = 34.0	.400
Phase of family life cycle (n=20)	X ² = .268	1.000
Household type (lone or two carer) (n=20)	X ² = .000	1.000
<i>Characteristics of the person with learning disability</i>		
Intellectual ability (n=20)	U = 45.5	.739
Physical limitation (n=20)	U = 40.0	.481
Extra work generated (n=20)	U = 41.5	.529
Number of challenging behaviours in service settings (n=20)	U = 34.0	.248
Supervision requirements (n=20)	U = 46.0	.796
Aggressive behaviour at home (n=20)	X ² = .220	1.000
Self injurious behaviour at home (n=20)	X ² = .840	.649
Destructive behaviour at home (n=20)	X ² = 2.027	.349
<i>Support from services</i>		
Number of professional workers involved (n=20)	U = 42.5	.579
Confidence in services to deal with any problems (n=18)	U = 39.5	.965
Type of day care (facility based or other)(n=20)	X ² = 2.531	.303
Perception of sufficiency of day care (n=17)	X ² = .004	.949
Perception of sufficiency of respite care (n=13)	X ² = .043	1.000
<i>Maternal characteristics and effects</i>		
Mother's age (n=20)	U = 44.5	.968
Mother stress level (Malaise Inventory) (n=20)	U = 37.5	.549
No. GP visits in last year (n=20)	U = 36.0	.497
No. Leisure and social activities affected (n=20)	U = 41.5	.780

[†] Two tailed probability was used because the variables examined here were not the same variables reported in the literature but the ones that were considered to reflect the factors found to be significant.

Summary of findings

The outcomes from this part of the analysis are . . .

- Variables identified by Qureshi (1990) as influential in predicting wish for alternative care soon did not differentiate between the groups of movers and non movers. However, it is possible that the analysis was not sensitive enough to detect such differences due to small group sizes.
- The Kiernan & Alborz (1995) variables which were predictive of a move, supervision problems in 1989, and injury to a parent, differentiated between the groups. This was to be expected as this subgroup formed part of the sample on which the analysis was based.
- There were no significant differences apparent between the groups of people with learning disability, effects on the family or support from services. This lack of significance is not taken to mean that there are no such effects but that it is not possible to detect differences with the small sample under study.

Summary

As shown earlier, age and gender are two significant variables which may greatly affect whether placement occurs. Age, because it is not current policy to place children away from the family home and, for older adults, because care by a parent may no longer be feasible. Gender may also have an indirect effect because of variables which are related to it. That is, there may be a number of biases introduced into the data in terms of the way specific disabilities may occur in males as opposed to females and vice versa (e.g. Turner syndrome / Fragile X or Tourette's syndrome etc), but also because of possible parental concerns over the welfare of daughters as opposed to sons. Due to the larger numbers of males compared to females who have learning disability, and also because they are found in larger numbers amongst the population of people with learning disability who show challenging behaviour, there may appear to be gender effects which are in fact due to some associated variable. In order to control for any extraneous effects such as these, age and gender were controlled in this section of the analysis.

The deficit in this strategy was data loss and the resulting small group of people for whom a parent interview was available from 1989, prior to moves taking place. The benefit was to obtain a 'controlled' sample of people with learning disability whose behaviour was challenging which might reveal factors which have a bearing on placement into alternative residential care. Information from the first part of this study indicated that people with greater physical care needs were less likely to have moved from home and that those whose behaviour was socially unacceptable were more likely to move. Further investigation suggested that those with a greater number of behaviours of this type were more likely to move. Analysis of the entire data set (N=695) showed that socially unacceptable behaviour was more likely to

be rated as serious where a larger number of behaviour types under this heading were present ($r = -.45$, $p = .000$).

Re-examination of variables relating to desire for alternative care (Qureshi, 1990) and those associated with moving (Kiernan & Alborz, 1995) was undertaken. As in the latter study supervision problems and injury to parent differentiated the groups. The result, confirmed by this small sample, suggests that the effect is substantial.

Findings in the literature could not be thoroughly investigated due to the small number of people for whom data was available prior to the move. However, the data was examined to establish whether any of these findings were reflected in these groups. No statistically significant differences were found.

The group under study was different from many on whom the general literature was based since they had been identified as showing challenging behaviour in service settings. This being the case there were potential stressors evident in the lives of all parents interviewed. In Sloper & Knussen's (1991) terms, they were vulnerable to stress due to the demand on their resources made by behaviour which could be difficult to live with.

Study three of this series will look at the actual circumstances of the movers just prior, and around the time of the move in order to identify any factors that appear to have been instrumental in occasioning a move.

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Chapter 6

Results

The experience of moving from the family home: Parents' experiences and views on their son or daughter's move to alternative residential care.

In this section of the thesis, answers to open ended and related questions are analysed to provide information on the experiences of parents of movers. Quotations are given to illustrate parental opinions and experiences (where names are mentioned these have been changed to preserve anonymity). Again level of disability is explored to place the experiences in context and is indicated, along with the reference number, after each quote. As indicated in Study 1a, it was considered that there might be different processes at work depending on the nature of the individual's disability and indices of intellectual ability and physical limitation were derived. Intellectual ability was based on verbal ability and comprehension as well as the ability to use money, presence of stereotypic behaviour and the extent to which the person could be occupied constructively. Four levels were derived ranging from the mildest level of disability - good - through fair and poor to low, which represented the most severe intellectual disability. Physical limitation was based on mobility, continence and ability to eat independently. Three levels were derived, none, where there were no limitations of this sort, through moderate and severe, where two or more of these limitations were apparent.

In the usual course of events parents and children begin separate lives when the then grown-up child chooses to move, possibly to go on to higher education, live with a partner, or for greater freedom and independence. Parents may, or may not, have input into this process. Where a child grows up physically but not intellectually they may not be capable of making such

decisions about their own future. Even where people with learning disability are able to express a wish to live separately, as brothers and sisters may do, they are not able to achieve this without help. The natural progression from dependence to independence becomes fogged and often parents are put in a position of making decisions on their behalf. These decisions shape their adult son or daughter's future life.

Where parents are unaware or unsure about the adequacy and/or appropriateness of residential provision, they may well decide that the best interests of their son or daughter will be served by keeping them in the family home. However, as circumstances change, and particularly where the person's behaviour is challenging, this option may, in the long run, be closed. At the time of this study this option appeared closed for several families. For these families the need to obtain alternative residential care was not so much a decision as a requirement.

There were transcripts from 15 families and quantitative data available for all (N=18). There were some written notes for the three families who declined a taped interview. Unfortunately the lack of transcripts reduced the depth of analysis for these families. However, there was enough information on the questionnaires to allow all of the families to be included in most analyses. Transcripts were read to develop broad categories in line with the aims of this research. They were then re-read and annotated to provide subheadings within each section. This analysis derived five stages or sections under which the open ended information was classified. These comprised Life at home before the move; Leaving home; Settling in; Relationships with the 'new' family; and Long term outcomes for parents and their sons and daughters with learning disability and challenging behaviour.

The description of the process of change below tries to illuminate those factors that appeared most influential in the need for change. It also describes how moves were achieved, the reactions of those involved initially, and in the longer term. In addition, the thesis examines the moves in the context of Essex et al's (1997) transition profiles. These profiles suggested three types of explanation for a move. The 'normative' pattern, including explanations emphasising the need for independence of the person involved. A 'postponed' launching pattern which, in addition to independence for the person concerned, stresses the need to see the person settled before parents become unable to care. The term 'postponed' is used because it is suggested that such moves take place when the person with learning disability is past the age at which moves in the general population usually take place (for the purposes of this study this is taken to be between the ages of 18 and 29 years inclusive). The third pattern Essex et al (1997) term the 'stress process' model. The explanations falling under this heading emphasise the inability of parents to continue coping with the person at home.

The interviews are also analysed in terms of the way moves were achieved and their effects on the son or daughter, as well as parents themselves, including a comparison with findings by Richardson & Richie (1989) and Bigby (1990). Finally, the study examines the continuing contacts with sons and daughters after the move and relationships with care staff. Each section contains a summary of the information derived from analysis of transcripts and descriptions of the circumstances of the families.

Life at home prior to the move

For fourteen of the eighteen families analysis of interview data showed that the primary influence in the decision to seek an alternative to family care was that life at home was very difficult. For the remaining four families home life was not an issue. In one of these a man was very challenging at school and in another was very dissatisfied with his life generally. The explanations given by parents of the remaining two people was that moving from home was the 'normal' thing to do. However, for most families a combination of factors were felt to contribute to the decision to seek change. The reasons given are summarised in Table 18 overleaf, in which people with similar levels of ability are grouped.

Parent explanations for moves

As may be seen in this Table, seven categories of explanation were derived from parent interviews. A fuller description of their meaning is given below

<i>Independence</i> <i>Do normal thing</i> <i>Get settled</i>	Explanations under this heading comprised notions that parents had decided that their son or daughter needed to lead a separate life to end dependance on them, to lead a near 'normal' lifestyle for their age. Some explanations suggested that they should settle elsewhere so that when their parents died they would not have to face bereavement, loss of their home, and care by strangers simultaneously.
<i>Bored</i> <i>Frustrated</i> <i>Ready to move</i>	These types of explanation emphasised that the impetus for change was coming from the son or daughter with learning disability themselves.
<i>Challenging</i> <i>Behaviour</i> <i>severe</i>	This heading indicates that parents were experiencing high levels of challenging behaviour at home impacting directly on their lives which was hard to cope with.
<i>Challenging</i> <i>Behaviour</i> <i>wearing</i>	Explanations under this heading acknowledged challenging behaviour as a factor in the decision to seek change because of its chronic nature or distress caused by witnessing its effect on their son or daughter.

Table 18: Parent explanations for placement of their son or daughter with learning disability and challenging behaviour in alternative care.

Ref - Gender - Age moved Intellectual ability / Physical Limitation	Independence Do normal thing Get settled	Bored Frustrated Ready to move	Challenging Behaviour severe	Challenging Behaviour wearing	Lack/reduced Day Service School or Respite	Family/Marital Problems	Parent Exhaustion or Ill health
111 Male 27 Good/none	✓	✓					
125 Male 23 Good/none	✓		✓	✓			✓
535 Male 27 Good/none			✓				✓
871 Male 20 Good/none	✓	✓					
116 Female 18 Fair/none				✓	✓		
124 Male 24 Fair/none	✓		✓				
336 Female 35 Fair/none	✓					✓	✓
355 Male 23* Fair/none			✓	✓			
487 Male 21 Fair/none			✓		✓		✓
144 Male 26 Fair/severe			✓	✓	✓		✓
723 Female 21 Poor/none				✓	✓	✓	
727 Male 22 Poor/none		✓	✓				✓
114 Male 14 Poor/moderate			✓		✓		
237 Female 27 Poor/moderate			✓	✓	✓	✓	✓
319 Female 26 Poor/moderate	✓			✓			
853 Male 22 Low/moderate			✓	✓	✓	✓	
231 Male 11 Low/severe			✓				
561 Male 29 Low/severe				✓		✓	✓

* This person was taken away from his parents at the age of 4. He later returned to the family home and had lived there for two years before he moved out once more.
NB. 114 and 231 were children at the time of the 1988 survey therefore their intellectual ability and physical limitation groupings reflect their early stage of development.

*Lack/reduced
Day Service, School or
Respite*

These parents acknowledged that lack of services had an impact on their situation such that they could not cope in the long run, or needed to seek educational provision out of the area.

*Family/Marital
Problems*

For these families there were additional difficulties in the family such as divorce or mental / physical illness of spouse or siblings not directly involved in caring for the person with learning disability.

*Parent Exhaustion or
Ill Health*

These explanations noted the fact that the parents themselves were feeling worn out or at the end of their tether. They might also have physical limitations themselves which were making caring difficult.

In terms of level of disability, it is clear that it was primarily parents whose son or daughter had a good or fair level of intellectual ability who talked about a need for independence, or to get settled in a new home, before parents became unable to cope or died. None of these people had physical limitations. The exception was a woman with a poor intellectual level and moderate physical limitations. Unfortunately, there was no transcript for this interview, however notes did emphasise that her parents found her behaviour (self injury) distressing to witness and wished to see her settled before anything happened to them. One might speculate that these factors may have had a profound influence on their decision. This woman was an only child so continuing care by a member of the immediate family was not an option.

All parents of people with poor or low intellectual ability mentioned challenging behaviour as a contributory factor (n=5 and n=3 respectively), as did 5 out of 6 parents of people with fair intellectual ability and 2 of 4 people with good intellectual ability. More parents of people with poor intellectual ability mentioned lack of services (3 out of 5) than other groups. Approximately half of each group mentioned their own exhaustion or inability to cope as a factor.

Transition profiles

Essex et al (1997) outlined three transition profiles - normal, postponed and stress process models - related to the family life cycle (Olson et al 1984) which accounted for the types of explanation given by families in their study. Only four moves in this study appeared to fall under the category of 'normal launching pattern', that is, the son or daughter was leaving home at an age typical of that for the general population and for reasons of greater independence, a separate adult lifestyle. The remainder (n=14) appeared characteristic of the 'stress process model' with parents unable to cope with caring for their son or daughter at home.

As can be seen from Table 18 the impetus for change came from the person themselves in only three cases, however in one of these (727) the major emphasis was on difficulties with challenging behaviour and need for independence was given with hindsight as a possible reason for the behaviour. Six parents acknowledged that it was time for their son or daughter to move either because this was appropriate for their age or to get them settled independently to prevent a later crisis. For two families (125, 336) this was a secondary reason for the move. In one case it was primarily the parents' ill health and feelings of exhaustion which was the main explanation of the need for a move and, in the other, high levels of challenging behaviour and the parent feeling intimidated were the main impetus, again the need for independence was a rationalisation provided in hindsight after the move had taken place.

For the four remaining families, who fell into the 'normal launching pattern' group, the wish to see their son or daughter living independently was the main reason for seeking change. In

two families the parents felt that their sons were also showing by their behaviour that they had had enough of life with 'Mum and Dad'.

Mother *"He was getting bored with his father and I, which was only natural I think it had all built up and he was getting really frustrated because he wasn't doing what he wanted to do and they were not interesting him enough at (the Day Centre). He was bored and he would come home and tell you 'bored, bored, bored'."*

(Interview 871 - good/none)

As stated above, the remaining fourteen families would all appear to come under the 'stress process' model because all of the explanations comprised an element of inability to cope with the person at home. However, the circumstances of these families were wide ranging and deserved more detailed analysis.

Types of explanation under 'stress process' model.

Examination of the circumstances of these parents revealed that although challenging behaviour was at the root of a need to move there were also in many cases other contributory factors. Analysis of the range of explanations given revealed three broad categories for the primary reason for obtaining an alternative placement. These categories were then subdivided to distinguish between different forms of each explanation type. These categories were

<i>Forensic</i>	Involving intervention by the police or may have done so were action not taken.
<i>Family</i>	Involving problems within the family not directly attributable to the person with learning disability.
<i>Service</i>	Related to a lack of service provision or lack of suitable services locally.

Forensic

Six families' explanations for moving fell in this category. However, these circumstances again might be split into two further divisions i.e. one in which the police were involved (Actual) and a second in which the police may have been involved at some stage if the behaviour were not controlled (Potential). The situations in which the families found themselves are given in Table 19 below.

Table 19: Explanations for the occurrence of a move which involved contact or potential contact with the Police

<i>Forensic</i>	Behaviour (Ref)	Other contributory factors
<i>Actual</i>	Violence to mother (237) Violence to mother (727) Sexual assault on girls (355) Stealing (125)	Lack of services Parents health problems Unsettled home life - many placements Aggressive towards mother
<i>Potential</i>	Criminal damage (487) Stealing (535)	Violence by parent to son Lack of services Mother health problems

As noted in this table there were other circumstances, as well as those which involved, or potentially involved the police, which contributed to the move. To illustrate, the situations of a woman (237), from the 'Actual' group, and man (535), from the 'Potential' group, are described below.

Example - Actual Police involvement

One woman's behaviour had deteriorated substantially just prior to the incident that occasioned the move and her mother would take her out in the car at night and drive for miles to keep her out of her father's way.

Mother *"I think, I think it was really what we were feeling was, it was, it was a more physical drain on us than anything. And physically I got to thinking, 'Well...', I thought, 'If I drop dead tomorrow somebody's going to have to do something about it.' And, and that, that was it. But there was no way I could have turned round and said, 'Look, there's somebody got to do something. I can't cope any longer.' I couldn't have gone and made a conscious decision to say that she'll have to go away."*

(Interview 237 - poor/moderate)

The woman was excluded from her Day Centre because she was hitting people and 'upending' chairs. Her mother felt that the staff were not sensitive to her needs and kept putting her in situations she could not cope with, for example in crowds.

Mother *"And so that just exacerbated the situation where I mean you can only say this on reflection now that things just went from bad to worse. And so instead of having her for roughly four and a half to five hour break in the day, it was twenty four hours a day, and she didn't sleep. She didn't sleep."*

(Interview 237 - poor/moderate)

Her mother would spend hours driving, taking her all over the country to provide her with some kind of activity that she enjoyed but it did not suffice.

Mother *"..... to me it was a big culmination of things, you know. Just like she couldn't take any more.... probably in her instance she just felt enough was enough... she'd had enough of what she was getting. And yet I thought her quality of life, apart from her not getting her, her day care, was jolly good."*

(Interview 237 - poor/moderate)

Finally an incident occurred which forced the intervention of the Police. The mother wanted to stop her daughter 'whooshing' water in the sink so she suggested walking the dogs. This appeared to break a kind of 'trance' that her daughter had gone into such that she turned on her mother and started to beat her in a sustained attack that lasted about an hour.

Mother *"..... she was absolutely beating me face..... And I was crying, I was pleading with her to stop hitting me, you know. And anyway after about an hour I just felt if I don't get up, if I don't get up I won't get up again. I felt she was going to kill me."*

(Interview 237 - poor/moderate)

The mother finally managed to control her daughter by holding on to her hair and then attracted the attention of a neighbour whom she asked to contact the Duty Social Worker.

This did not prove possible and so the Police were brought in.

Example - Potential Police involvement

In the second case, though the Police had not been involved, there were legal implications to the man's behaviour. His mother described a worsening in her son's behaviour and how he would hit out if he couldn't have his own way.

Mother *"He's... The last few years he's got a bit aggressive, you know, with people in the house. Because he was frustrated - I think he was frustrated. He'd like, you know, hit out, if he couldn't just get his own way. When he was here he monopolised the television and video all the time, and he had to watch. He used to record things, and he had to have things at a certain time, listen to things - listen to his records at a certain time, watch his programmes at a certain time, and if he couldn't do that, you know, like, the others had to do that as well, and if he couldn't do that he got (annoyed) and hit out. And he's a big lad, there's seventeen stone!"*

(Interview 535 - good/none)

He had also recently started stealing.

Mother *".....another thing we've had with him was stealing. He's been stealing off us for a few years..... money kept going missing. And we realised it was Edward..... We had to start hiding money in different places and he'd find it. He just had to have money all the time. He's still like that now. He goes out and sells things to get money, just to buy another record. And he doesn't get much money for it. He just has to spend all the time. It's like a sickness."*

(Interview 535 - good/none)

Even though he was difficult to live with his family wanted him to remain at home. His mother felt that part of the problem was due to her son growing up and asserting himself and partly to her own medical problems which reduced her ability to cope with him.

Mother *"It's actually been going on for a few years, but we didn't want him to go away. They've been asking us about 'do you feel he needs to go away?' but we'd never wanted him to go away from home. It's only like in the last few years we felt like we couldn't cope with him."*
 (Interview 535 - good/none)

In the latter case there was a potential problem should the man have extended his stealing to settings outside home. There was some evidence that this might occur as he took some money from a fund raising event at his Day Centre on the day he was leaving. It was discovered and he was made to return it. Another man who had a problem with stealing was categorised under the 'Actual' group because he had eventually been arrested by the police and was sent to a Medium Secure Unit.

Family

The second broad category, Family, comprises explanations which, along with handling challenging behaviour at home, stressed other difficulties within the family. These could be further described in terms of family member/marital problems, where difficulties lay with other members of the family or a marital problem between parents, and parental distress, where the emphasis was on the inability of the parent to cope due to their own mental and/or physical exhaustion. Five parents' explanations were categorised under this section as follows.

Table 20: Explanations for the occurrence of a move which involved difficulties within the family

Family	Behaviour (Ref)	Other contributory factors
<i>Member/marital problems</i>	Self injury (723) Overactivity / destructive (561)	Divorce/ mother's health problem. Lack of services Father and brother mental illness
<i>Parental distress</i>	Aggressive / destructive (144) Destructive / inappropriate sexual behaviour (853) Self injury (336)	Visual impairment / severe epilepsy Visual and hearing impairment Father's angina

For those parents whose explanations were classified in the member/marital problems group, although challenging behaviour played its part in complicating family life, it was primarily difficulties stemming from other members of the family that caused the inability to continue caring at home. In the second grouping, parents emphasised their own exhaustion as the main reason for instigating a move, though again challenging behaviour made a large contribution towards this. Two examples of these types of descriptions are given below.

Example - Member/marital problems

The mother of a woman described a range of contributory factors, however separation from her husband made coping more difficult.

Mother "Oh, been building up a long time, yes. I think we'd pressure from friends and parents, I think, really. And the obvious realisation that things weren't going to get any better you know... and life was very restricted, and especially when my husband left you know, because I was left with Helen. I mean he was quite good about coming and sitting but it was a day to day, you know, coping with her that was..... And I suppose it's like having a permanent baby, you know....."

(Interview 723 - poor/none)

Day to day difficulties coping alone with a daughter with learning disability and challenging behaviour was then compounded by an inability to obtain respite care.

Mother "I think what precipitated it was the fact that we got her in this private place in (another town) and they finally threw her out of there. They wouldn't, they couldn't cope with her you see and (the local facility) which was doing the short care rotation they were closing down, they went, so we weren't going to be offered any respite care..."

(Interview 723 - poor/none)

Example - Parental distress

In the second case the man had a visual impairment and severe epilepsy which along with his severely challenging behaviour made him especially hard to cope with.

Mother "when he goes into... one of those rages is pretty frightening, for him - not for me, I was never frightened of him - never would have been frightened of him, no matter what he'd have done. But to see him smashing his head like that, I just couldn't take it, and his dad couldn't.... All along his dad and I have said there's no way Vince would go away from home - you know, we'd cope with him till the day we died. And that's the way we felt, but in the end we were getting tired because we weren't sleeping at night."

(Interview 144 - fair/severe)

This mother described how she and her husband could not sleep properly because they had to be ready if their son had a fit in the night - he often required oxygen and an ambulance. She also explained how lack of sleep was making her and her husband irritable, which then in turn made their son bad-tempered. There had been times when she felt quite desperate and even suicidal. His behaviour was also extremely difficult.

Mother "Well usually it's himself, usually it could be verbal, it could be just that he doesn't want to know. Just maybe that he's what we would say maybe bad-tempered.... But we have a mood rating scale from one to six - one is when Vince's quite happy and compliant, but from two up there's a deterioration. And when he goes up to five or six, believe you me, you watch out, you don't turn your back on him."

(Interview 144 - fair/severe)

Quite apart from physical attacks he would throw any objects that came to hand, including knives or electrical appliances (still plugged in). It was not surprising that his parents had come to need more than short respite.

*Mother "My husband and I were really in need of respite and help, and we'd had to call the team (Crisis Intervention*1) out twice that week, and we'd had to call the paramedics out three times that week, which was last week, the week before last, and in that week we've had a real traumatic week, and they thought that on the basis of that they would try and get him in sooner."*

(Interview 144 - fair/severe)

Despite the parents' wish to keep their son in the family home, therefore, caring in this case had become too stressful and they were no longer able to do so.

For the families categorised under this heading, the behaviour of their son or daughter was a serious challenge but it was primarily the health problems of parents or other family members which finally tipped the balance and made it impossible to continue care in the family home.

Service

The third broad category was related to lack of suitable facilities locally as the prime reasoning for a move, quite apart from the presence of challenging behaviour per se. This was again divided in to two categories, one representing moves for specialist treatment available out of area and the second concerning moves out of area due to a lack of alternative locally (having been excluded or withdrawn from the local service). Three parents stressed these kinds of explanations as shown below.

*1 'Crisis Intervention Team' was one of a number of names given to specialist challenging behaviour teams which were created in the early 1990s as a means to support carers coping with people with learning disability and challenging behaviour in the community. However they were not commonly involved in the family home (Kiernan & Alborz 1995).

Table 21: Explanations for the occurrence of a move which involved lack of services.

<i>Service</i>	Behaviour	Other contributory factors
<i>Treatment</i>	Aggressive behaviour (231)	(Child)
<i>Deficit</i>	Aggressive behaviour (114) Non compliant / aggressive (116)	(Child) Nothing suitable for person with autistic tendencies post 18

Again to clarify between these categories an example of each is given.

Example - Treatment

This child was excluded from a school for children with severe learning disabilities because he would attack other children.

Father *"he's got this aggressive behaviour of pokin' people. And when I say pokin' people he doesn't just go for the body he'll go for the eyes, the bum and things like that....."*

Mother *"When he was at (school) he badly scratched some child's eye that had to be taken to hospital to check it out. (there was) another child who he poked his backside and caused it to bleed.*

(Interview 231 - low/severe)

Mother *"... he was indefinitely excluded from (school) because of his challenging.... what they call challenging behaviour."*

Interviewer *"When it was decided that he would go to (specialist school), was that because of his behaviour?"*

Mother *"That's the only school that the authorities could find was suitable for him."*

(Interview 231 - low/severe)

The boy had spent several months at home having been excluded from full-time education, only part of the time with a personal tutor. Funding was eventually obtained to allow him to

attend a school specialising in the treatment of challenging behaviour in children with learning disability. The school was about fifty miles away from his home.

Example - Deficit

The second example is of a young man who was also a child at the time he moved from home. His behaviour was difficult at school, but, in the opinion of his mother, no more challenging than many other pupils.

Mother "The school he was goin' to er, were having problems with his behaviour. Er, but in all fairness to Nigel I must say they didn't put a lot of effort into it er, due to a clash of personalities. I wasn't very happy with the school at all. So we said we wanted him to go to another school. Er, unfortunately there was nothing local so er, Education Authorities came up with one or two which we looked at which weren't acceptable. Weren't acceptable at all. Er, we wanted, really, him to go to a day, you know, a day service school. We didn't want him to go away. Then we said we'd consider Monday to Friday, you know. Er, but there still wasn't anythin', nothin' at all. So he went away and just come home every six weeks which broke our 'earts. You know, I'll be quite honest wi' you, it did..... We just wanted a change of school. We didn't want him to go away but there was absolutely nothin'."

(Interview 114 - poor/moderate)

This boy attended the residential school for six years and at the time of the interview had just moved to a house in the community close to his parents.

In several of the examples given above, it is apparent that there were a combination of factors at work and explanations could be placed under two or more headings. The reason why the parents' explanations were placed under particular headings was based on the reason given greatest emphasis or the incident leading directly to a move. The tables above attempt to give an idea of the challenging behaviour exhibited in the home prior to moving and the main reasons given for a move at that time. It appeared that many of the reasons given arose out of difficulties in handling challenging behaviour over the long term.

There was no 'postponed launching' pattern discernable amongst the above cases. The oldest 'mover' was 35 at the time she left home and although this would seem to fulfil the 'postponed' criteria the main reason she moved at that time was due to parent distress. Her mother emphasised her own and her husband's exhaustion. The move was not primarily to preempt a crisis when her parents eventually die, though this reasoning did figure in the explanation given by her mother. One might argue however that this was, in fact, what was achieved.

The next section of this study looks at the moves themselves, the extent to which they were planned and the feelings of parents at this transition stage.

Summary of findings

- In terms of Essex et al's (1997) transition profiles, only 4 people with learning disability and challenging behaviour had a 'normative' launching pattern. The remaining 14 people moved under the 'stress process' model. No one was categorised under the 'postponed' launching pattern.
- Reasons for placement in alternative care were given as - independence / to see person settled; challenging behaviour; lack of services; member/family problems; and parental distress.
- Parents of people with good or fair intellectual ability were more likely to see moves as a way for their son or daughter to gain independence, or to say that they wished to see them settled before they were incapacitated or deceased.
- Parents of people with poor or low intellectual ability all mentioned challenging behaviour as instrumental in seeking a move. Most parents of people with a fair level

of intellectual ability (5 out of 6) also cited challenging behaviour as a factor in their decision to seek an alternative.

- More parents of people with a poor level of intellectual ability (3 out of 5) mentioned lack of services as instrumental in the decision to place their son or daughter, than other groups.
- Approximately half of each group gave their own exhaustion or inability to cope as a reason for the placement.
- 'Stress process' moves were analysed and three broad categories emerged.

Forensic - which emphasised the actual or potential involvement of the law due to the person's behaviour.

Family - which stressed difficulties within the family or exhaustion of parents as the main impetus for change.

Service - which was noted by parents whose son or daughter had been excluded or withdrawn from local services due to their behaviour and moved away from home for treatment or because nothing suitable was available locally.

2 Leaving home

Transcripts were examined for evidence that parents were looking for a placement before the move occurred. In all but four cases there was an element of planning involved, however several moves happened very quickly and in only five of the eighteen cases was the move achieved over a period of months. This information is summarised in Table 23 overleaf. The speed of the moves to alternative care is summarised in Table 22 below.

Table 22: Number of people with learning disability and challenging behaviour who made 'Immediate', 'Quick', or 'Gradual' moves by level of intellectual ability (N=18)

<i>Speed of move to alternative care</i>	<i>Immediate/'crisis' - no prior visits</i>	<i>Quick - one prior visit before move</i>	<i>Gradual - visits building up over period of time to move</i>
Good Intellectual Ability (n=4)	1	2	1
Fair Intellectual Ability (n=6)	2	2	2
Poor Intellectual Ability (n=5)	3		2
Low Intellectual Ability (n=3)	2	1	

This table shows that for most people with learning disability whose parents were interviewed (n=13), the move to another home occurred with little or no chance to acclimatise to the new environment before leaving home. In eight cases there were no prior visits, four of which were 'crisis' moves. In three of these cases there was a violent situation at home and in the fourth case, the man was required to move by the Police or face prosecution. Other immediate moves, though not made at the height of a critical incident, might also be very stressful. For example, in the case of a man with low intellectual ability his family were

Table 23: Speed of move to alternative residential care for people with learning disability and challenging behaviour (N=18).

Ref - Gender	Intellectual ability / Physical limitation	Planned Move?	Speed of Move
111 Male	good/none	Yes	Gradual - some prior visits
125 Male	good/none	Yes	Quick - Moved after several months discussion of his need for 'independence'.
535 Male	good/none	Yes	Immediate - No residential visits to treatment facility before move though had been involved in choosing.
871 Male	good/none	Yes	Quick - One weeks holiday before place became available
116 Female	fair/none	Yes	Quick - Had been seeking placement for some time. Had visited the Autistic Community in which place suddenly became available.
124 Male	fair/none	Yes	Gradual - moved to house purchased by parents. Care provided by private organisation with funding from Social Services.
336 Female	fair/none	Yes	Gradual - moved to home of Adult Placement Carer
355 Male	<i>fair/none</i>	No	Immediate - Forced to seek residential placement by police because of inappropriate sexual behaviour towards young girls living locally.
487 Male	<i>fair/none</i>	No	Immediate - Removed by Social Worker after incident, though parents had been seeking a placement.
144 Male	fair/severe	Yes	Quick - Had respite stays before place suddenly became available. Moved one week later.
723 Female	poor/none	Yes	Gradual - Several short visits building up over a three month period before move.
727 Male	<i>poor/none</i>	No	Immediate - Removed by Police after emergency call to Duty Social Worker.
114 Male	poor/moderate	Yes	Immediate - No prior visits. Residential school for children with learning disability. Parents had visited before move.
237 Female	<i>poor/moderate</i>	No	Immediate - Removed by Police after unsuccessful attempt to contact Duty Social Worker.
319 Female	poor/moderate	Yes	Gradual - several prior visits.
853 Male	low/mod	Yes	Quick - One weeks 'holiday' at treatment facility before moving.
231 Male	low/severe	Yes	Immediate - No prior visits. Residential school for children with challenging behaviour. Parents had visited before move.
561 Male	low/severe	Yes	Immediate - No visits to facility before move. He was assessed at home and moved about 3 months later.

Those in italics were crisis moves

under immense stress from a variety of sources apart from his challenging behaviour. There was no opportunity to move locally and so this man was visited at home by staff and then moved directly to a residential home approximately thirty miles from his family.

The tables above show that those people whose move was not planned had fair or poor levels of intellectual ability. None of the people with a low level of intellectual ability moved gradually. Only one of the three had actually stayed at the residence he was to move to before moving in permanently.

The quick moves, by and large, occurred because a place at a desired residence or treatment centre suddenly became available and pressure came to bear to take up the opportunity or lose it. Parents decided to take it, worrying that if they did not there might not be another opportunity for several years.

Even with some of the gradual moves places suddenly became available, however they were in the fortunate position of having had several prior respite visits. Only two parents described a planned gradual transition from home to alternative care. Examples of these types of moves are described below.

Immediate or 'crisis' moves

There were eight moves in which there was no prior visit to the new residence. Examples of these are given below.

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In two cases the move was totally unplanned and the people concerned were taken away by the Police. As described above these people had physically assaulted their mothers and the Police were called as a last resort. Unfortunately, the presence of the Police only acted to heighten the mothers' distress.

Father *"They had to arrest her you see. Its, its ironic really that, that they couldn't do it somewhere that'd cause Teresa (wife) you know."*

Mother *"Its all terrible. (weeping)"*

(Interview 237 - poor/moderate)

Mother *"I mean I can still picture it now. I sat there bloody shrieking my eyes out when he went in that Police van, with the Police, you know."*

(Interview 727 - poor/none)

In a third case, although the parents had been actively seeking a placement for their son they were unable to find anything. In this case the man had been to a local shop for a newspaper as usual, however on the way back he had gone into a neighbour's garden and smashed through their front door with a concrete garden gnome. His father was incensed by this behaviour and attacked his son. The man's sister contacted their GP and the man was removed by a Social Worker.

Father *"..... he was carted off on Saturday morning..... they could have taken him away and locked him up in prison for me that day, wouldn't have bothered in the slightest"*

Interviewer *"So there was no chance of a discussion with anybody about, you know, what you wanted or where he would go or....."*

Father *"No, he (Social Worker), came along, we threw his bag in the back, chucked him in and he went."*

(Interview 487 - fair none)

In another case the Police had recommended that the family find alternative care for their son or he would face prosecution for his inappropriate sexual behaviour to young girls.

Mother *"...me husband went down with the police lady 'cause she was a bit erm.... And he didn't protest about going out of the house. No, he was quite quiet and, like I say, that was about the first week in October. But as, as me husband said it was either, if he'd stayed at home, it was either if he stopped at home he would be prosecuted. Or he could either go away, . . . or if he stayed at home he could be prosecuted. So we had to make a decision, so....."*

(Interview 355 - fair/none)

In these situations there was no opportunity for reflection on where their son or daughter should go or what type of facility would best meet their needs. The prime motivation was to end an unacceptable situation. Even when the person had been moved by the police there could be difficulties in finding temporary accommodation. As one mother explained.

Mother *"they took her eventually up to (the local psychiatric hospital) and they wouldn't admit her. Because they're psychiatric. And that lad over there (who was the Policeman dealing with the situation) would not leave (the hospital) until they'd admitted her. They said 'Can you not take her back home?' He said, 'Indeed we can't take her back home.' He said 'You want to see the state of her mother.' He said 'It is an impossibility to take her back to that environment because that would finish her off.' So they said 'Well, can you not put her in the cells?' He said 'Nope.' He said he wasn't doing that. He finished work at 11 o'clock at night, and at quarter to 12 he came knocking on our door, and he had just finished. He said 'I thought I'd just let you know how she is.'"*

(Interview 237 - poor/moderate)

An Asian man with severe learning disability and physical problems also moved without prior visits. This appeared to have occurred because no place could be found locally and the family were distressed. The man's father and brother were ill and his mother could no longer cope.

Social Worker (on behalf of Mother) *Um actually the manager from (The residential care facility) came to assess him. They came to see him about two or three times you know and to work and spend time with him, you know, his behaviour and what sort of activities he is interested in, you know, so they did a full assessment. After that, that was in December I think, after assessing his needs and everything and having to get use to him then they sent him to (this facility).*

(Interview 561 - low/severe)

In four cases these moves were in response to crises. The remaining moves were to residences out of area, usually for treatment.

Quick moves

Most other moves were more planned but there was not a lot of time, in most cases, for the individual to acclimatise to their new surroundings. There were five 'quick' moves involving only one stay at the residence before moving permanently. Three examples are given below.

The first man moved for treatment. He was deaf and blind.

Interviewer *"Did he go for short stays first before moving permanently or..."*

Mother *"...he'd been there before, for the holidays, you know, he had like a week down there"*

(Interview 853 - low/moderate)

The second example is of a man who had shown by his behaviour that he was ready to move.

He and his parents chose his new home.

Mother *"Yes we waited. We waited three years before he could go for a week. We kept at them and he went for a week and it wasn't long before he went in permanently. It happened really fast after he had been in for a week but it was three years before."*

(Interview 871 - good/none)

The mother below had started thinking about a move because she knew of a person who's son was resident in a particular facility and had commented how wonderfully he was doing. This,

in conjunction with comments from family and professional staff to the effect that they needed to plan for the future so that their son would not get 'dumped' somewhere unsuitable if anything happened to them, spurred them to try to get a placement in the same facility as her friend's son.

In the end, with a great deal of correspondence and appeals to those involved, when a place became vacant it was offered to this young man.

Mother "I think they realised the situation was desperate. he said 'Vince can move in Saturday if you like', and I says 'Oh, so soon?'.... we'd discussed about leaving it longer..... But (the keyworker) felt that Vince, my husband and I were really in need of respite and help.... but then it took a week till they got everything settled because they'd the room to get ready and everything. And that's when he went in, so it was pretty quick. It was a matter of a week after we were told that he was going - he had gone the following Monday like."

(Interview 144 - fair/severe)

Four of the five quick moves occurred because a place at a preferred facility suddenly became available. In the fifth case life at home was difficult and therefore the first placement available was taken.

Gradual moves

There were five moves categorised as gradual, that is, there had been a number of visits to the residency before the person had moved permanently. In 'gradual' moves the process of moving overlaps to some extent with that of 'settling in'. However for the purposes of this study moves were only considered to be complete when the person was spending more time in their new residence than in the family home. Two mothers described a gradual planned transfer from the family home to the new home.

Mother *"Yes she, the first couple of times she just went for tea and the first time I got a phone call said 'Mrs..... when are you coming to pick her up?' So didn't start off very well. But she went for tea a couple of occasions and then she built up and stayed over night and then stayed a long weekend until they gradually decided that she was ready to come in so....."*

Interviewer *"How long would you say it took?"*

Mother *"Oh about a three month period"*

(Interview 723 - poor/none)

Another family had taken a decision to purchase a small house nearby for their son. He was not keen on the idea of moving out but was happy with the idea of having two houses. The move was made very slowly indeed, working at the man's own pace.

Mother *"when he first went when it was only like one night, erm they didn't have permanent staff then, so she (carer) was only actually slotting in. So when it went up to two nights she was working with another service so he had to have a different carer then, and we noticed the difference then. Erm, he didn't seem to mind much, but he would ring us up.... he didn't really rebel, he didn't say 'Right. I'm not goin', or, 'I want to come home', but he'd just ring up to check on us, like that. And that happened for quite a while. Once he was on three days he still had L. His worker then became permanent with him."*

(Interview 124 - fair/none)

The three remaining parents also described the move from home as being made after a number of short stays in the residential facility.

Summary

- A large minority of people with learning disability and challenging behaviour in the study moved to their new home without prior visits (n=8).
- None of the people with low levels of intellectual ability moved gradually and only one had had a prior visit to his new home.
- Immediate moves tended to occur due to a crisis at home or the sudden availability of a place at a treatment facility.
- Quick moves were often made because a place suddenly became available at a preferred residence or treatment facility.
- Gradual moves were made by only five of the eighteen people with learning disability and challenging behaviour involved in this study.

3 *Settling in*

As described above, the circumstances in which the change from home to residential care occurred were difficult in many cases. For a variety of reasons the situation at home was fraught and the move to an alternative residence speedy. Most parents (n=12) describe an initial period when their son or daughter was, quite naturally, upset at their change of circumstances. Those whose move had been occasioned by extremely challenging behaviour and parents inability to cope, continued to present serious challenges in their new home (n=5).

As mentioned previously, some people were moved in the course of violent conflict with their parents (n=3) and one person because of his behaviour outside home. Others moved because very difficult circumstances within the home were compounded by the individual's challenging behaviour to the extent that their parents were no longer able to cope (n=3). For some, residential treatment was thought to be the best solution (n=7), to try to overcome challenging behaviour and to teach new skills so that they could become more independent. A boy moved to a residential school because no suitable school could be found locally. Only four people moved because their parents perceived that they were ready for a move and would lead a more enjoyable and fulfilling life elsewhere.

Information about the settling in period is summarised in Table 24 below. This includes the immediate reactions to the move by the person with learning disability and the time away from home at the time of the interview.

Table 24: Reactions to leaving home and time away from home for people with learning disability and challenging behaviour (N=18)

Ref - Gender	Intellectual ability / Physical limitation	Reaction to move	Time away from home
111 Male	good/none	Gradual - Upset for short period	2 years
125 Male	good/none	Quick - Not known	4 years
535 Male	good/none	Immediate - Anxious	1 month
871 Male	good/none	Quick - A little upset at first	4 years
116 Female	fair/none	Quick - Didn't mind	5 years
124 Male	fair/none	Gradual - Didn't mind	2 years
336 Female	fair/none	Gradual - Treated it like a holiday	2 years
355 Male*	<i>fair/none</i>	Immediate - Not known	5 months
487 Male	<i>fair/none</i>	Immediate - Challenging behaviour continued	2.5 years
144 Male	fair/severe	Quick - Distressed	1 week
723 Female	poor/none	Gradual - Distressed - behaviour challenging - sedated	5 years
727 Male	<i>poor/none</i>	Immediate - Challenging behaviour continued	2.5 years
114 Male	poor/moderate	Immediate - Happy	6 years
237 Female	<i>poor/moderate</i>	Immediate - Challenging behaviour continued - sedated	3 years
319 Female	poor/moderate	Gradual - Incontinence increased	7 months
853 Male	low/mod	Quick - No obvious reaction	4 years
231 Male	low/severe	Immediate - Not known	2 years
561 Male	low/severe	Immediate - Upset didn't understand	1 year

* This person first left home aged 4 yrs and had six moves before returning to his family, after 2 years at home he moved again.

Italics indicate people who moved from home as a result of crisis situations.

Reaction of the person with learning disability to the move

In examining reactions to moves from home it was deemed appropriate to group people into those who had moved recently and those who had moved more than a year ago, either under crisis conditions or for other reasons. This was done so that any details regarding the move which may have been overlooked in retrospective accounts may become apparent. In addition, parents of those who had been in alternative residential care for longer periods had a wider experience of their son or daughter's adaptation to their new home and wider experience of relationships with care staff which may reasonably be expected to develop over time.

Recent moves

The two men described below had moved away from home only one week and four weeks prior to the interview respectively. The first made a 'quick' move to a house in the community where he had previously stayed for respite care.

Mother *"Karen's (Keyworker) just told us he's not too happy today, but we expected that. But you see he's like, he can be like that here as well. Now I don't know how he was during the weekend, but we've had, on and off, days like this. I try to be as laid back about it as possible - it's not easy 'cause I'm not there to see what's happening and why."*

(Interview 144 - fair/severe)

This second man had gone to a treatment facility for people with Asperger's syndrome.

Mother *"He didn't want to go really. He were very upset when he went. I don't know whether he's settled in or not. I still think he's not settled in. I don't know..... He's wanted to come home. We're giving him the six months anyway, see how he goes on..... He keeps ringing everybody up, you know. 'When are you coming to see me?', 'Are you coming to tea?' (laughs)"*

(Interview 535 - good/none)

The first man is blind and has severe epileptic fits, his behaviour was also extremely challenging, particularly injury to himself. His mother was naturally concerned to see him settle well, as described above she was not well enough to cope with him at home any longer. In the latter case, the person had left home for treatment but was not expected to return permanently once the period of treatment was over. There had already been discussions on the area he might move to when the time came. His mother described him as still rather anxious after four weeks away.

Two other people had left home in the last year. One was a man who had been in and out of residential care throughout his life and, as was described above, went to his new home accompanied by his father and a policewoman. He did not object, perhaps because this was his eighth change of residence in all. The other person was a woman of 26 years. Her mother said that she became more incontinent but her behaviour remained at the same level. Overall, she felt that her daughter had coped well with the move (no transcript).

Moves over a year ago

'Crisis' moves

There were three crisis moves which had occurred more than a year before the interview took place. A man who had been very aggressive at home continued similar behaviour after he had moved.

Mother "I should think about six month when we noticed a change in him. And then -'cause you see, Phil got set in a routine at home, set in his ways, that it took them quite a while at (the hospital) to get him out of all that, you know. 'Cause I mean they didn't, (at the hospital) are like these carers, they didn't like bully them, you see, and they took it like one step at a time, you know."

(Interview 727 - poor/none)

This man attacked his mother and other members of his family when living at home and was removed by the Police. In this, and the other case where the individual had to be arrested, the circumstances of the removal were very distressing to the parents. Both these individuals then spent several months at a hospital for people with learning disability where they received treatment for their behaviour. In both cases the parents maintained regular and frequent contact with their son and daughter.

The man whose behaviour had eventually provoked an attack from his father also continued his difficult behaviour in hospital.

Father *"And the first week he tried to burn the place down a couple of times and then he ran off"*.

Mother *"Set light to the curtain, it's all attention seeking....."*

(Interview 487 - fair/none)

The hospital successfully treated his behaviour and his parents were thrilled with his progress. In all these cases an initial period of behaviour therapy ensued which appeared to be a difficult, though constructive, time for parents and son or daughter alike.

'Other' moves

There were eleven 'other' moves which occurred more than a year before the interview. Although most people appeared to have settled quite well once they had time to get used to their new surroundings (n=10), this was not the case for everyone. A parent who had sought a placement because she and her husband were suffering ill health and in need of relief from the stress and worry of caring for their daughter, found the move a real dilemma.

Mother *"Well at first she thought it was a holiday so she looked for trips out and all the er, like as if you're on holiday you see. And, you see, at first of course they did, they took her out, er, to get her used to it all. And, er, that was at first and then when she realised she was stayin' of course, it got a bit difficult because she really didn't want to leave home. She really accused me of gettin' rid of her. So it was a bit stressful for her really. And even now, y'see, she'll say to me 'I want to live at home Mum. This is my home'."*

(Interview 336 fair/none)

The daughter moved two years prior to the interviews. This mother speculated that if things were different, if her behaviour was not an issue, and if there was adequate support in terms of day and respite care she could come home. However, this was not the only consideration.

Mother *"And then, y'see, I start to think 'Well, what happens after my death', and I worry. For her..... It's very hard because I do know a lot of people who er, well they die and they leave the family, and nobody wants the mentally handicapped person, do they? So, erm, I've seen that side of it as well. And they just stayed away, y'see."*

(Interview 336 fair/none)

Four of the eight people who had moved more than a year ago and for whom the information was available showed some initial distress. A Social Worker, speaking on behalf of an Asian mother, describes the reaction of a man with low intellectual ability and severe physical limitations who had no prior visits to his new home.

Social Worker *"He, I think, got use to it really. At the beginning he wasn't because he knew that it wasn't his bedroom. I took him upstairs to show him his bedroom and everything and he wouldn't go in. I think he must have sensed it was not his bedroom, you know, he is quite conscious about his things. I think we had a bit of difficulty trying to adjust him at the beginning. He gradually got use to it. I took Mum down to see him within two months time, you know, eight weeks break, I took her to have a look. At first he wouldn't come close to his Mum. He saw his Mother and he just ignored her, and Mum thought he had forgotten her and she was upset. Slowly he came close to her and then started touching her and then he started communicating. It was wonderful to see."*

(Interview 561 - low/severe)

Another mother, whose daughter was introduced gradually to her new home over a three month period also described a stage when her daughter was obviously upset at the change, and how this was dealt with.

Mother *"She was unsettled at first, she was bound to be you know, found it... very puzzled but.... well (she reacted) the way she always reacts at first when it's things strange. She was, she was disturbed, she stopped eating or ate very little and lost weight. And she was settled down quite quickly you know when I got her, when she came home for a first visit, she was fine but very puzzled when she went back. And it was about six months before she lost that sort of look in her eyes and suddenly started going quite happily without a backward glance. So no, she was obviously... was a bit, wasn't thrilled because it was strange. . . . gradually, because she was going to (the same Day Centre) so that was a sort of set familiar things, she began to settle down."*

(Interview 723 - poor/none)

The two individuals described above were moved due to a combination of their own behaviour, which could be very difficult, and other crises within the family. In the latter case the lack of respite care was also contributory.

The mother of one man who moved from home because he seemed ready for a move, was also apprehensive about how her son was settling in and how he would react to home visits.

Mother *"We was a bit hesitant, you know, what are they going to be like. Really it is a nightmare for you (more) than it is for them, so we did leave him a little while, a couple of months I'd say. I mean, we went to visit and we was a bit hesitant then because we thought 'If he wants to come home what do you do?' Anyway he didn't bother, he accepted it. We just walked around the grounds at first and he'd say 'Are you coming back for a brew?', I'd say 'Are you doing it?', 'Yes', 'All right then'. He sort of accepted that and we went back and he was fine."*

(Interview 871 - good/none)

In this case the mother felt that her son settled well into his new home. He had had a say in the decision to put his name down to go there. His mother emphasised that she would never

have forced him to go somewhere he didn't want to go. This may have contributed to the ease with which he settled into his new home. However, such involvement in the choice of a new home may not be feasible for a person with poorer intellectual ability and their introduction to their new home would not benefit from this factor.

Of the remaining people three were said not to mind the change, or have no obvious reaction to it. One boy was happy about the move. In his case he had been unhappy at his previous school and bored at home. However, all but the parent mentioned above felt that their son or daughter settled well after this initial period.

Parent's feelings during the transition

All parent's expressed mixed emotions around the time of the move. A combination of relief and distress typified their feelings. Most admitted that life was much easier but that they missed their son or daughter, wondered if they had done the right thing or worried about possible problems in their new home.

Recent moves

Most parents described a period of adjustment to the new situation and the thoughts of two mothers whose sons had moved very recently illustrate this. The parent whose son had left home only one week previously expressed some of her thoughts.

Mother *"A bit like missing a headache at times, but I miss him nonetheless..... I mean it's hard to believe that he's only away a week. It seems to me like it's about six months at least.... the only thing that's making me feel better about Vince going away. . . .(is if) I'm not fit to do it, Vince's suffering..... It's different. When he went for respite - I knew he was coming back. Well I'm not saying he's not coming back, but it's hard to explain to you. It's different, it feels different, it felt different from the day he went*

away. It was like an end of an era if you like, it feels different now..... But logic tells me that it's the best thing I've done both for Vince and for us if you like, but we're not getting a great deal of comfort out of it because we've got very little left."

(Interview 144 - fair/severe)

The mother of a man who had left home only four weeks previously also expressed some of the same mixture of feelings about the benefit to her son from being away from home but at the same time wishing he was still there and holding the door open to his return.

Mother *"We were very apprehensive about him going away from home. I feel he should be at home. It's his home really..... It's to help him in life really, to live with other people and look after himself. I suppose it's really, if anything happened to us then he wouldn't be suddenly forced into somewhere..... In fact I was upset all week, I just cried all week. I mean, it's a big thing. It's like your little child going away, isn't it? I mean, it's been a lot easier with him being away, but I still feel that, you know, I know he's got... he's twenty-six and he's got to make his own way in his life, I suppose, but it's just... I'll see how he goes on in the next few months."*

(Interview 535 - good/none)

Moves over one year ago

'Crisis' moves

In cases where moves had occurred due to crises connected with the person's behaviour, the relationship between parent and son or daughter had to be rebuilt. This was the case, for example, with a woman who had assaulted her mother and was arrested by the Police. Her mother described a process that took two or three months.

Mother *".....I just let her see me face. 'Oh go away, go away.' That went on for about three weeks. And I, I used to go up with a few grapes and a banana. Sort of trying to tempt her with - its like holding the carrot to a donkey. And when, eventually when I managed to get as far as the door - the corridor was the limit for about a week - and I got to the door and did this Harry Worth Thing, you know Harry Worth? And I got a smile from her. But she still wouldn't look at me.... But its, it is only because I was determined I wasn't going to let her get away with it. Shutting me off."*

(Interview 237 - poor/moderate)

This woman communicated with her father and sister but was uncomfortable with her mother for several months due, in her mother's opinion, to guilt. Eventually, however, a new and better relationship developed.

These moves demonstrated that although relationships between parent and son or daughter may have been very difficult, they did not discontinue when the person with learning disability moved away from home. On the contrary, it appears that parents worked hard to maintain, or re-establish, relationships with their son or daughter.

'Other' moves

Other parents whose sons and daughters had been away from home for over a year remembered a difficult few months just after they had left home.

Father *"The first few months that Terry went was er, I think we were a bit lost because we were not used to having so much time to ourselves."*
(Interview 853 - low/moderate)

Once the person had moved, in several cases, parents were advised to leave a settling in period before visiting or having their son or daughter home for a visit. However, even when moves were undertaken because the person appeared ready to go, some parents questioned their own motives and wondered whether they had, in fact, pushed them out against their will.

Mother *"I can't explain you have mixed feelings. I knew it was the right thing for him and yet you feel as though you are pushing him away. But you know it is the right thing, the right place and the right time for him to go. You want them to have a life when you are not here I want him to be happy, see him happy before anything happens to me or his father. "*

(Interview 871 - good/none)

Summary of findings

- Most people with learning disability initially showed some symptoms of distress regardless of the speed of the move.
- Those with extreme forms of challenging behaviour continued to have problems in their new home where treatment was undertaken in the first instance.
- Almost all parents expressed mixed emotions at the time of the move. For the most part there was relief from the burden of care but also disorientation and distress.
- Distress occurred for various reasons including the circumstances of the move; parting from the son or daughter; worry about the suitability of the new residence; anxiety about continuing challenging behaviour; and questioning their own motives.
- Regardless of the circumstances of the move, no parent discontinued their close relationship with their son or daughter.

4 *Relationships with the 'New Family' - the son or daughter and their Care Staff*

Once a son or daughter has left home in the ordinary course of events they are usually in control of their own life, free to make their own mistakes and able to turn back to their family for support, guidance and friendship. Parents for their part may wish to maintain contact and proffer such advice or practical help as it is requested. The difference for these people, because of their disability, was that they were not able to have complete control of their lives and it necessarily fell to someone else to look out for their welfare. The fact that day to day welfare had passed on to professional care staff did not imply that parents did not or should not have an input in their son or daughter's life. However relationships had to be negotiated with those who were now assuming that responsibility. It was also necessary to redefine the relationship that the parent had had, until the move, with their son or daughter.

Patterns of contact

Once parents had had time to adjust to the new situation they appeared to develop a new pattern of contact with their son or daughter. The parents below described their contact with their daughter two and a half years after a critical incident in which she attacked her mother.

Mother *"Being that the relationship between her and meself's I would say ninety nine per cent better in't it?"*

Father *"Oh yeah, yeah, yeah..... Plus the fact that as I say her mother goes down, her mother goes down on a Monday and they go swimming.... And I go on a Tuesday. Her mother goes again on a Thursday and she goes swimming again. I and her sister and me eldest daughter go on a Sunday so like she's - out of the seven days a week she's four times when she's seeing us you know,"*

(Interview 237 - poor/moderate)

Other parents had less frequent but regular contact. The first parent below, also attacked by her son two years previously, described the continuing contact with him after he moved to a house nearby.

Mother *"He comes Christmas Eve and stays over 'till Boxing night...., otherwise it's once, he comes once a fortnight for his tea. And I go round there - the week he doesn't come for his tea I go round there..... And any do's come up in the family, he's invited and a carer comes with him, you know, and that's it.."*

(Interview 727 - poor/none)

Another parent whose son moved because he was ready, lived about 30 miles from his parent's home.

Mother *"He comes here for short holiday you know. He will say 'Can I come home?' and I say 'OK' and then he comes. We fetch him home in between like, he does come home a lot..... He mostly comes for a week because a weekend he will no sooner be here and then he will be going back so it would be a bit too short for him.... When it has been a week he is ready to go. You can see he is getting fed up, it is comical.... I think he thinks he is missing something there."*

(Interview 871 - good/none)

One family still felt it necessary to reinforce the fact that their son had a new home. The father below attacked his son because he was enraged by his behaviour. They had a good relationship two and a half years later.

Father *"Yes, no, no he comes occasionally and we deliberately make it so in order to reinforce the fact that this isn't his home, his home is where he lives..... when he comes home here he's, you know, I know we're home dad!"*

Gran *"He likes coming home but you know he wants to go back home"*

Father *"Honestly, to his house"*

(Interview 487 fair/none)

Only the woman described earlier who wanted to move back to her parents' home seemed to have any reservations about her new home.

Mother *"Basically I would say she'd prefer to be at home. That's a bit hard for me to say. If she was here she would say 'I want to come home', but having said that the place isn't a terrible place. If you see what I mean."*

(Interview 336 - fair/none)

All but one parent felt that they had a good relationship with their son or daughter when they had settled in. The exception was a mother whose son was in a medium secure unit. She visited him regularly and more recently was able to meet with him outside the unit. However, she was not comfortable with him and worried about his behaviour.

Summary of findings

- All parents continued regular contact with their son or daughter after the move.
- All but one parent, whose son or daughter had been away for a year or more, stated that they were happy in their new home.
- Only one parent still felt that her relationship with her son was strained after four years away from home.

Relationships with Staff

Moves to alternative residential care are necessarily the start of new relationships with those people who take care of the person with learning disability on a day to day basis. As mentioned in the literature review parents do not end contact with their son or daughter because they no longer live at home but develop an alternative pattern of contacts which, it is suggested, are maintained over considerable periods of time (Baker et al, 1996). The mother of a man who had very recently left home reflected on her hopes for the future.

Mother *"my son and my daughter both have a key, so Vince can do the same. And as far as I'm concerned the staff are extended family. And that's the way. . . I'd like to get to know them well enough so's that that could actually be the case. But that's the way I'm hoping to see them if they're permanent, and that'll be the good thing if they're permanent, because it'll be like an extended family."*

(Interview 144 - fair/severe)

Parents described how they had to learn to trust their son or daughter's new 'family' which, after twenty or more years of providing all care themselves, did not come easily. The same mother explained.

Mother *"I try to be as laid back about it as possible - it's not easy 'cause I'm not there to see what's happening and why. And even although I can say to you: 'Oh, some days there's no, seems to be no trigger to his behaviour', it doesn't stop me still wanting to know what's happened. It's a bit, it's a bit silly because there may be no reason at all, but I'm not there so I can't see for myself that there's no reason at all....."*

(Interview 144 fair/severe)

The father of a man who had moved to hospital two years earlier but then moved to a house in the community expressed his feelings about the new venture.

Father *".....they had the house about the beginning of October didn't they, and they went, the group who were gonna look after him started to go to the hospital. And then there was quite a lengthy period when they were taking him out and taking him for walks and having problems. And then they took him and the other two lads out and they chose the furniture and the carpets and the soft furnishings. And they bought pans and pots, and then they delivered the furniture a couple of days before they turned up. And then they just moved them and we held our breath and waited for it to go wrong, and we're still holding our breath and waiting for it to go wrong!"*

(Interview 487 fair/none)

The father above had worked hard to try to facilitate a move from hospital to the house. One area where there was some disagreement between parents appeared to be over the issue of

when parents should be informed when problems occur. Two parents stated their opposing positions on this issue.

Father *"No, no, we don't see these problems and in fact, nor should we because they say these are their responsibility now. But I still think there's a, an interesting comundrum that will come about when they want to do something, with or for him, that we don't approve of. And we haven't come across that yet and I think it's gonna be a testing time when that happens..... My views should affect (his life) less and less. If he was normal, if any of us are normal, and left home to live on his own, then I'm sure if we interfered, he'd very soon tell us to bugger off! And the fact that he can't tell us to go away and mind our own business is not his fault and I, and therefore I think we've got to consciously let him do his own thing, and let them do things with him."*

(Interview 487 fair/none)

Mother *"She's your daughter but she's in their care, and their way of looking after her isn't yours, and what they consider unimportant might be very important to you. I think one essential ingredient of any son or daughter going away, that there is openness. There should be no secrets good or bad. The parents should be - if, if they're at all involved with them, they should know about everything."*

(Interview 237 poor/moderate)

This disagreement seems to revolve around the amount of autonomy the person with learning disability should have once they had left home. One significant factor in this issue may be the extent of the learning disability. Parents may be more open to the idea of greater autonomy or 'secrets' on the behalf of their son or daughter if they are more able intellectually.

In the case of the latter parent, her daughter had lived for two and a half years in a facility meant only for respite care. The relationship in this instance was perhaps understandably different from that where staff and parent know that they will be in contact for possibly many years.

Mother *".....no they're not listening. You could say things till you're blue in the face but its just like sometimes - staff change, ones on one shift, ones on another, 'Oh I don't know. I didn't do anything. I don't know this.' 'Do you know where such is ..?' 'No, I don't know that.' And so you get the, there's just the one or two that are really conscientious and will see things through. And you see you, you're - the frustrating thing is that you're still involved as a parent, and you expect everybody else to do the same as you would. To a point, you know it, you know it can't be fully, but them being out in the community and in these places is to - for them to live as normal a life as possible. Or as near to what they had when they were at home. But its - they're well meaning in what they're doing, what they say, but they're not prepared to carry it out. Its like a new toy. You know when the newness has worn off they get complacent about things, you know."*

(Interview 237 - poor/moderate)

In this situation, the woman's mother naturally worries about whether she liked the staff she lived with, other residents of course kept changing on a regular basis. She explained that on occasions her daughter would tell her 'Don't want (residence)' in a quiet voice, as if she was telling a secret. This naturally made her worry about what exactly was troubling her. Whether there was a problem in her new home which staff were not telling her. However, it sometimes takes the evidence of the parent's own eyes to reassure them.

Mother *"when I saw her I thought - you see the thing is - and a lot of parents will tell you this - you can go somewhere and they'll say, 'Oh they've been great,' and all the - but at the back of your mind you still got this, 'I don't believe them.' It happens so often, and unless you see it and you're convinced ... You've got to see it with your own eyes. And so I really do welcome little things like that. You know. And I think about it afterwards, and I've a sort of picture in me mind going back to when I saw her and I think, 'I can see her as clear as anything', and she was linking this lady and she was looking up at her, she was walking like this, you know. She was really happy. And it does you good."*

(Interview 237 poor/moderate)

A father expressed his suspicions as to whether staff were honest when he enquired about his son's behaviour.

Father *"It's the lack of information. He might be doing things wrong, what we would consider wrong, but in their eyes isn't wrong. They seem to accept bad behaviour, which seems to be a problem. But as I understand it, there's been no sexual behaviour, 95% of the time he's been virtually behaving normal. Now I've been down and em... he's come out to see me, and he's gone back and he's been alright. The last time after he came here he was.... I thought we was goin' to have problems with him*

then, but we did, because he burst out cryin' after I left 'im at er... (the residence). He was cryin' like when we was in the place. Really upset. Of course when I got back 'ome I rung 'em. Said he was OK. You have to believe 'em don't you?"

(Interview 355 - fair/none)

This statement seems to restate the question over parents willingness to accept different standards to their own in the care of their son or daughter. Where a person has challenging behaviour parents may have particular anxieties about the influence of behaviour on relationships with other residents and staff. This may reflect concerns about a possible breakdown in the placement which would be difficult for parents who acknowledge they could not cope with their son or daughter at home. Where the organisation providing care had a policy of 'complete' parental involvement in the placement, which was the case for one person, his parent was very satisfied with the arrangement.

Nevertheless, parents felt that their son or daughter had a better quality of life in their new home. The quote below was typical of many.

Mother *"I must admit they're braver than I am. I mean they take her out for meals and they take her to the cinema and she'll, you know, accept that and do very well with them so you know that obviously has improved....."*

(Interview 723 - poor/none)

Parental concern over the welfare of any adult child once they have left home is to be expected. For most families, however, demonstrations of the capabilities of the son or daughter to fend for themselves are likely to allay fears in the long run. Parents with a son or daughter with learning disability, however, are aware that they will never fend for themselves and that they are reliant on strangers to enable them to live a full, happy and healthy life. One may speculate that these parents need the same demonstrations of capability, but from care

staff, in order to allay their fears and build trust. As in many areas in life there may be no right or wrong approach to the issue of parental involvement in the life of their son or daughter with learning disability, once they have moved away from home. The best interest of the person with learning disability is, or should be, the goal of parent and care staff alike. The interaction of parent and staff influence over aspects of his or her life, a matter of negotiation. However, there were few residences which formalised such a partnership. This omission may have been the root of many parents' uneasiness.

Summary of findings

- Parents had different approaches to their relationship with staff. Most, however, expected to have a significant input in their son or daughter's care. Only one organisation formally incorporated parental input into the care they provided.
- Most parents were happy that staff were closer in age to their son or daughter and saw them as 'friends'. Parents acknowledged that such friendships were not the same as friendships between people in the general population but a by product of their role as carer.
- Several parents expressed concern over the permanence of staff. Staff who stayed long term had a greater chance of developing good relationships with the resident and their parent and being aware of needs and preferences.

5 *Long term outcomes for parents and their sons and daughters with learning disability and challenging behaviour.*

Quite apart from adjusting to their son or daughter's new life style and the people who care for them, parents had to acclimatise to a life without the caring role they had undertaken for so many years. The length of time needed to adjust to a new lifestyle might be expected to vary depending on the individuals involved and the circumstances of the move.

Outcomes for parents

Recent moves

Four people with learning disability and challenging behaviour had moved away from home in the year before the interview. The mother whose son had left only one week earlier was, understandably, feeling disorientated.

Mother *"Being Vince's mum for 26 years I haven't had much time to think about what I'd like at all. In fact I don't know, I honestly don't know. If someone said to me: 'There's this, this and this and this and this - take your pick', I wouldn't know. I wouldn't even know where to begin. It's just been Vince's mum and that's been it..... I really don't know how to do things for myself any more. Does that sound daft?"*

(Interview 144 fair/severe)

For another set of parents, their son had moved to a residential treatment facility only four weeks before the interview. His mother was still feeling anxious about the move and whether it would improve his behaviour. However, she did acknowledge that life at home was easier since he had moved away. He had been stealing from the family and was aggressive if he didn't get his own way. This mother and the remaining two parents all noted that the main difference in their lives was greater freedom, particularly not having to be home in the middle of the afternoon to await their return from day services.

The parent below, whose son had moved a week earlier, also saw it as an advantage that a return home would be possible should things not be going well.

Mother *"I'm hoping and praying to God that it works. And in saying that, if it doesn't work, at least one thing he's got now he wouldn't have if we weren't around - he's got a home to come back to. He's got two homes if you like. At least we're here if it doesn't go right. This way at least we've some input, and at least he's got somewhere to come home to for a change or a break or whatever."*

(Interview 144 fair/severe)

Moves over a year ago

Other parents, who had had longer to adjust, also tended to note this freedom as the main benefit. Having undergone the process of moving from home in more positive circumstances, the mother whose son had himself seemed ready for a move was just feeling as though her life was her own after a period of about four years.

Mother *"I am just getting used to living my life as I want to, without having to run back for him. It takes you a long time when you have done it, you know, more or less all your life. You think oh, I've got to get back and then you realise. It makes you live a different life. It sounds silly but it is true. You have done it that long that you think you can't go and then it dawns on you that you can go.....Now you can go to places and enjoy it. You wouldn't have enjoyed it with our George because he would be bored so really you do find a different life altogether."*

(Interview 871 good/none)

Many parents expressed the benefit they felt from relief from the caring role, in terms of their own health, as well as in the sense of there being a more peaceful and relaxing atmosphere at home.

Father *"Very, very pleased how wonderful, we've got a lovely (life), and he has too, he has too! I mean hindsight is a good thing to have, isn't it? But there's little doubt that we were relieved then and we will be relieved now"*

Gran *"And he's happier i'n't he, he's got things to do, not bored"*

Mother *"We're a lot more relaxed aren't we....."*

Father *"Oh yes, you see a much happier family"*

(Interview 487 fair/none)

At least one parent, however, seemed to suffer a residual cost of caring for so long for her daughter in difficult circumstances. This mother, who was attacked by her daughter after caring for her at home without day services for about 18 months, had developed a much better relationship with her daughter two and a half years later. She acknowledged that now she would not be able to cope with the physical demands of handling her daughter when she was upset. However, she described an inability to settle in herself.

Mother *"I find, since our Maria went, (it's) very difficult to sit for more than an hour. Even less because I get so irritable sat, and I can be tired but I've got to get up and do something. And as long as I'm occupied doing something I'm alright, but I want to sit down. And this - but I thought after so long of Maria being away that would diminish but it does.. it doesn't."*

(Interview 237 poor/moderate)

It appeared that this parent was suffering a mental health problem which may well have been due to the strain of caring and the incident which lead to the move. No parent reported any kind of support to them, from any source, in dealing with their own health problems connected to caring or incidents of challenging behaviour. Even where parents were the victims of assault there appeared to be no follow up on their health.

The parents of the young man who is blind and deaf also felt that the physical demands of handling their son over the years may have contributed to their physical difficulties now. These and other parents felt that these problems were such that they could not now cope physically to give the care their son or daughter needed.

Mother *"I mean what we used to do with him years ago was swing him round and, which we could do and we were young enough to do it, swing him, lift him up and down, give him shake-a-beds and that which, he loves a rough and tumble. Now he's getting that with the younger ones there. And when we go and see him and he's trying to get us to pick him up. I mean he's a man and we can't do it. So we've got to, like, say no and pass him on to somebody else anyway because we just aren't capable of lifting him."*
(Interview 853 - low/moderate)

Nevertheless, all the parents appeared to see the move as having been beneficial to both parties, in that they all gained a better quality of life and several also mentioned the satisfaction of seeing their son or daughter settled somewhere whilst they were still able to have an input.

Father *"Its been the best thing that's happened. Are you with me? Because, because you know one of the things that parents do you've probably found, when they say, 'What are - do think of what's going to happen when you get into old age.' You keep hanging on and you keep saying, 'Well alright we'll think about it.' And then of course you think about it and its too late. You both die, the client is taken away from their home and just the shock of moving also - and its wrong..... Where at least we know that by the time - well I'm hoping I'll live another twenty years and p'raps so does Teresa. But we're hoping that, by the time we do die, she's settled. You with me? And she doesn't have all that upheaval. And again there's so many things that what happened that particular day has brought out, and instead of it being. . . its done a lot of good."*
(Interview 237 - poor/moderate)

Parental concerns did not end with a move into permanent residential accommodation. As has been already mentioned, for one woman her present accommodation was not permanent. She had been living in a facility designated for respite care only for two and a half years and there was no sign of a permanent placement. Her parents would have loved to see her settled in a

house in the community. In another case, parents whose son went away for treatment explained that funding was coming to an end within the next year and there was the problem of 'what next'. Given his very complex needs they were concerned that, wherever he moved to, he continued the same type of regime that had been so successful during the period of his treatment.

Mother *"If they ever said they'd send him back here, there's no way, because he'd go twice as bad as what he was before he went in there plus they'll have wasted all that money and there's no way I'd have him back here for nothing. Now, up to now we're still OK, we know we've got funding up to next year but then we see what happens then."*

(Interview 853 - low/moderate)

A parent whose son had had several residential placements, all of which had broken down because of his tendency to wander and get into difficulties through stealing, felt uncertain as to what his future might be. The man was in hospital but also wandered off from there because he was no longer in secure accommodation. On the whole, however, parents' feelings were very positive about the outcome of the move.

Mother *"Oh quite happy, as long as he is happy I am all right. It was only his happiness that we were concerned about you know. Now we know he is happy and established then that is fine with us. At least if he loses us he is with people who know him which is a lot better."*

(Interview 871 - good/none)

Outcomes for people with learning disability and challenging behaviour

Parents whose sons or daughters had been away from home for two years or more (n=13) found changes in them overwhelmingly for the better. Only one mother, whose son originally left home because it was felt that his aggressive behaviour might be related to a need for

greater independence, felt unsure of her son's progress. As mentioned above, he was arrested and sent to a secure unit at a hospital for people with learning difficulties for treatment. Staff at the MSU felt that he had made real progress and had moved him on to a less secure environment within the same hospital. However his mother was unsure, based on past experience, and was anxious about a return to former difficulties.

'Crisis' moves

Two people who were taken away from home after assaulting their mothers and were both taken to hospital for a period of treatment, then moved on to residential accommodation in the community (one in a permanent and one in a temporary placement). They had also made considerable progress.

Mother *"I'm saying now he's perfect because he's so much different, you know, I mean he's not attacking folk. Once or twice he's attacked one of the boys in the flat, because he's, he is a villain, you know, and I mean he'll sit there and he'll make fun of our Phil, you see, he'll..... our Phil will be playing with these cards and he'll come, and he'll pick one up and he'll just rip it in half. Well I mean that annoys Phil, so of course he'll just punch him, you see, and that's it.... But I'll not forget the day he moved in this flat. He was so happy, you know,"*

(Interview 727 - poor/none)

Mother *"She's absolutely brilliant compared with what she was. She's wonderful.... I mean the language is a lot better ... I mean she used foul, absolutely foul language."*

Father *"Of the whole time that she's been there (two and a half years), I've only heard of a couple - two, three times when she has struck, struck out if that."*

Mother *"I think she was a few days before she settled down into (the Short term Care Facility) because she'd been in there before, and oh you mention (this Facility) and she didn't want to know it. But you see now she calls it her house."*

(Interview 237 - poor/moderate)

As mentioned above, the man who so enraged his father that he struck him, was also removed to hospital where his behaviour was treated, but then had difficulty obtaining a placement in the community. His father, who at the time of departure was glad to see the back of him, rebuilt his relationship with his son and did everything in his power to facilitate a move from hospital. Since his move this man had also progressed immensely.

Father *".....he seems to be coping in the community quite well, he goes to the bank and he goes to the building society and he goes to the benefit so..... I don't think, I don't think people in Edward's position have wide circles of friends, particularly round about because there's still a, you know, an iffy feeling towards challenging behaviour in the community. But he's, but he has friends in the house and he has friends in the carers looking after him, he has friends in adjacent, nearby properties where there are similar, you know, these bursaried houses, and he has friends in the family."*

(Interview 487 - fair/none)

However, he still felt that his son's behaviour was potentially challenging.

Father *"I don't think we see very much of a, when he comes out with us, we're all, we're sure that his aggressiveness is still there, below the surface. Were it not for the medication which they control very carefully, and were it not for the fact that the view of the helpers in the house, the carers, is that they can get these lads to do absolutely anything providing they do it in the right way"*

(Interview 487 - fair/none)

The family themselves found him much more affectionate than he had ever been. He was much more interested in the family as a whole, as opposed to just his father which had been the case in the past.

'Other' moves

Perhaps some of the most marked improvements were in a young man who is blind and deaf.

This man left home to attend a specialised treatment facility.

Mother *"Yeah it is awkward to explain because you've got to see Terry, how Terry was and see Terry as he is now and you can see how much he's progressed while he's been there, it's unbelievable..... When we used to take him for a meal, or anything like that, it would be chaos. He wouldn't sit down, he wouldn't do anything, he'd be screaming all over the place and you just couldn't take him because people don't like that kind of thing. Where they take him now, he'll sit, he'll eat a meal, he behaves himself. It's just fantastic you know, it really is. And just by making a few simple signs to him they've got him to do what they want him to do, sit down and behave. But we had hell on earth didn't we!"*

(Interview 853 - low/moderate)

One major achievement for this man was in his ability to communicate.

Mother *"All the tension..... you can talk to him. Whereas before he used to be like this, you know, and you couldn't talk to him and it was terrible, but now it's brilliant..... they said, in the flat he's in now, he's the A1 student in the flat, against all the others he's the cleverest one in the flat. So that's good news isn't it? 'Cos we never thought that we'd ever hear anybody say that when he's pulling the radiators off the walls and all things like that, and flooding the bathroom out and everything, I mean he even runs his own bath now."*

(Interview 853 - low/moderate)

The two people who left home because of other difficulties in their families, as well as their own difficult behaviour, are likewise felt to have settled well and to be happy. One mother described how her son gained weight as evidence that he enjoyed his new home. The other mother felt that her daughter enjoyed the activity in the hospital she moved to. However, this hospital was due to close and the residents were to move to houses in the community. This mother was a little unsure that her daughter would like this move but was prepared to be guided by the staff as to what type of house would suit her daughter. A house shared with three or four others was proposed.

Mother *"I think she's thoroughly accepted it, you know. As I say, she's always pleased to see me but she's quite relaxed about seeing me going back..... I really do think it's improved Helen's life so much going into that place that it's, you know, out of all.... I mean forgetting mine, it's wonderful but she has improved I think so much, because of it, in terms of being calmer. I think it's because they worked and pulled her into the activities. She's met with young girls of her own age who, you know, like making her up, doing her hair. Helen loves that sort of thing. So she's*

almost having friends, though she's not having proper friendships but I think it was, it's been one of the best moves for Helen."

(Interview 723 - poor/none)

One man who moved because he was ready to, had also changed for the better in his mother's view.

Mother *"Oh yes he has changed a lot, he has changed tremendous..... he is more outgoing. You see I think going to (this Facility) has been the best thing for him because he is living his own life. Once he said, 'You're upset', I said, 'I'm not.' He said, 'Yes you are. You've got your life, I've got mine!' and stomped upstairs. I thought 'That is good enough for me. That is all I wanted to know!' He did tell me straight. He thought I was getting upset because he was going back you see..... Well now, he is occupied at everything and he is fulfilling his life as a twenty five year old should do."*

(Interview 871 - good/none)

Parents' feelings about their son or daughter's placement are summarised in Table 25 overleaf. This table also shows the number of moves the person had experience after leaving home. Five people had had one or more placements since moving. Three of these were people who moved initially for crisis behavioural treatment. One other had moved from residential school to a house in the community.

All but one of the parents were satisfied with their son or daughter's home at the time of the interview. The parent who still had some anxieties had a son in a Medium Secure Unit (125) and was not convinced that, were he to have more freedom, he would not revert to old habits.

Table 25: Parental comments on current placements of their son or daughter with learning disability and challenging behaviour at the time of interview.

Ref - Gender Intellect abil./ Physical lim.	No. Moves Since Left Home	Parental Satisfaction with Current Placement.
111 Male good/none	None	Steven loves it now. Parents concerned that it wouldn't work at first but happy with the way he has settled.
125 Male good/none	Five	Resident in MSU of hospital for people with learning disabilities. Mother not happy with this but cannot see any alternative at moment.
535 Male good/none	None	Had only been away from home about four weeks and seemed a bit homesick though he did come home some weekends. Mother still concerned about him being away from home.
871 Male good/none	None	Parents very happy with his new home. They and son chose it together.
116 Female fair/none	None	Amy did not seem to mind sudden move to an Autistic community and settled well after 8 weeks. Parents feel that apart from a village community the place she is living is the best for her.
124 Male fair/none	None	Very happy with placement - their own choice and close to home. Only changes in staffing cause son to become a little unsettled but these have been few so far.
336 Female fair/none	None	Mother happy with placement but daughter wants to move back home. Mother upset because couldn't cope without reliable service support but wants to see her settled and happy away from home.
355 Male <i>fair/none</i>	None*	Happiest they have seen him. Adam had run away about five times in the five months he had been there but this was seen as great improvement.
487 Male <i>fair/none</i>	One	Very happy. Son settled well into house in community and seems very happy.
144 Male fair/severe	None	Moved only one week before interview. Mother has high hopes of this placement in specialist facility in community.
723 Female poor/none	None	Happy with placement in hospital. Concerned about planned move into community.
727 Male <i>poor/none</i>	Two	Very happy. Now in house in community near mother and appears very settled.

(Continued . . .)

Ref - Gender Intellect abil./ Physical lim.	No. Moves Since Left Home	Parental Satisfaction with Current Placement.
114 Male poor/moderate	One	Moved to small supported house only 5 weeks before interview. Had been difficulties with funding - obtained after intervention by solicitor and MP. Before that at residential school.
<i>237 Female</i> <i>poor/moderate</i>	Two	Placement temporary and currently no plans to move to permanent home. Causing some anxiety for parents.
319 Female poor/moderate	None	Parents very happy with the placement which they feel is better than they had thought it would be. Daughter's behaviour had deteriorated but they felt she was happy with her new home.
853 Male low/mod	None	Parents very happy with the place son had been staying. Concerned as to future when funding for treatment ended. Person deaf and blind.
231 Male low/severe	None	Happy that behaviour improving generally but main challenge infrequent and only recently experienced at residential school. Difficulties over continued funding for placement.
561 Male low/severe	None	His mother felt that her son was happy but the residence was a considerable distance from the parental home and this made visiting difficult.

* This person first left home aged 4 yrs and had six moves before returning to his family, after 2 years at home he moved again.

Italics indicate people who moved from home in crisis circumstances.

Another parent was happy with her daughter's home but concerned because it was supposed to be temporary. Although she had been there for two and a half years, there had been no offer of an alternative (237). There were problems with funding. In all, eight parents mentioned difficulties with funding and, in the case of the people who had attended treatment facilities (n=4), obtaining funding to continue the treatment or obtain a suitable follow-up placement was an issue.

Eleven parents (61%) stated that the homes their son or daughter had moved to were just what they wanted for them. A further four parents (22%) felt that the residence was close to ideal.

For three parents, however, the placement was not what they had wanted for their son or daughter. These three parents include the two mentioned above (in temporary accommodation and MSU) and the parent of a man with Asperger's syndrome who had been sent to a treatment facility. His mother did not feel that the placement was really suitable for him because other people attending the same facility had more severe learning disabilities.

Summary of findings

- Most parents in the long term were happy with their son or daughter's new home.
- Long term outcomes for the majority of people who had lived away from home for a year or more were felt to be excellent. All but one parent felt that they and their son or daughter had a better quality of life.
- Sons and daughters were felt to have more age appropriate friends and acquaintances. They were also seen to take part in wider, 'more adventurous' activities.
- Parents noticed more freedom in day to day activities due to not having to be home for their son or daughter returning home in the mid afternoon.
- There did not appear to have been any specific support offered to parents who were in difficulties as a result of their son or daughter's challenging behaviour nor any follow-up to find out how parents were adapting to their new relationships.
- Many parents acknowledged that they could not now cope with their son or daughter at home due to physical care needs or difficulties with behaviour.

Chapter 7

Discussion

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Chapter 7

Discussion

1 Relationship of findings to psychological and sociological theory

Discussion of the studies detailed above will be taken in the round and related to theories described in Chapters one and two which are addressed by this thesis. The importance of recognising the heterogeneity of groups of people with learning disability was not in evidence in the research reviewed above, but was demonstrated by analysis of survey data and corroborated by qualitative analysis of transcripts in this study. Level of intellectual ability and physical limitation appeared to affect perceptions and expectations of, as well as matters relating to, the individuals involved. The data presented here suggests that capability is an important factor in when and why a person with learning disability is placed in alternative residential care. The only characteristic that people with learning disability as a whole would appear to share is that they are likely to require support in some aspect(s) of their daily life. The extent and range of differences and difficulties are immense and these necessarily have implications for the way they are cared for and, seemingly, for the decisions others make about their welfare. Discussion of the results will reflect these differences.

The findings of this thesis support the conceptualisation of placement into alternative care as a transition process in which the need or wish for separation is acknowledged; a residence provided; a period of settling experienced; and new relationships and patterns of contact established. The contribution of this work is to extend the work of Essex et al (1997) by defining key factors in moves made as part of the stress process (Folkman & Lazarus, 1984). It also illuminates the patterns of experience of both parents and son or daughter with learning disability, from the perspective of the parent, and defines areas of similarity and difference in

the paths taken to achieve alternative care. The findings are then discussed in relation to recent policy initiatives and implications for practice.

Characteristics of the people with learning disability

The survey data confirmed that those who were in alternative residential care were more likely to be older, and that those with good intellectual ability who lived away from home tended to be male, while those with poor or low levels of intellectual ability were likely to have fewer physical limitations. This picture does not entirely accord with other research in the field which identified advancing age and severe learning disability as predictive of living in alternative residential care and may reflect some confounding of intellectual ability with physical problems (eg Meyers et al, 1985; Borthwick-Duffy et al, 1987; Hayden & Goldman, 1996). Several researchers have suggested that challenging behaviour can be a significant source of stress for carers and predict residential placement (Borthwick-Duffy et al, 1987; Black, Molaison & Smull, 1990; Heller & Factor, 1993). However, Essex et al (1997) found no relationship between number of behaviour problems and placement in residential care. As the presence of challenging behaviour was a particular feature of the people with learning disability involved in this study, there was an opportunity to examine factors such as number, frequency, and typology of challenging behaviours in relation to residential provision.

Data from the 1988 survey showed that residential placement was associated with frequency of incidents of challenging behaviour only for those with a fair level of ability. There was no relationship between challenging behaviour variables for those with good, poor or low levels of intellectual ability. However, a similar analysis of data from the 1995 survey found that those with better intellectual ability (good and fair) who lived in alternative residential accommodation differed from those living at home in terms of level of aggressive behaviour,

with those in residential care tending to show more aggression. The group with 'poorer' levels of intellectual ability tended to be in alternative residential care if they were older and showed destructive behaviour.

The reason why the characteristics distinguishing the groups varied between the two studies is difficult to determine. However, the service culture in which the data was gathered in 1995 differed from that in 1988. In the earlier study many people were resident in hospitals or large hostels, by 1995 there had been a shift out of hospitals to smaller homes in the community. Similarly the services provided by Day Centres had changed from ones which were almost entirely site based to a situation where many centres provided a base from which various activities were co-coordinated. It is possible that this difference in service delivery may have had an effect on how challenging behaviour was construed and the frequency with which it was perceived to occur. The smaller numbers involved in the second study, and the broader categories of intellectual ability, also mean that this study may have been less sensitive to differences. However, evidence from the second study suggested that placement may have become more directly related to prioritisation of provision towards people with behavioural challenges .

A study on persistence and change in the challenging behaviour of adults with learning disability, data from whom was used in this thesis, (Kiernan et al, 1997b) suggested that challenging behaviour may be highly persistent over time. Improvements in behaviour were more likely to occur in more able people who had better communication, social, and occupational skills. Conversely, there was a greater likelihood to be an escalation in self injurious behaviour in people with severe or profound levels of learning disability. The matched group comparisons made in this thesis found that a greater number of socially

unacceptable behaviours were displayed by those in residential care. However, the numbers involved in this analysis were small and therefore may not be taken as evidence of such differences in the wider population. These analyses are cross-sectional and as such cannot provide evidence as to whether these behaviours existed in the same way prior to placement nor whether they were a significant factor in the decision to place the person into alternative care.

The qualitative analysis provides evidence of the impact of challenging behaviour on decision making. This showed that challenging behaviour was implicated in the decision to seek alternative care for all those with poor or low levels of intellectual ability but for the majority this was not the primary impetus for the move. Challenging behaviour was a factor in several moves for those with a good or fair intellectual level but was only the primary impetus in the crisis moves. These 'stress process' moves involved three incidents where there was actual police involvement and one where there was the potential for police involvement. Other 'stress process' moves occurred for three people who had been children when the moves took place. Their challenging behaviour had occasioned the need to seek alternative educational provision which was only available out of district. The data here suggests that moves tended to occur primarily for the older children (ie 11 years old or more) who were likely to be male and have lower levels of intellectual ability. This data appears to support the literature which suggests that there may be a relationship between increasing difficulties in the family when child is entering adolescence (Krauss & Seltzer, 1993) which may result in placement away from home. It also replicates the findings of other researchers regarding an association for children between placement, and being older and having severe learning disability (Meyers et al, 1985).

Characteristics of carers

In terms of influences on the decision to place a son or daughter with learning disability and challenging behaviours into alternative residential care, poor health figured prominently as it had in many other studies of placement (Suelzle & Keenan 1981; Essex et al, 1997). Research has suggested that high stress levels over time affects a carer's ability to continue, due to a depletion of physical and psychological resources (Johnson & Catalano, 1981; Parker, 1990). Evidence from this thesis, and an earlier study which included some of the families involved in this study (Kiernan & Alborz, 1995), suggests that continuing high stress levels are associated with caring for a son or daughter with learning disability and challenging behaviour. Around two in three of mothers of both 'movers' and 'non-movers' had stress scores which indicated the possibility of psychological distress (Study 2b). Therefore, although high stress level may contribute to a decision to place a son or daughter in alternative care it does not appear to be a primary factor. Evidence of adaptation to the caring role as advocated by Townsend et al (1989), was provided by the Kiernan & Alborz (1995) study with families of adult sons and daughters with learning disability and challenging behaviour. In this study parents said that they believed that their son or daughter's behaviour had improved over a period of three years even though there was evidence of an ongoing behavioural challenge. This suggests that to an extent parents may have adapted to the challenges presented by the person, or in the words of many parents, they became 'used to it' (Kiernan & Alborz, 1995).

As mentioned in chapter one, the concept of adaptation and high stress do not appear mutually exclusive. One may accept the limitations of a loved one and be content with the caregiving role but at the same time suffer the consequences in terms of personal deficits in physical and/or psychological well-being. This conceptualisation appears consistent with the transactional model of stress and coping (Folkman & Lazarus, 1984), and Heller & Factor's

(1993) view that, given adequate resources, positive perceptions of an event may buffer the experience of stress. One aspect of adaptation, or in other terms 'habituation', to challenging behaviour may conceivably be a reduction in the experience of associated stress at a conscious level. It is a matter for speculation whether this type of 'reappraisal' of challenging events based on past experience is associated with genuine increments in well-being for parents, or only a psychological 'screen' for protection against the immediate psychosomatic effects that stress produces in the individual. Grant et al (1998), suggested that success in coping with challenging situations may lead to increased levels of satisfaction and a re-evaluation of the caring role leading to greater rewards. However, data from the parents involved in this study suggested that only a small percentage felt that their strategies for dealing with challenging behaviour were usually or always helpful (20%). This suggests that these parents were not gaining satisfaction from this aspect of caring for their son or daughter. However, with such small numbers, it is not possible to ascertain whether this would be reflected in a larger population of parents whose son or daughter had learning disability and challenging behaviour, and had left home.

Several researchers have commented on the correlates of successful coping. Amongst these have been the resources that parents can call upon be it their past experience in parenting or successful coping (Koch-Hattem, 1987; Quine & Pahl, 1991), support networks (Dunst et al, 1986; House, 1998), perceptions of the adequacy of resources (Minnes, 1988; Herman & Marcenko, 1997), or material resources such as time and money (Agosta, 1989; Tunali & Power, 1993; Frey et al, 1989; Koch-Hattem, 1987). All of these resources, it is proposed, act of as a buffer to stress, a lack of which may confer vulnerability to stress (Sloper & Knussen, 1991). Most of these parents, it appeared, had been exposed to high stress levels for some time. This may have been due to dealing with challenging behaviour and in particular

experiencing problems in supervision of a son or daughter with learning disability and challenging behaviour. An expected finding of this thesis and the Kiernan & Alborz (1995) study was that problems with supervision differentiated those whose son or daughter moved from those who remained at home. Problems with supervision occurred across ability levels, but the actual amount of time committed to supervision did not relate to the extent of difficulty experienced. This result may provide evidence that where events occasioning supervision are appraised as personally threatening, or beyond the coping resources available to the parent, this may be a contributory factor in seeking alternative residential care. It does not support the view that stress is related to supervision or 'higher levels of personal care' per se (Hayden & Goldman, 1996; Factor et al, 1990; Agosta, 1989).

Social support

The available data provided little information on the extent of social support networks open to these families. Analysis of wider data, which includes some from families involved in this study, showed that there was little support to mothers in terms of domestic or caregiving help from members of the household (Qureshi, 1990). It also showed that support from the extended network of family members, specifically grandparents and parents' own siblings, had diminished from the time when their son or daughter had been a child. Grant (1993) also found that social networks tended to decrease rather than increase over time. In addition, other research with families of older adults found little evidence of active support from members of the immediate or extended family into the care of the person with learning disability, regardless of the size or proximity of the social network (Prosser & Moss, 1996). The limited data available here, from matched groups of young adults with learning disability and challenging behaviour, revealed no differences in changes in membership of social network prior to placement away from home. The implication, in terms of placement in alternative

care, is that as a whole parents (usually mothers) provided care to their sons or daughters with learning disability and challenging behaviour, with little external support, and that as help had always been minimal this factor did not impact to any great extent on the decision to place their son or daughter in alternative residential care.

Planning

Prior to moving many of the families who are the subject of this thesis had put off making concrete plans regarding the future life of their son or daughter. This finding was entirely consistent with other research in the field (Grant, 1993; Qureshi, 1990; Essex et al, 1997, Kaufman et al, 1991; Richardson & Richie, 1989). In terms of the nature of caregiving the data presented here provided some evidence of anticipatory planning in that many families had given some consideration to future residential care. However, in line with other studies (Essex et al, 1997; Kaufman et al, 1991), few had taken this further than an acknowledgement that something would have to be sorted out eventually. To the extent that, at least at a cognitive level, the issue had been recognised, appears to lend weight to Nolan et al's (1996) conceptualisation of 'anticipatory planning' occurring throughout the caregiving period and not confined to an early pre-care stage (Bowers 1987). As described above, the latter does not appear relevant to the group of carers whose dependant is their own son or daughter where the decision to 'take on' the caring role is less premeditated.

Research on uptake of respite care services provides some indication of the sorts of issues which may be important to parents when considering longer term placements. Quality of placement as defined by extent of knowledge of the person with learning disability, (Taraberrelli, 1993) and sympathetic attitude on the part of staff, as well as appropriacy of the physical attributes of the placement, may ease parents' concerns over asking for help (Lewis

& Meredith, 1989). These attributes seem likely to be equally important in the consideration of alternative residential care.

The analysis of data from the two surveys, and to some extent from the matched comparison of 'movers' with 'non-movers', showed that sons and daughters with greater physical care needs appeared to remain with their families longer. Those who were more intellectually able and had few or no limitations tended to be placed at a much earlier age, compared to the general population, than people with more severe learning disability who had significant physical limitations (Parrott et al, 1997). The latter were placed in residential care at widely ranging ages but two of three were in their mid to late twenties rather older than the median age (21) for the population covered by the Sheffield register. This result may provide support for the notion of greater caregiving satisfaction is derived when caring for people with lower levels of functioning (Heller et al, 1997). That is, they would otherwise have been placed at a younger age than in the general population, in line with the more able participants. However an alternative explanation may be that carers found it more difficult to accept residential care for their severely disabled son or daughter, if they felt that formal care staff lacked knowledge of them (Taraberrelli, 1993) and might find gaining such knowledge difficult due to the level of their disability. There are also issues about the availability of suitable provision, particularly where the physical environment would have to be adapted and staffing levels enhanced. However, this group was small and further study would be needed to establish whether this is a trend.

Accounts from carers in the Kiernan & Alborz (1995) study appeared to support the notion that their standards of care were high and doubts were expressed about the capacity of formal care staff to provide the same 'quality' care, particularly in a climate of high staff turnover.

Compared to families of people with better levels of intellectual ability this may have delayed any decision to place a son or daughter with significant care needs into an alternative placement. This thesis provides support for findings in other studies in the field, in that actual moves were not related to prior planning to a significant degree (Hanneman & Blacher, 1998; Freedman et al, 1997).

Placement decisions

A major theme of this thesis was the application of theory relating the family life cycle to transition to alternative care. In particular, the analysis sought to test the applicability of Essex et al's (1997) placement profiles, based on parents' explanations of why their son or daughter had been placed in alternative care, to a group who had learning disability and challenging behaviour. Analysis of information regarding life cycle stage showed that the majority of families were in the 'post-parental' stage (Olsen et al, 1984) and it was suggested that this may have eased transition for some families as a sibling had provided a role model for transition from family to independent living. However as only two families were in the 'launching' stage it was not possible to explore this further.

Circumstances contributing to a decision to seek a move were complex for most families. Relative contributions of one factor over and above another difficult to determine. It appeared, more often than not, that circumstances changed and/or incidents built up until some kind of 'last straw' was encountered. It was this 'last straw' that was taken as the primary impetus to the move.

As mentioned above, there was no significant difference in stress level prior to the moves between the group of parents whose son or daughter had moved, and those whose son or

daughter remained at home. Indeed, the majority of mothers in both groups scored sufficiently high on the Malaise Inventory (Rutter et al, 1970b) to signal that they might be suffering psychological distress. It must be stressed, however, that these explanations were rarely the only factor involved and the tables in Chapter 6 indicate other contributory factors.

'Normative launching'

The explanations given by parents as to the impetus for the move included only four where the primary reason was that their son or daughter should have greater independence, or 'do the normal thing'. This type of explanation and the timing as defined by the age of the person involved could be described as 'normative' launching in terms of Essex et al's (1997) transition profiles. That is, these people moved at a similar age and for similar reasons as may be found in the general population. This type of explanation was more likely to be given by parents of people who had a good or fair level of intellectual ability and no physical limitations. This finding suggests that 'independence' or 'doing the normal thing' may be related to the parents' perception of the actual physical and intellectual capabilities of their son or daughter. The concept of 'independence' for a son or daughter who is intellectually very young, or who has physical care needs, may appear ludicrous to their parents. Where a person is incapable of true independence - in self care, social interactions, daily living skills - it appears that 'normative' launching may be rare.

'Stress process model'

The remaining families experienced moves as part of a 'stress process'. It was considered that the Essex et al (1997) conceptualisation of a 'stress process' model, though apt, was too broad and that an analysis of the types of circumstances which led to this categorisation would be beneficial. A detailed analysis of transcripts was undertaken in order to reveal a more detailed

categorisation. This analysis suggested three types explanation within this model, Forensic, Family, and Service.

Forensic explanations emphasised involvement with the police or concern that the person's behaviour might eventually lead to conflict with the law. The circumstances in which such involvement had occurred, or was likely to occur, varied with the intellectual ability of the person in question. Most people placed in this category had a good or fair level of intellectual ability and for them difficulties arose as a consequence of their behaviour in the community. For the two people with a poor level of intellectual ability, problems involved physical attacks on family members within the home. All but one person in this category had no physical limitations in terms of mobility, continence or eating independently. The one person with physical limitations had only moderate difficulties. These types of problem, where challenging behaviour occurs outside the home, gives an indication of why supervision could prove problematic for some parents of the more intellectually and physically able people (Kiernan & Alborz, 1995).

Family explanations emphasised problems in the family such as divorce, or physical or mental illness of other family members which exacerbated difficulties in coping with the person with learning disability and their challenging behaviour at home. Sons and daughters whose parents' explanations fell into this category tended to have lower levels of intellectual ability and/or severe physical limitations. In these cases, parents emphasised their own exhaustion and inability to cope any longer, and acknowledged the difficulties occasioned by their son or daughter's challenging behaviour, as well as the limitations placed on their own life style. However, the majority conceptualised their son or daughter as the 'victim' of circumstances beyond their control and not as the cause of family difficulties.

Service explanations related to people with learning disability who were children when the decision to seek alternative provision was made. In all these cases parents' explanations revolved around an unwillingness to see their son or daughter leave home but acceptance that suitable provision was only available out of district. This latter set of explanations, therefore, differs in substance from the other two categories. For these parents the wish was not to find a new home, but secondary or continuing education. The explanations were categorised as 'stress process' because the need to seek services elsewhere was triggered by challenging behaviour.

'Postponed launching'

It is notable that there were no families who appeared to fit into the 'postponed' launching category of explanation. This type of explanation emphasises moves from home at an older age than one would find in the general population (say aged 30 or more), as a preventative strategy or 'anticipatory planning' (Nolan et al, 1996) against the time when parental health may fail (Essex et al, 1997). There was only one woman who fell into this age group. This woman's mother had stated that she wanted to see her settled, but had also reported that the reason for the move at that time was because she and her husband were exhausted and because her husband had angina. This explanation suggested that the move was not preventative planning, but a response to already failing health.

From the data analysed here it seems possible that, had events not overtaken them, people with physical care needs may have eventually moved as part of a 'postponed' launching pattern. That is, they would not move because their parents felt that they needed independence from them but because they would wish to ensure they were adequately cared for while they

themselves were still able to have an input. However, without further evidence, this is a matter of speculation.

To summarise, it was found that those with better levels of intellectual ability were more likely to have been placed because parents wished for them to have greater independence from the family. They were also more likely to have been placed following episodes of behaviour which affected the well-being of their local community and brought them into contact with the law. Where those with poorer intellectual ability had been in contact with the law it was due to violence towards a member of the family. Those with poorer levels of intellectual ability were more likely to have been placed because of other difficulties within the family, including parental exhaustion. Challenging behaviour was invariably mentioned as a contributory factor for this group.

Moves for children were to residential schools for treatment. The number involved was small and might not generalise to the general population of children with learning disability who have challenging behaviour.

The discussion to this point has centred around factors associated with the decision to place a son or daughter in alternative residential care. It has indicated that these factors appear to differ with the intellectual and physical ability level of the person concerned. Different characteristics seem to lead to different challenges and expectations. The discussion below concentrates on the consequences of these decisions, or in the case of 'crisis' moves, what might be termed the consequence of indecision, or delay, in seeking a suitable alternative.

Moving

Literature on the experience of actual moves from the parental home to residential provision is sparse. This thesis fills a gap in knowledge in the field by examining the experiences of a group of people with learning disability and challenging behaviour. Reports given by parents of the process of moving to alternative accommodation suggested that, for most people with learning disability who have challenging behaviour, the transition is not gradual but often rushed and achieved over brief periods of time. The group compared poorly to a group of older adults with learning disability who moved to residential care in Australia, almost half of whom moved gradually into their new home (Bigby, 1996). Only a little more than one in four of the people with learning disability and challenging behaviour experienced a gradual transition to residential care. Amongst Bigby's (1996) sample only one (2%) had been in contact with emergency services compared to four people (22%) in this study. This seems to suggest that many of the moves experienced by the families involved in this study may have been more distressing. There was no evidence of a 'key person' who acted as an advocate for parents and took over the arrangements for the move as in the Bigby (1996) study, apart from a social worker who had to liaise between parents and services because the parents did not speak English. This may be a manifestation of the absence of an active social support network for these families of people with learning disability and challenging behaviour.

Those sons or daughters who made a 'normative' move tended to have a gradual introduction to their new home. Only one of the four moved quickly, however this was after having his name on the waiting list for a place for three years. Only one in seven people who had moved as a response to stress (family) moved gradually to their new home. 'Crisis' moves were, by their nature, quick and without prior planning. Other 'quick' or immediate moves tended to occur because a place at a treatment facility or preferred residence suddenly became available.

However, this did not explain why the move to take up that place also needed to be sudden rather than gradual. In the circumstances of some of these moves, the speed was particularly distressing.

Almost all parents interviewed here expressed mixed emotions at the time of the move, characterised by relief, disorientation and distress. Distress centred on the circumstances of the move, missing their son or daughter, worry about the success of the placement and anxiety about challenging behaviour. In this regard these parents of people with learning disability and challenging behaviour appear to reflect similar concerns and dilemmas as parents interviewed by Richardson & Richie (1989). Parents who reported a gradual move to the new residence, although no more likely to see their son or daughter as entirely happy with the placement in the first week or so, did feel that having had several stays prior to a permanent move had made the move easier. In Richardson & Ritchie's (1989) study it was found that when a move to alternative provision occurred quickly parents tended to experience disorientation, however they also expressed relief that the ordeal was not protracted.

Regular contact between parent and son or daughter continued despite the distressing circumstances surrounding some of the moves. Where contact was less frequent, this was due to the distance of the residence from home and problems with transport. This above analysis suggests that people with learning disability who have challenging behaviour may be more open to sudden, inappropriate placement due to the stress that their behaviour, amongst other factors, may be occasioning. Crises or delays in planning appear to result in loss of control over where a son or daughter with learning disability will live.

Anehensel et al (1995) suggested that placement of a son or daughter into alternative residential care marks a new phase in their relationship with their parent, and that this is also potentially stressful. It has been suggested that once a relative is placed into residential care formal care staff may perceive that the families' problems are over (Lewis & Meredith, 1989). Bowers (1988) suggested that parents seek a new role in monitoring quality of care, and expect staff to be proactive in seeking biographical details about their relative. Similarly, Kellet (1996) suggested that after a move parents seek a new way of caring which maintains attachment and their sense of worth. Analysis of transcripts lends general support to this view of continuing parental involvement and concerns over the day to day life style of a son or daughter.

The analysis of parents' experiences and views seems to suggest that, despite the circumstances under which moves occurred, new and often better relationships were established with their son or daughter after they had moved from the family home. They also suggest that relationships with care staff were, on the whole, positive, with no parent reporting that they were discouraged from close involvement with their son or daughter, except in cases where parents were advised not to contact them for the first six weeks or so after moving. The reason given for this was that this allowed the person to acclimatise to their new home more easily, but this practice appears questionable. There appears to be no logical justification for separating a person physically and emotionally from their family for approximately two months while they settle in a new environment. The practice mirrors 'flooding' for treatment of phobias which, though effective, is particularly unpleasant because it involves extensive prolonged contact with the feared object or situation. Cutting off contact with family members appears particularly unkind when adopted in relation to those with the lower levels of

intellectual ability who may not understand, nor be enabled to appreciate why their parents have disappeared along with other familiar items.

A dilemma that surfaced from the qualitative analysis was the amount of autonomy or privacy an 'independent' son or daughter with learning disability and challenging behaviour, should have. It appeared that, for parents of people with good levels of intellectual ability and no physical limitations, true 'independence' from parents was desirable and the notion of a 'private life' accepted. However, for parents whose son or daughter had a more severe level of learning disability there was a need for complete openness. This appeared necessary to allow them to effectively monitor care, as well as reduce their own anxieties, and to be even more important where a person was unable to express preferences or disagreement in any straightforward fashion.

Despite some initial problems for those who made crisis moves most were said, in the long run, to be happy in their new home, and that their challenging behaviour had improved. Relationships with staff were on the whole good. Parents were happy that their son or daughter had someone closer in age to relate to and often felt they had a better and more adventurous social life. As mentioned above, the main dilemma for parents was the amount to which they should be involved in their son or daughter's day to day life, or be informed of episodes of challenging behaviour.

2 *Relationship of findings to policy issues*

Policy statements declare that a person with a disability should be cared for at home as long as this does not place undue burden on that person or their family (HMSO 1971, Cmnd, para 40). Where a person has challenging behaviour in addition to their disability it appears that most families are willing to care past the point at which they and their sons or daughters are deriving mutual benefit from the relationship. This appears to mirror families of people with learning disability more generally (Twigg & Atkin, 1994). However, these families appear to reach a point at which they are no longer able to care rather sooner than in the general population of people with learning disability, particularly where the person has fewer or no physical limitations. This finding requires further investigation.

The lack of residential places highlighted in the literature review (e.g. Emerson et al, 1996) is corroborated to some extent by parental reports of difficulty with funding and, in some cases, placements many miles from home. Such a deficit is reported to have the effect of providing accommodation only in the event of crisis or only to those who shout loud enough about it (Twigg & Aiken, 1994). Reports of having a name on a waiting list for three years and then having to fight for top up funding to take up the offer of a place would seem to verify this. Lack of what is perceived as suitable provision, as found in the Richardson & Richie (1989) study, is unlikely to encourage parents to make adequate plans at an early enough juncture to prevent the stressful situations experienced by the majority of parents studied in this thesis. This may be exacerbated where service providers themselves do not seek out those in need of services (Twigg & Atkin, 1994). This policy of not seeking out cases may have had the effect of averting a crisis over lack of residential provision thus far (McGrother et al, 1996).

The recent 'Caring about Carers' strategy document (Dept of Health, 1999) signals a change of direction and encourages those who provide services to be more proactive. This is embodied in requirements to provide information on the type and availability of services, as well as encouragement to include carers in service planning. A major tenet of the strategy is support for carers to have an independent and healthy lifestyle, achieved with the aid of 'breaks' from care. This aim is to be realised through the provision of a range of sitting and respite care options, as well as other support services to provide practical and emotional support.

In addition, the government document 'Better Care, Higher Standards' (Dept of Health & DETR, 1999) details a commitment to improve services for people needing long term care and support. Local Charters, to be in position by the middle of 2000, set out standards and goals for improvement in services by providing information, and understanding and responding to the needs of people with care needs and their carers. This is to involve identification of suitable accommodation, support for independent living, provision of appropriate health care and support to carers in caregiving. The charter promotes joint working between the different departments which provide social, health and housing welfare and encourages the service user to give permission for personal information to be shared. It is proposed that understanding and responding to the needs of users and carers be achieved through assessment under the NHS and Community Care Act 1990, or the Carers (Recognition and Services) Act 1995. Full participation and openness in assessment, including access to records, is promised.

The findings of this study have relevance to the issue of a 'suitable place to live' which may involve help to remain in the family home, a move for the family to a more suitable home, the provision of support services in the home, or alternative residential accommodation. The

Charter for long term care addresses the needs of users and carers in general and therefore some support initiatives may be more relevant to the group of carers who care for a son or daughter with learning disability than others. However, the findings of this study suggest that it is not only the needs of the person with learning disability and those of the carer that need to be addressed. The relationship between those two individuals was one amongst many in the majority of families, intense though it was. The need to seek alternative care for many of these families arose from a variety of causes not least amongst which were problems which were being experienced due to the difficulties of another family member. Any programme of support to those with disability or caring for a person with disability needs to recognise the interactions with the remaining family members. In this regard support needs to be aimed at the family as a whole and not just the carer / cared for dyad though this should be the primary focus.

Policy initiatives for people with disability and, in particular, their carers have taken enormous strides forward over the past five years. The message from this study suggests a more holistic approach to family welfare where the influences and needs of those who are 'satellites' to the 'user and carer' should be properly addressed. In relation to influences on the decision to place a son or daughter with learning disability in alternative residential care an additional element outside the control of families is the availability of suitable provision. The shortfall in residential places highlighted above is a key element in such decisions and the difficulties experienced by families in this study in obtaining funding for the placement of their choice point to a bottleneck where even where a move is assessed to be in the interests of the person with disability and/or their carer it may be difficult to achieved.

3 *Implications for practice*

The initiatives outlined above provide for support to people with disability and their carer via, for example, the provision of 'breaks' including day care and overnight stays as well as other 'minding' services. Evidence from this study suggests that exclusion from such service provision was a significant factor for several families in the decision to place a son or daughter into alternative care. It is not clear why, given that a person's behaviour was so challenging in a service setting, alternative day or respite provision was not provided. One would assume that, where a team of people find an aspect of an individual's behaviour unacceptable to the point that they are excluded from a particular facility, those caring for the person at home may also experience some difficulty. It would seem humane to provide assistance to help to care for such an individual until they could be provided a suitable daytime occupation or respite placement. This type of help may fall under the remit of Community Learning Disability Teams, however evidence from the Kiernan & Alborz (1995) study suggested that input from such teams was rare. It is possible that this type of support may be tackled through the National Carers Strategy which suggests that carer support may be best achieved through the use of volunteers. However, emotional and practical support to parents and people with learning disability and challenging behaviour is unlikely to be a popular choice for a volunteer workforce, and quite probably should only be undertaken by support staff properly qualified in this role.

The evidence provided by this thesis suggests many people with learning disability and challenging behaviour may require a placement at an earlier age than their counterparts who do not present behavioural challenges, and perhaps for this reason experience poorly planned moves. Parents whose sons or daughters have a good level of intellectual ability, but

particularly those with sons, appear to require the earliest placement, especially if supervision is problematic.

Parents of people with poor intellectual ability appear to need support to recognise the effect that caring may be having on themselves and to monitor other family difficulties. Again, if supervision is problematic this may be an indicator that remaining at home is not viable in the long run. Where a whole family approach is taken it may be possible to provide support to alleviate some difficulties which are not connected to the son or daughter with learning disability directly. This may enable the person with learning disability to remain with the family longer if this is their wish. Richardson & Richie (1989) commented that parental anguish over a move may be expedited by a quick transfer from the family to a service based home, but that, for people with learning disability, a number of prior respite visits may ease the transition. It appears that quick moves may have curtailed the anguish for some parents but may not best suit their son or daughter. Despite variation in the speed with which moves were achieved most parents reported that their son or daughter was initially upset.

Several of the 'immediate' and 'quick' moves occurred because a place at a treatment facility or preferred residential home became available. It appeared that many of these residences operated a 'dead man's shoes' policy. In many residential homes there were no extra places coming 'on stream' and, as a consequence, unless a person was moved or died, the prospective resident may wait many years for a place. However, this does not explain why, given that a place is suddenly available, the person with learning disability must take up full-time residency immediately, or almost immediately. One suspects that the answer may lie in resourcing issues, with effective operation of a facility requiring full capacity occupancy, part-time

residents occasioning a reduction in income pro rata. This is speculation but is an issue which requires investigation.

Active planning may help to overcome some of the difficulties experienced by families in this study. This might initially involve acknowledgement that, at some point, the son or daughter will need to move on. Whether this is conceived as for greater independence or for when parents are no longer coping is not an issue. The need is for a safety net which meets with the approval of parents, as well as their son or daughter with learning disability, and one in which they have had an input. Active planning might also involve visits to a range of residences in the hope of finding one where parents, and son or daughter where possible, feel that they would be happy. The findings of this thesis suggest it may be reasonable to identify residences whose philosophy reflects the parent's own view on parental input into their son or daughter's daily life. For families of people who are more able this may entail identifying a residence which conforms to the normal rules of adult relationships so that the person with learning disability has a 'private life' in as far as this is possible. Families of people whose abilities are poor on the other hand, appear likely to reject the idea of 'independence' as inappropriate and find secrecy disturbing. These families appear to prefer full disclosure and expect to be involved in all 'significant' decisions about their son or daughter.

Once such a place is identified then visits for respite care would allow the person to become familiar with the staff and the environment. This would seem to be particularly important for people with the lowest levels of intellectual ability some of whom may be particularly distressed at the change in residence. The findings of this study showed that these people were the least likely to have had an opportunity to accustom themselves to their new home before they moved. Putting a person's name on a waiting list for a place would seem expedient.

However, in the families studied here, such a decision still appeared to result in a sudden move as a place became available. A prior relationship with the residence as a regular 'visitor' may have eased this situation though these short term places do not appear to be universally available. In fact the Caring about Carers (1999) strategy states that short term places should not be provided at long-term care residencies unless they are in a separate unit. It is arguable that short term places are valuable in easing transition for potential residents and to enable carers to build relationships of trust with care staff. Alternatively, as stated above, there appears to be no obvious explanation as to why a new tenant should have to take up full-time occupancy from the outset and not be allowed a phased introduction to their new home.

Evidence from the qualitative study suggests that parents of people with learning disability who have challenging behaviour often reach the point of seeking, or requiring, an alternative placement after considerable difficulties in the home. However, the departure of the person with learning disability may not be the end of their difficulties or anxiety. There may well be a considerable aftermath in terms of the parents own health particularly where 'crisis' moves are made which are related to behaviour. It would seem appropriate, therefore, for services to assess parents needs along with those of their son or daughter as moves are taking place, to establish what (if any) support they need to cope with their difficulties. The new, Carers Strategy (1999) documents a willingness to provide such assistance. Although the strategy stresses an intention to help carers to 'rebuild their lives', and the provision of training to update skills so that they may return to employment, it is unclear as to whether physical or psychological health needs arising from their former caregiving role would be assessed and met in a continuing way when they are no longer a 'carer'.

The suggestions outlined above are an ideal, however as stated previously there is known to be a shortfall of many thousands of residential places (Emerson et al, 1996). Until there has been a significant attempt to deal with this problem it is unlikely that more gradual transitions will become the norm for people with learning disability and challenging behaviour.

4 *Directions for future research*

There are many ways this work could be taken forward to add further to the body of knowledge on planning and placement in alternative residential care for people with learning disability. Several of these are listed below.

- 1 An area of particular concern was that of 'crisis' moves and an examination of other crisis moves may help to identify warning signs and establish what could have been done to avert such situations.
- 2 The analysis of explanations given about the circumstances of the moves suggested that difficulties within the family more generally had been the primary, or a significant, influence in the decision to place a son or daughter into alternative care. Further research could usefully investigate ways in which whole family issues might be taken into account in provision of support. In particular, whether the development of specialist social workers, or 'family care workers' with specific training in family systems, individual and group psychology, and learning disability, would be feasible. The role of such workers might be to provide general support to families, as well as to monitor the well-being of 'carer' and 'cared for' alongside other family members, and to refer on to other services where appropriate.
- 3 In order to obtain examples of 'good practice', a comparison of districts using different approaches to service delivery for people with learning disability and carers could provide useful information on effective service provision which might then be disseminated to other districts.

- 4 A follow-up study of other members of the group interviewed in 1989, after moves to residential care, would provide a useful opportunity to extend this database. It would then be possible to examine the applicability of the findings of this work in the light of other moves to alternative care for people with learning disability and challenging behaviour, and to examine aspects of stress, coping, and psychological and physical well-being not possible in the present study.
- 5 Finally, factors relating to 'delay' in placing people with physical limitations into alternative care, compared to those who were more able, could be investigated. This study could usefully address whether greater satisfaction with caregiving, or dissatisfaction with the quality and/or availability of alternative provision were determining factors.

5 *Critique of study*

This study provided a valuable opportunity to examine the factors influencing parental decisions to place a son or daughter with learning disability and challenging behaviour in alternative care. The derivation of the participant group from an epidemiological survey provided a solid background against which the investigation could take place. Access to this large database provided an opportunity to use sophisticated quantitative techniques to generate robust indices of intellectual ability and physical limitation, through which more meaningful analysis could subsequently take place. In addition, this large sample enabled comparisons to be made between groups of people residing in family and service settings, and provided confidence that the findings were a reflection of actual variances in the population.

The weakest part of the study was Study 2 which analysed quantitative data from the 1988 survey and from 1989 parental interviews. The approach taken involving matching movers to non-movers, though potentially informative in providing a 'control' group of sorts, suffered due to the small number of participants (movers) who could be included. The consequence of this is restricted generalizability of findings, and lack of sensitivity to potentially influential variable in the analysis. The problem of small numbers could have been overcome by using the entire group of 'non-movers', however, as stated previously it was felt that the correspondingly wider range of ages, and different gender distribution, may have introduced confounding. In addition, it was hoped that this analysis might take the research a step beyond the factors found significant in the related Kiernan & Alborz (1995) study.

The subsequent qualitative analysis of parent interviews gave balance to the quantitative findings and provided a view of moves to alternative care which was not possible from analysis of quantitative data sets. The major advantage of using qualitative analysis is the

validity of the findings in relation to the topic under investigation. Findings from this study provide a clear signal of the influences on families when deciding that a son or daughter is to be placed into alternative care. Criticism could be levelled at this part of the research due to its reliance on retrospective accounts of events which may have occurred up to six years previously. However, the nature of the events which were the focus of this work were such that no parent reported difficulty in recalling details. These were significant life events and comparison of reports from the minority of parents whose son or daughter had moved more than four years previously, with those who had moved within the last year, showed no noticeable lack of detail. Only one mother had difficulty with the sequence of events, but nevertheless was able to relate the full extent of the difficulties the family had experience at what had been a very traumatic time. What the experience of these families added to the study was detail on the ongoing pattern of contact with a son or daughter in alternative care in the longer term.

Significant limitations to the study arose from the use of secondary analysis. It was not possible to explore all of the variables thought to have a bearing on this type of decision because the data was pre-existing and therefore information on some areas considered potentially influential was not available. This put constraints on what could be achieved with the data set, however the thesis nevertheless demonstrated usefulness of 'multi-disciplinary', mixed method approach to investigation of complex matters such as those which were the subject of this study. It must be pointed out, however, that data sets of the size and complexity of the ones used for this thesis would be beyond to capacity of a single research student to produce. Bearing this in mind the benefits appear to outweigh the deficits resulting in research which adds to the body of knowledge on transitions from family to agency care for people with learning disability, and which has implications for policy and practice relating to these people and their carers.

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Appendix 1

Letter to prospective parents to inform them of the study and ask for their help.

Dear

I am writing to ask for your help with a research project that the Hester Adrian Research Centre is doing in your area.

In 1988 we did a large survey of seven districts in the North West which was paid for by the Dept. of Health. This study looked at people with learning disability and any difficulties faced by the services they went to.

We are now looking at some of the people who were receiving services then to find out what has happened to them over the last seven years.

In 1988 we also asked some parents for their views and visited most of them again in 1993. The information these parents gave us was written up in reports and sent to those people who work in services as well as those who fund them.

Now we would like to see more parents to find out what they think of services today and how their lives are affected by having a son or daughter with learning disability. For some of you we know your son or daughter will no longer be living at home but we would still like your views.

Taking part would mean a researcher from Hester Adrian will phone to make an appointment to see you. When she comes to see you she will ask questions about.....

- what your sons and daughters are like, what they can do for themselves and what you have to help with
- whether you have any extra expenses because of their disability
- if there is anything your son or daughter does that you find difficult to deal with and what help services give you with that.
- which services your son or daughter uses and what you think of them
- what effect you feel having a son or daughter with learning disability has on you and the rest of the family

For those whose sons and daughters are no longer at home

- about moving out, how it went and what you think of their new home

There are a lot of questions as you can imagine! We feel it is important though to get your point of view so we do hope you will take part.

Everything you tell us will be strictly confidential to us and no one will be named in anything we write about the research afterwards.

If you **do not wish to take part** please complete the *slip at the bottom* of this letter and post it to us in the envelope provided *as soon as you can*.

If you are **happy to take part** do nothing! One of us, that is myself, Rebecca Swarbrick or Heidi Mason *will phone you* (or write to you again if we cannot find a phone number) *within the next four weeks* to arrange to come and see you.

We look forward to meeting you.

Yours sincerely

Alison Alborz
Research Fellow

To Alison Alborz,
Hester Adrian Research Centre, The University, Manchester M13 9PL

Interview about and Family

I do not wish to take part in the research you have described.

Signed

Date

Appendix 2

Edited version of the 'Individual Schedule' (1988 version) comprising those parts of the schedule containing variables used in analysis.

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--	--

Health Authority
(code as opposite)

(1-3)

(4-5)

Hester Adrian Research Centre - Behaviour Problems Survey

CARD 1

Information about Individuals

1.	Age (in years)	<table border="1"> <tr> <td></td> <td></td> </tr> </table> Years			(6-7)										
2.	Sex	Male.....1 Female.....2	(8)												
3.	Marital status	Single.....1 Other (please specify).....2	(9)												
4.	Place of residence	Family home.....1 Foster family home.....2 SSD or NHS hostel.....3 Hospital Ward.....4 Independent.....5 Other.....6	(10)												
5.	Most recent IQ score (If not known, go on to question 6)	<table border="1"> <tr> <td></td> <td></td> </tr> </table>			(11-12)										
	Name of test	<table border="1"> <tr> <td></td> </tr> </table>		(13)											
	Year in which test was administered	19 <table border="1"> <tr> <td></td> <td></td> </tr> </table>			(14-15)										
6.	Degree of mental handicap (Severe handicap is understood to mean an IQ of 50 or less)	Borderline.....1 Moderate.....2 Severe/Profound.....3 Not assessed/cannot say.....4	(16)												
<p>* HARC USE ONLY</p> <table> <tr> <td> <table border="1"> <tr> <td></td> <td></td> <td></td> </tr> </table> (73-75) </td> <td> <table border="1"> <tr> <td></td> <td></td> </tr> </table> (76-77) </td> <td> <table border="1"> <tr> <td></td> <td></td> </tr> </table> (78-79) </td> <td> <table border="1"> <tr> <td></td> </tr> </table> (80) </td> </tr> </table> <p>COLUMNS (73-80) ARE CODED <u>AS ABOVE</u> ON ALL 4 CARDS</p>				<table border="1"> <tr> <td></td> <td></td> <td></td> </tr> </table> (73-75)				<table border="1"> <tr> <td></td> <td></td> </tr> </table> (76-77)			<table border="1"> <tr> <td></td> <td></td> </tr> </table> (78-79)			<table border="1"> <tr> <td></td> </tr> </table> (80)	
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7. Legal status of person

2

Not applicable.....	0	
Informal.....	1	
Detained through the courts on a hospital order.....	2	(17)
Detained for assessment or treatment.....	3	
Child in Care.....	4	

8. How long has the person been attending, or living in this setting? (in years, if less than one year, enter 1).

(18-19)

--	--

9. Are any of the following conditions present?

Downs syndrome?	No.....	0	(20)
	Yes.....	1	
	Don't know.....	2	

Cerebral palsy?	No.....	0	(21)
	Yes.....	1	
	Don't know.....	2	

Autism?	No.....	0	(22)
	Yes.....	1	
	Don't know.....	2	

Other known syndrome? (Please specify)	No.....	0	(23)
	Yes.....	1	

10. Psychiatric disorder (only enter if such a diagnosis has been made by a psychiatrist, do not guess).

Don't know.....	0	(24)
No psychiatric disorder.....	1	
Depressive illness.....	2	
Other affective disorder.....	3	
Schizophrenia.....	4	
Psychotic condition (unclassified).....	5	
Neurosis.....	6	
Other (not included above or unknown psychiatric disorder).....	7	

11. Does the person suffer from fits?

No (no medication, no seizures).....	1	(25)
No (controlled by medication).....	2	
Occasional seizures (less often than monthly).....	3	
One or more major seizures per month.....	4	

a) Has there been a definite diagnosis of Temporal Lobe Epilepsy

Yes, Definite.....	1	(26)
Yes, Query.....	2	
No.....	3	
Don't know.....	4	

12. i) Vision (If glasses are worn, code vision with glasses)

329

Normal.....	1	(27)
Poor.....	2	
Blind.....	3	
Not sure/difficult to say.....	4	

ii) Hearing (If hearing aid is worn, code hearing with aid)

Normal.....	1	(28)
Poor.....	2	
Deaf.....	3	
Not sure/difficult to say.....	4	

13. Mobility

No difficulty walking.....	1	(29)
Walks without aid but with some difficulty.....	2	
Walks with aids (or mobile in wheelchair) indoors and out.....	3	
Unable to walk but can get around indoors.....	4	
Gets around with human aid only.....	5	
Immobile.....	6	

14. Continence.

Doubly incontinent.....	1	(30)
Incontinent (soiling or wetting) once a week or more.....	2	
Sometimes incontinent but less often than once a week.....	3	
Usually fully continent.....	4	

Does s/he show deliberate incontinence: that is, willful urination or defaecation in inappropriate places?

Never.....	1	(31)
Don't know, not sure.....	2	
Yes, isolated occasions only.....	3	
Yes.....	4	

15. Self care skills.

Does s/he perform the following tasks?

i) Feeding

- Usually does so independently.....1
 Physically capable but sometimes needs supervision.....2 (32)
 With some assistance.....3
 Completely dependent on others.....4

ii) Washing

- Usually does so independently.....1
 Physically capable but sometimes needs supervision.....2 (33)
 With some assistance.....3
 Completely dependent on others.....4

iii) Dressing

- Usually does so independently.....1
 Physically capable but sometimes needs supervision.....2 (34)
 With some assistance.....3
 Completely dependent on others.....4

Does s/he show unwillingness to perform any of the self-care tasks listed above which s/he is potentially capable of doing?

- All or most of the time.....1
 Sometimes.....2 (35)
 Never, or hardly ever.....3

16. Domestic skills - table laying, washing up etc.

- Works well with little or no supervision.....1
 Sometimes with supervision.....2 (36)
 No domestic skills.....3
 Do not know or no opportunity.....4 → GO TO 17

Does s/he show unwillingness to perform domestic tasks which s/he might otherwise be capable of doing?

- All or most of the time.....1
 Sometimes.....2 (37)
 Never, or hardly ever.....3

17. Occupation.

- Occupies self constructively or can easily be occupied constructively.....1
 Does not occupy self constructively, but cooperates in constructive activities.....2 (38)
 Hard to keep occupied constructively may need one-to-one attention to keep occupied.....3
 Never or, hardly ever possible to keep occupied constructively.....4

18. Handling money.

- Could go shopping and check change.....1
 Can use money, but not check change.....2
 Realises money has value but does not use money.....3
 Has no idea that money has value.....4
 Don't know.....5

(39)

19. Communicative use of Speech and Gestures.

- Communicates regularly using varied phrases
 or sentences.....1
 Only uses a few words, sounds or gestures as
 communication.....2
 Little or no communication.....3

(40)

20. Understanding communication (ring the highest number
which applies only)

- Understands little or nothing.....1
 Understands a few simple commands (e.g. come here,
 sit down).....2
 Understands a fair range of instructions or questions
 related to practical needs.....3
 Understands comments, questions and instructions
 related to personal needs and experiences (e.g. did
 you enjoy the trip to the zoo?).....4
 Understands information about things outside own
 immediate experience (e.g. stories or accounts of
 other peoples experiences).....5

(41)

21. Understanding of speech by others.

- Clear enough to be understood by anyone.....1
 Can be understood by close acquaintances but
 difficult for strangers.....2
 Difficult to understand, even by close
 acquaintances, impossible for strangers.....3
 Not enough speech to rate.....4

(42)

22. Stereotyped behaviour.

Does s/he engage in behaviour such as body rocking, finger tapping, hand waving, or other physical stereotyped behaviours? (Ring the first code which applies only)

- Most of the time.....1
 At least daily.....2
 At least weekly.....3
 At least monthly.....4
 Less Often.....5
 Never.....6

(43)

23. Appropriacy of behaviour in interactions: With people who are well known to him or her.

- No social responses.....1
 Interacts to satisfy own needs only.....2
 Sometimes interacts appropriately but frequently does not.....3
 Generally interacts appropriately but sometimes does not.....4
 Almost always interacts appropriately.....5

(44)

24. Appropriacy of behaviour in interactions: With other people not well known.

- No social responses.....1
 Interacts to satisfy own needs only.....2
 Sometimes interacts appropriately but frequently does not.....3
 Generally interacts appropriately but sometimes does not.....4
 Almost always interacts appropriately.....5

(45)

25. Participation in group activities.

- Initiates group activities (leads and organises).....1
 Participates in group activities spontaneously and willingly.....2
 Participates positively if encouraged to do so.....3
 Actively disrupts group activities.....4
 Does not participate in group activities - (an isolate).....5
 Varies too much to say.....6

(46)

26. Friendships.

333

Does the person have any friends among the other residents/pupils/trainees? (Include anyone who as far as possible actively seeks and/or enjoys this person's company in a mutually rewarding way, including boyfriends and girlfriends).

No, no one.....1
 Yes (at least one).....2 (47)
 Do not know/cannot say.....3

27. How would you describe his/her relationships with other residents/pupils/trainees?

Indifferent.....1
 Generally positive.....2 (48)
 Generally negative.....3
 Mixed.....4
 Other.....5

28. How would you describe his/her relationships with staff?

Indifferent.....1
 Generally positive.....2 (49)
 Generally negative.....3
 Mixed.....4
 Other.....5

29. How often does s/he see a family member?
(Code first which applies)

Lives with family.....1
 More than weekly.....2 (50)
 Weekly.....3
 Once a month or more.....4
 Once a year or more.....5
 Less often.....6
 Never.....7

Type(s) of behaviour problem displayed

Below will be found a number of descriptions of types of behaviour problem. For each problem there follows a set of different questions. Please show by ringing the correct number whether the type of problem indicated is:

1. One of this person's most serious management problems.
2. Present, but a lesser problem.
3. Previously or potentially a serious problem but controlled in this setting.
4. Not a problem for this person.

	Serious	Lesser	Controlled	No
1. Physical attacks on other people	1	2	3	4
2. Self Injurious behaviour	1	2	3	4
3. Destructive behaviour	1	2	3	4
4. Other difficult, disruptive or socially unacceptable behaviour	1	2	3	4

(51)

(52)

(53)

(54)

FOR EACH PROBLEM RATED AS SERIOUS OR CONTROLLED PLEASE ANSWER THE APPROPRIATE QUESTIONS DEFINED AS FOLLOWS:

1. Physical attacks - questions on BLUE paper
2. Self injury - questions on YELLOW paper
3. Destructive behaviour - questions on GREEN paper
4. Other - questions on PINK paper

01. Other Difficult, Disruptive or Socially Unacceptable Behaviour

What form (or forms) does this behaviour most frequently take?

1. This person's most serious management problem (more than one problem may be rated if necessary).
2. Present, but a lesser problem.
3. Previously or potentially a serious problem but controlled in this setting.
4. Not a problem for this person.

	Serious	Lesser	Controlled	No	
Non compliance, refusal to co-operate	1	2	3	4	(25)
Verbal abuse	1	2	3	4	(26)
Temper tantrums	1	2	3	4	(27)
Antisocial behaviour: bullying, cheating, lying, inciting others, actively disrupting others' activities, interfering in other's affairs.	1	2	3	4	(28)
Stealing	1	2	3	4	(29)
Stripping	1	2	3	4	(30)
Running Away	1	2	3	4	(31)
Overactivity, constantly pacing about	1	2	3	4	(32)
Repetitive pestering/ exaggerated fears	1	2	3	4	(33)
Prolonged or frequent screaming, roaring moaning or other unaccept- able noises	1	2	3	4	(34)
Unpleasant habits such as smearing faeces, self-induced vomiting, spitting	1	2	3	4	(35)
Eating non-food objects	1	2	3	4	(36)
Socially unacceptable sexual behaviour	1	2	3	4	(37)
Other (please specify)	1	2	3	4	(38)

Complete remaining questions, in this (PINK) section, only in relation to behaviours rated (1) Serious or (3) Controlled.

JOHN P. L. S. S.
UNIVERSITY
LIBRARY
MANCHESTER

OVERALL SUMMARY QUESTIONSCARD 3 ³³⁶

1. How often has this person displayed any behaviour problems in the past month?

All or most of the time.....1
 Daily, at least.....2
 Weekly, at least (4 times in a month).....3
 Once, at least.....4
 Not at all.....5

(66)

2. Consequences of Behaviour

- a) Disruption of ward/centre/class activities for:
 (Please ring one number in the first column and one number in the second column).

	Usually	Most Serious
Not at all.....	0	0
A few minutes only.....	1	1
Up to an hour.....	2	2
Longer.....	3	3

(67)

(68)

- b) Additional work for staff in:

i) Clearing up? Usually.....1
 Sometimes.....2
 Never.....3

(69)

ii) Calming other residents? Usually.....1
 Sometimes.....2
 Never.....3

(70)

BLANK
 (71)

3

(72)

CARD 4

iii) Other additional work (please specify) Usually.....1
 Sometimes.....2
 Never.....3

(1)

c) Other consequences for the individual:

Termination of event or activity

Yes often.....	1	(2)
Yes, has happened.....	2	
No.....	3	

Complete exclusion from this setting for a period of time

Yes, has happened.....	1	(3)
No.....	2	

Intervention by the police

Yes, in this setting.....	1	(4)
Yes, but not in this setting....	2	
No, do not know.....	3	

Involvement with the courts

Yes, whilst in this setting....	1	(5)
Yes, but not in this setting....	2	
No.....	3	

3. Does behaviour disturbance prevent this person from taking part in programmes or activities which would otherwise be appropriate to his or her level of skills and competence?

Always.....	1	(6)
Most of the time.....	2	
Has at least once.....	3	
No.....	4	

4. Is behaviour disturbance a factor that would prevent this person's relocation to a less restrictive setting (if one were available)?

No.....	1	(7)
Yes, the main factor.....	2	
It is one factor among others....	3	
Do not know.....	4	

5. Was behaviour disturbance one reason for the person's admission to this setting?

No.....	1	(8)
Yes, the main reason.....	2	
yes, one reason among others....	3	
Do not know.....	4	

Appendix 3

Parent Interview (Qureshi 1988).

Parent InterviewSECTION I

Structured information - question form optional

Family Composition (Respondent first)

Include all people in household and all siblings of the individual but not the individual.

Relationship					In H/H?		Sex		Age	Married				Work Status (in H/H only)							
M	F	S	O	N	Y	N	M	F	Yrs	M	S	W	D	FT	PT	U/R	RET	ED	HW	SK	OTH
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2		1	2	3	4	1	2	3	4	5	6	7	8

(3 - 9

(10 - 16

(17 - 23

(24 - 30

(31 - 37

(38 - 44

(45 - 51

(52 - 58

Mother figure is:

Natural Mother 1
 Adoptive Mother 2
 Stepmother 3
 Foster Mother 4
 Other (specify) 5
 Absent 6

(59)

Father figure is:

Natural Father 1
 Adoptive Father 2
 Stepfather 3
 Foster Father 4
 Other (specify) 5
 Absent 6

(60)

If Father absent, does he have any contact with

Yes 1
 No 2

(61)

IF YES, how often?

(How long since Father's departure?)

--	--

(62 - 63

How long widowed?

--	--

(64 - 65

--	--	--

(66 - 68)

1

(72)

--	--	--

(73 - 75)

--	--

(76 - 77)

--	--

(78 - 79)

4

(80)

CARD TWO

2.	Race/Ethnic Origin/Nationality: <table> <tr> <td>White</td> <td>.</td> <td>.</td> <td>.</td> <td>1</td> </tr> <tr> <td>Afro Caribbean</td> <td>.</td> <td>.</td> <td>.</td> <td>2</td> </tr> <tr> <td>Asian</td> <td>.</td> <td>.</td> <td>.</td> <td>3</td> </tr> <tr> <td>Other</td> <td>.</td> <td>.</td> <td>.</td> <td>4</td> </tr> <tr> <td>Mixed</td> <td>.</td> <td>.</td> <td>.</td> <td>5</td> </tr> </table>	White	.	.	.	1	Afro Caribbean	.	.	.	2	Asian	.	.	.	3	Other	.	.	.	4	Mixed	.	.	.	5	(1)										
White	.	.	.	1																																	
Afro Caribbean	.	.	.	2																																	
Asian	.	.	.	3																																	
Other	.	.	.	4																																	
Mixed	.	.	.	5																																	
3.	Is this your own house or is it rented? <table> <tr> <td>Own</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>1</td> </tr> <tr> <td>Rented</td> <td>[</td> <td>Council or H.A.</td> <td>.</td> <td>2</td> </tr> <tr> <td></td> <td>[</td> <td>Private</td> <td>.</td> <td>3</td> </tr> <tr> <td>Relatives house</td> <td>.</td> <td>.</td> <td>.</td> <td>4</td> </tr> <tr> <td>Other (specify)</td> <td>.</td> <td>.</td> <td>.</td> <td>5</td> </tr> </table> How long here (in years) <div style="display: inline-block; border: 1px solid black; width: 40px; height: 20px; margin-left: 10px;"></div> <div style="display: inline-block; border: 1px solid black; width: 40px; height: 20px; margin-left: 10px;"></div>	Own	1	Rented	[Council or H.A.	.	2		[Private	.	3	Relatives house	.	.	.	4	Other (specify)	.	.	.	5	(2) (3 - 4)									
Own	1																																
Rented	[Council or H.A.	.	2																																	
	[Private	.	3																																	
Relatives house	.	.	.	4																																	
Other (specify)	.	.	.	5																																	
4.	For the person with mental handicap is the household (usually)?: <table> <tr> <td>Main place of residence</td> <td>1</td> </tr> <tr> <td>(4 nights or more a week)</td> <td></td> </tr> <tr> <td>Regular residence</td> <td>2</td> </tr> <tr> <td>(1-3 nights a week)</td> <td></td> </tr> <tr> <td>Secondary residence</td> <td>3</td> </tr> <tr> <td>(less than one night a week)</td> <td></td> </tr> </table>	Main place of residence	1	(4 nights or more a week)		Regular residence	2	(1-3 nights a week)		Secondary residence	3	(less than one night a week)		(5)																							
Main place of residence	1																																				
(4 nights or more a week)																																					
Regular residence	2																																				
(1-3 nights a week)																																					
Secondary residence	3																																				
(less than one night a week)																																					
Information about Child																																					
5.	Name of any Syndrome or Condition <div style="display: inline-block; border: 1px solid black; width: 40px; height: 20px; margin-left: 10px;"></div> <div style="display: inline-block; border: 1px solid black; width: 40px; height: 20px; margin-left: 10px;"></div>	(6 - 7)																																			
6.	Cause of Handicap <table> <tr> <td>Present at Birth</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>1</td> </tr> <tr> <td>Vaccination</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>2</td> </tr> <tr> <td>Other injury or infection after Birth</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>3</td> </tr> <tr> <td>Other (specify)</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>4</td> </tr> <tr> <td>D/K</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>.</td> <td>5</td> </tr> </table>	Present at Birth	1	Vaccination	2	Other injury or infection after Birth	3	Other (specify)	4	D/K	5	(8)
Present at Birth	1																															
Vaccination	2																															
Other injury or infection after Birth	3																															
Other (specify)	4																															
D/K	5																															

Characteristics of Child

7. **Mobility**

No difficulty walking 1
 Walks without aid but with some difficulty 2
 Walks with aids (or mobile in wheelchair) indoors and out 3
 Unable to walk but can get around indoors 4
 Gets around with human aid only 5
 Immobile 6

(9)

Is s/he physically fit? → Yes 1
 Strong? No 2
 Stronger than you?

(10)

8. **Vision**

Normal 1
 Poor 2
 Blind 3
 Not sure/difficult to say 4

(11)

9. **Hearing**

Normal 1
 Poor 2
 Deaf 3
 Not sure/difficult to say 4

(12)

10. **Does the person suffer from fits?**

No (no medication, no seizures) 1
 No (controlled by medication) 2
 Occasional seizures (less often than monthly) 3
 One or more major seizures per month 4

(13)

11. **Language**

Communicative use of Speech and Gestures

Communicates regularly using varied phrases or sentences 1
 Only uses a few words, sounds or gestures as communication 2
 Little or no communication 3

(14)

12. Understanding communication (ring the highest number which applies only)

- Understands little or nothing 1
 Understands a few simple commands (e.g. come here, sit down) 2
 Understands a fair range of instructions or questions related to practical needs 3
 Understands comments, questions and instructions related to personal needs and experiences (e.g. did you enjoy the trip to the zoo?) 4
 Understands information about things outside own immediate experience (e.g. stories or accounts of other peoples experiences) 5

(15)

13. Understanding of speech by others.

- Clear enough to be understood by anyone 1
 Can be understood by close acquaintances but difficult for strangers 2
 Difficult to understand, even by close acquaintances, impossible for strangers 3
 Not enough speech to rate 4

(16)

14. Contenance

- Doubly incontinent 1
 Incontinent (soiling or wetting) once a week or more 2
 Sometimes incontinent but less often than once a week 3
 Usually fully continent 4

(17)

Does s/he show deliberate incontinence: that is, wilful urination or defaecation in inappropriate places?

- Never 1
 Don't know, not sure 2
 Yes, isolated occasions only 3
 Yes 4

(18)

15. Self care skills

Does s/he perform the following tasks?

i) Feeding

Usually does so independently	1	
Physically capable but sometimes needs supervision	2	
With some assistance	3	(19)
Completely dependent on others	4	

ii) Washing

Usually does so independently	1	
Physically capable but sometimes needs supervision	2	
With some assistance	3	(20)
Completely dependent on others	4	

iii) Dressing

Usually does so independently	1	
Physically capable but sometimes needs supervision	2	
With some assistance	3	(21)
Completely dependent on others	4	

Does s/he show unwillingness to perform any of the self-care tasks listed above which s/he is potentially capable of doing?

All or most of the time	1	
Sometimes	2	(22)
Never, or hardly ever	3	

Does s/he cooperate with these tasks or can it be a struggle to get them done? How often?

Some problems	1	(23)
No Problems	2	

Does s/he compromise or cooperate when you want to get things done round the house? To deal with other children?

Some problems	1	(24)
No problems	2	

16. Sociability?

What is s/he like as a person?

Does s/he like other people?

Does s/he get on well with people?

Have any special friends?

Can s/he be charming?

Does s/he show affection?

Can s/he consider other people's feelings?

Do people enjoy being with him/her?

Are there particular things which worry or upset him/her?

Any obsessions or fixations?

Fixed routines?

Helping, Cooperating. Doing what s/he is asked

For
Transcription

17. Occupying Self

- Occupies self constructively or can easily be occupied constructively 1
Does not occupy self constructively, but cooperates in constructive activities 2
Hard to keep occupied constructively, may need one-to-one attention to keep occupied 3
Never, or hardly ever, possible to keep occupied constructively 4

(25)

18. Supervision

- a) In the last month, please indicate the length of time you have been able to leave (name) unsupervised - alone in a room, perhaps watching T.V. when you are in another room, without going in to check on him/her.

- unable to leave even for a moment 1
15 minutes or less 2
between 15 and 30 minutes 3
between 30 minutes and 1 hour 4
between 1 and 2 hours 5
over 2 hours 6

(26)

- b) How much of a problem is this?

- not a problem 1
a nuisance only 2
a slight problem 3
a definite problem 4

(27)

- c) Who supervises (name) when at home? For what proportion of time?
Evenings and Weekends?

Evenings	M	F	J	H/H	R	I	S	V	O
1	1	2	3	4	5	6	7	8	9
2	1	2	3	4	5	6	7	8	9
3	1	2	3	4	5	6	7	8	9
4	1	2	3	4	5	6	7	8	9
5	1	2	3	4	5	6	7	8	9

(28)

(29)

(30)

(31)

(32)

Weekends

a.m.	1	2	3	4	5	6	7	8	9
p.m.	1	2	3	4	5	6	7	8	9
evening	1	2	3	4	5	6	7	8	9
a.m.	1	2	3	4	5	6	7	8	9
p.m.	1	2	3	4	5	6	7	8	9
evening	1	2	3	4	5	6	7	8	9

(33)

(34)

(35)

(36)

(37)

(38)

- d) Can you give me an example of the kind of things s/he might do/does which makes supervision necessary?

Transcription

19. Questions about Behaviour Problems

To be
Transcribed

- (1) Do you have an idea **why** s/he?
- (2) What do you do **when** s/he?
- (3) Do you/are you able to do anything to try and prevent?
Or to reduce the consequences of?
Costs of this
- (4) Has s/he always done this or was there a particular age when s/he
started to behave this way?
- (5) Have you ever had any advice from professionals on how to deal
with?
Who? What? How Useful?
- (6) Do you think s/he intends to harm people/harm herself/break
things/upset people? Is s/he aware that what s/he has done is wrong?
Sorry afterwards?
- (7) Do you think s/he can help it?
- (8) Does s/he behave in the same way wherever s/he is?
- (9) Is there any particular aspect of his/her behaviour which causes you
most concern?

What? Why?
- (10) What do you think are the costs to him/her of his/her behaviour?
- (11) Do you ever get angry with him/her? Describe the last time.
- (12) Are you ever worried that you don't know what s/he's going to do next?
How often?
- (13) Has there ever been a point at which you felt you wanted to give up?
- (14) Has his/her behaviour become worse or improved or stayed about the same
over the past few years?
- (15) Do you think it is likely that his/her behaviour will improve in future
or not?

What do you think you can realistically expect?
- (16) Has his/her level of skills changed over the past few years?
Has s/he changed as a person?

1. Physical Attacks

a) Does s/he ever physically attack you or any other members of the family who live here?

Yes	1
No	2

(39)

If No: Does s/he ever cause any injury to anyone in any other way, for example, by grabbing them tightly when agitated, or by throwing objects at people?

Yes	1
No	2

(40)

If YES (to either)

b) How often in the past month:?

All or most of the time	1
Once or more a day	2
Once or more a week	3
Less often	4
Not at all	5

(41)

If not at all in the past month, how long is it since the last incident?

--	--

months ago

(42 - 43)

c) Usual form of attack?

Brief episodes	1
Sustained attacks	2
Either	3

(44)

d) Who most often?

Respondent	1
Spouse	2
Sibling	3
Other (specify)	4

(45)

c) What are the consequences of the attacks in terms of injury?

Physical injury

-----	-----
Usual	Most Serious
-----	-----

None

1

1

Minor injury (e.g. bruises) not sufficient to impair functioning for more than a few minutes

2

2

Serious injury (e.g. broken bones, stab wounds: requiring treatment in hospital)

3

3

21. Self Injury

a) Does s/he ever injure, or attempt to injure, her/himself?

Yes . . . 1
No . . . 2

(48)

b) How frequently has any form of self-injurious behaviour occurred in the past month?

All or most of the time . 1
Once or more a day . 2
Once or more a week . 3
Less often . 4
Not at all . 5

(49)

c) If not at all in the past month, how long is it since the last incident?

Months

--	--

(50 - 51)

d) What are the consequences of this behaviour: please ring one number in the first column (usual consequences) and one number in the second column (most serious consequences).

	Usual	Most Serious
No physical injury	1	1
Minor tissue damage	2	2
Life threatening injury or permanent impairment	3	3
In between minor and life threatening	4	4
	(52)	(53)

Destruction

a) Does s/he ever break, destroy or damage things as a consequence of his/her behaviour?

Yes . . . 1
No . . . 2

(54)

b) Type of damage?

c) How often in past month?

All or most of the time . 1
Once or more a day . 2
Once or more a week . 3
Less often . 4
Not at all . 5

(55)

d) If not at all in the past month, how long is it since the last incident?

Months

--	--

(56 - 57)

e) Cost of repair and replacement in past month?

£

--	--	--

(58 - 60)

f) Was this typical?

Yes . . . 1
No . . . 2

(61)

g) Cash and labour

h) Any major costs in past year (over £100)?

Yes . . . 1
No . . . 2

(62)

Amount

£

--	--	--

(63 - 65)

23. a) Is there anything about his/her **behaviour** that causes you difficulty or embarrassment when you take him/her out among strangers?

Yes 1
No 2

(66)

IF YES

b) What is the problem? What do people do? What do you do?

Transcribe if interesting

24. a) Is there anything about 's **appearance** that means that other people can immediately identify him/her as handicapped when you are out?

Yes 1
No 2

(67)

IF YES

b) What?

c) Have there been any changes in the way people react to his/her behaviour since s/he has grown older?

Transcribe if Yes

25. a) When you are out do you feel that other people see you as responsible for his/her behaviour?

Yes 1
No 2

(68)

b) Do you ever feel that other members of the family see you as responsible for his/her behaviour?

Yes 1
No 2

(69)

c) Has 's behaviour caused any family quarrels or disagreements? If yes, problems?

With any of the above .
With husband
With children at home .

Transcribe

d) Are any of these long-running disagreements?

2

(72)

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(73 - 75)

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(76 - 77)

--	--

(78 - 79)

4

(80)

26. a) Has affected the amount of contact you have with members of your family who live outside the home?

	More	Less	Same	N/A	Varies	
Own parents .	1	2	3	4	5	(1)
In-laws .	1	2	3	4	5	(2)
Own independent children .	1	2	3	4	5	(3)
Own siblings .	1	2	3	4	5	(4)

- b) Has the amount of help you get from family members changed since was younger?

	None Anyway	Less Now	More Now	Unchanged	Varies	
Own parents . 1		2	3	4	5	(5)
In-laws . 1		2	3	4	5	(6)
Own independent children . 1		2	3	4	5	(7)
Own siblings . 1		2	3	4	5	(8)

- c) Some parents have said that they wish they had been firmer with their children in the past. Do you ever feel that way or not?

Yes . . .	1	(9)
No . . .	2	

27. a) If you compare yourself to other parents of your age, does the care or behaviour of mean you have to restrict or completely cut out any of the following:

	No Effect	Restrict	Completely Cut Out	Have More	
Holidays . . .	1	2	3	4	(10)
Social outings (to public places) .	1	2	3	4	(11)
Visiting friends .	1	2	3	4	(12)
Having friends round	1	2	3	4	(13)
Making new friends .	1	2	3	4	(14)
Pursuing your own interest or hobby	1	2	3	4	(15)
Leisure activity at home . . .	1	2	3	4	(16)

- b) Do you feel that the differences between you and other parents are greater now than they were in the past or not?

Yes . . .	1	(17)
No . . .	2	
Other . . .	3	

28. Flexibility in Caring

- | | | |
|--|---|-----------|
| a) If you wanted to go to an evening meeting could you? | <input type="text"/> | (18) |
| b) How achieved? | <input type="text"/> <input type="text"/> | (19 - 20) |
| c) If spouse is substitute carer, ask: If you wanted to go with your spouse? | <input type="text"/> | (21) |
| | <input type="text"/> <input type="text"/> | (22 - 23) |
| d) If you wanted to go away for a weekend ? How achieved? | <input type="text"/> | (24) |
| | <input type="text"/> <input type="text"/> | (25 - 26) |
| e) Other source of substitute care not mentioned above | <input type="text"/> <input type="text"/> | (27 - 28) |

Answer Codes:

- | | |
|-------------------|---|
| Yes spontaneously | 1 |
| Yes with notice | 2 |
| Maybe/don't know | 3 |
| No | 4 |
| N/A | 5 |

How Achieved:

- | | |
|--------------------|----|
| Leave (name) alone | 1 |
| Take (name) | 2 |
| Spouse | 3 |
| In H/H | 4 |
| Out H/H relative | 5 |
| Other informal | 6 |
| Statutory | 7 |
| Paid | 8 |
| Voluntary | 9 |
| Other | 10 |
| N/A | 11 |

There are two main areas which I would like to go on to cover.

These are your views about services, and costs and consequences for you and your family of looking after (name) at home.

SECTION II - CONSEQUENCES AND COSTS

Ask if child living with Natural/Foster Parent

29. Does having(name) cause you to have to carry out any extra household tasks or make things more difficult for you.....? Does(name) make more work for you....? Is this a little more work or a lot.....?

	No	A Little	A Lot	N/A	
Cleaning and tidying the house	0	1	2	9	(29)
Decorating	0	1	2	9	(30)
Cooking and preparing meals	0	1	2	9	(31)
Washing (because of incontinence, destruction of clothes)	0	1	2	9	(32)
Shopping (because of difficulty looking after [name])	0	1	2	9	(33)
Other (Specify)	0	1	2	9	(34)

30. a) Who did the last time it was done?

Answer Codes are:

Mother	1
Father	2
Did jointly	3
Other household member	4
Other	5

Enter one of the above codes for each task below:

List of Tasks:

	M	F	J	H/H	0	
Shopping (main shop)	1	2	3	4	5	(35)
Ironing	1	2	3	4	5	(36)
Hoovering	1	2	3	4	5	(37)
Cooking	1	2	3	4	5	(38)
Washing Up	1	2	3	4	5	(39)
Washing	1	2	3	4	5	(40)
Cleaned the Kitchen	1	2	3	4	5	(41)

- b) Have you had to make any adaptations to the house?

If so, what?	Yes	1	(42)
	No	2	

- c) What was the cost of the adaptations?

£

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(43 - 46)

- e) Does(name) do any tasks around the house?

Yes	1	(47)
No	2	

31. Do you have to spend more on particular items because of
.....'s (name) behaviour or handicap?

	Yes Behaviour	Yes Handicap	No	
Laundry	1	2	3	(48)
Clothes	1	2	3	(49)
Transport	1	2	3	(50)
Bedding	1	2	3	(51)
Shoes	1	2	3	(52)
Furnishings	1	2	3	(53)
Fuel	1	2	3	(54)
Food	1	2	3	(55)
Aids	1	2	3	(56)
Other (specify)	1	2	3	(57)

32. Do you have a telephone?

(don't ask if you rang to make the appointment)

Yes	1	(58)
No	2	

33. Do you have a car?

Family has car	1	(59)
No car	2	

a) Are you able to use it if needed for (name)?

Can't drive	1	
Main user	2	
Can by arrangement	3	(60)
Weekends/evenings only	4	
No	5	

b) Are there any problems in taking (name)
in a car?

Yes	1	(61)
No	2	

c) If you are driving - alone? accompanied?

d) Are there any problems connected with 's
behaviour in using public transport?

No problems	1	
It can be difficult	2	(62)
Cannot do	3	

-17-

34.	Do you have a garden?	No	2	Ask (i)	(63)
		Yes	1	Ask (ii)	
(i) Is this a problem in relation to (name)?					
		Yes	1		(64)
		No	2		
(ii) In relation to (name) is garden of sufficient:					
a)	Size -	Yes	1		(65)
		No	2		
b)	Safety -	Yes	1		(66)
		No	2		
(iii) Do you have any difficulties with neighbours as a consequence of 's behaviour?					
		Yes	1		Transcribe (67)
		No	2		

3

(72)

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(73 - 75)

--	--

(76 - 77)

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(78 - 79)

4

(80)

FINANCIAL SUPPORT

Do you get any benefits provided to help families with a handicapped member?

	Yes	Refused	No	Applied For	
Attendance allowance (day and night)	1	2	3	4	(1)
Attendance allowance (day only)	1	2	3	4	(2)
Invalid care allowance	1	2	3	4	(3)
Mobility allowance	1	2	3	4	(4)
Severe disablement allowance	1	2	3	4	(5)
Supplementary benefit (for individual)	1	2	3	4	(6)

If anything refused discuss

When claimed? Why refused? Fair? Comments on process?

a) Is(name) able to handle his/her own money?

Transcribe

b) Have there ever been any problems within the family over how the money from benefits is spent?

Yes	.	.	.	1	(7)
No	.	.	.	2	

c) Do you have any worries about money or finances not connected with (name)?

Yes	.	.	.	1	(8)
No	.	.	.	2	

d) Household income?

(9)

would now like to ask whether looking after(name)
affected you or your husband's work (or ability to work) in any way?

IF FATHER IN WORK (FULL/PART-TIME)

37. What is your husband's occupation?

(10)

a) During the past year, has(name) affected his/her work in any way? For example, has he/she:

N/A	Yes	No but has in past	No
-----	-----	-----	-----

Caused him to take time off? . . . 0 1 2 3 (11)

Affected the number of hours he works (e.g. reduced overtime) . 0 1 2 3 (12)

Danger/loss of job 0 1 2 3 (13)

Caused a reduction in his earnings . 0 1 2 3 (14)

Caused him to change jobs . . . 0 1 2 3 (15)

Damaged his promotion prospects . 0 1 2 3 (16)

READ
OUT

If number of hours affected ask b)

b) Has he worked more hours or fewer hours as a result?

More	1
Fewer	2
N/A	0

(17)

38. If mother not in employment:

a) Has(name) affected your opportunities to take paid employment or not?

Would not wish to work	1
Employment status not influenced by (name)	2
Would otherwise seek part-time work	3
Would otherwise seek full-time work	4

(18)

b) What was (would be) your occupation?

(19)

If in Employment

39. What is your occupation?

(20)

a) Are you generally content to work the number of hours you do, OR would you prefer to work more hours OR fewer hours?

content with present hours	.	.	1
prefer to work more hours	.	.	2
prefer to work fewer hours	.	.	3
prefer not to work at all	.	.	4
N/A	.	.	0

(21)

b) During the past year, has(name) affected your work in any way? For example, has he/she:

	N/A	Yes	No but has in past	No
--	-----	-----	--------------------------	----

Caused you to take time off?	0	1	2	3
------------------------------	---	---	---	---

(22)

Affected the number of hours worked (e.g. reduced overtime)	0	1	2	3
---	---	---	---	---

(23)

Danger/loss of job	0	1	2	3
--------------------	---	---	---	---

(24)

Caused a reduction in earnings	0	1	2	3
--------------------------------	---	---	---	---

(25)

Caused you to change jobs	0	1	2	3
---------------------------	---	---	---	---

(26)

Damaged your promotion prospects	0	1	2	3
----------------------------------	---	---	---	---

(27)

Effects on other siblings if at home

40. a) Do you feel that the activities of the other children are in any way restricted by (name)?

Yes	.	.	.	1
No	.	.	.	2
N/A	.	.	.	0

(28)

IF YES

b) In what ways?

	Yes	No
--	-----	----

Study child disturbs their activities	.	.	1	2
---------------------------------------	---	---	---	---

(29)

Fewer outings/holidays	.	.	1	2
------------------------	---	---	---	---

(30)

Have to carry out extra duties	.	.	1	2
--------------------------------	---	---	---	---

(31)

Restriction on bringing friends home	.	.	1	2
--------------------------------------	---	---	---	---

(32)

Other (Specify)	.	.	1	2
-----------------	---	---	---	---

(33)

41. If siblings not at home

42. a) Do you (or your husband) ever have to get up during the night to attend to(name)?

Yes	1	(35)
No	2 ---->skip to next Qu.	

IF YES

(b) Does this happen every night of the week or just some nights?

Not disturbed	1	(36)
Some nights	2	
Most nights	3	
Every night	4	

(c) Who deals with any problems at night?
(Code as for Supervision)

(37)

(d) Do you (and your husband) feel you get enough sleep because of(name)?

	Respondent	Husband	
Yes	1	1	(38 - 39)
No	2	2	
Varies	3	3	
Don't know	4	4	

43. a) Have you or your husband consulted your G.P. because of any illnesses during the last 4 weeks? (I mean a consultation on your own behalf either in person or by telephone).

	WIFE	HUSBAND	
Yes	1	1	(40 - 41)
No	2	2	
N/A	0	0	

b) How often have you and your husband consulted your G.P. during the last year? (I mean a consultation on your own behalf).

WIFE

Number of consultations
in last year

(42 - 43)

HUSBAND

Number of consultations
in last year

(44 - 45)

N/A = 99

c) And have you or your husband had to go to hospital as an in-patient in the last year?

	WIFE	HUSBAND
Yes . . .	1	1
No . . .	2	2
N/A . . .	0	0

(46 - 47)

d) What was this for?

e) Have you or your husband been to a hospital as an out-patient in the last year?

	WIFE	HUSBAND
Yes . . .	1	1
No . . .	2	2
N/A . . .	0	0

(48 - 49)

44. a) Over the last 12 months, have you (or your husband) ever had to take any of the following?

Read out items in grid below and code whether taken.
For each one taken, ask:

b) Is this often OR only just now and then?

Code response in grid

	WIFE	
Tablets for your nerves including tranquillisers and anti-depressants	No 1 Rarely 2 Often 3 N/A 0	(50)
Sleeping tablets	No 1 Rarely 2 Often 3 N/A 0	(51)
	HUSBAND	
Tablets for your nerves including tranquillisers and anti-depressants	No 1 Rarely 2 Often 3 N/A 0	(52)
Sleeping tablets	No 1 Rarely 2 Often 3 N/A 0	(53)

45. a) Do you feel that looking after(name)
all these years affected **your** health, physically,
or in a mental or emotional sense?

No reported effect on health	1
Physical health only	2
Mental/emotional health only	3
Physical and mental/emotional health	4

(54)

b) Do you feel that looking after(name)
(all these years) affected your **husband's** health,
physically, or in a mental or emotional sense?

No reported effect on health	1
Physical health only	2
Mental/emotional health only	3
Physical and mental/emotional health	4

(55)

Transcribe if
detail given

SEVERE LIFE EVENTS

46. Ask only if respondent is child's Parent or Foster Parent

- i) I would now like to ask you a bit about other things which might have caused you problems or difficulties. During the past year have you or anyone in your household:

Read out and record each in turn

- 0 = No problem
1 = Mild problem
2 = Serious problem
9 = N/A

DO NOT CODE
SAME EVENT
TWICE

- a) had a serious accident or illness or been in hospital? ☐ (56)
- b) had someone close to you die or fall seriously ill? ☐ (57)
- c) had serious marital difficulties or become separated/divorced from your husband? ☐ (58)
- d) Son or daughter leaving home? ☐ (59)
- e) had serious problems with children (not study child)? ☐ (60)
- f) had serious difficulties at work - become unemployed/made redundant/downgraded? ☐ (61)
- g) had difficulties with your husband's job - unemployment/redundancy? ☐ (62)
- h) moved house? ☐ (63)
- i) any other serious event or long-term difficulty which caused you distress (not related to study child) ☐ (64)

- ii) Is there someone you can confide in or talk frankly to if anything should worry or upset you about (name)?
- Yes . . . 1 (65)
No . . . 2

- iii) Anyone you confide in generally, someone you feel close to?
- Yes . . . 1 (66)
No . . . 2

4

(72)

(73 - 75)

(76 - 77)

(78 - 79)

4

(80)

SECTION III

47. Services

- a) Can I check which of the following services
(name) has used in the past
 12 months?

	No	Yes	
Day Care	2	1	(1)
Short-term residential	2	1	(2)
Family-based short-term care	2	1	(3)
Hospital	2	1	(4)
Other	2	1	(5)
Evening clubs	2	1	(6)
Minding, Sitting-in	2	1	(7)

- b) Have any of the following professional workers
 been involved with in the past 12
 months? If yes, have you spoken with them yourself
 about?

(Do not count contact about this survey only as yes)

	Met	Involved Not Met	D/K	No	
Social worker	1	2	3	4	(8)
ATC Manager/Instructor	1	2	3	4	(9)
Other Care worker (S.S.)	1	2	3	4	(10)
Community Nurse	1	2	3	4	(11)
Health Visitor	1	2	3	4	(12)
G.P.	1	2	3	4	(13)
Psychologist	1	2	3	4	(14)
Psychiatrist	1	2	3	4	(15)
Other Medical Specialist	1	2	3	4	(16)
Speech Therapist	1	2	3	4	(17)
Occupational Therapist	1	2	3	4	(18)
Privately paid helper	1	2	3	4	(19)
Housing Officer	1	2	3	4	(20)
D.H.S.S. visitor	1	2	3	4	(21)
Other (specify)	1	2	3	4	(22)

If yes, sources:

365

S.S.D.	1	(44)
N.H.S.	1	(45)
Voluntary organisation	1	(46)
Education	1	(47)
Privately paid	1	(48)
Informal help	1	(49)
Other	1	(50)

c) When did you last discuss with anyone who works with him/her during the day? (Apart from escorts on transport)

Within past week	1	
Within past month	2	(51)
D/K C/R	3	

OR months ago (52 - 53)

50. a) Is transport provided to day care?

Yes	1	(54)
No	2	

IF YES:

b) Can you rely on it arriving on time?

Yes	1	(55)
No	2	

Maximum wait in past two weeks:

minutes (56 - 57)

c) Has transport failed to arrive at any time in the past 12 months?

Yes	1	(58)
No	2	

d) If yes in past year, how long is it since the last time this happened?

months (59 - 60)

e) Any other problems regarding transport?

Yes	1	(61)
No	2	

Transcribe if Yes

51. a) Have you ever been asked to collect from day care services or been told s/he was being sent home early because of his/her behaviour?

Yes	1	(62)
No	2	

b) When was the last time this happened? months ago

(63 - 65)

c) Has ever been excluded from day care services for a period of time?

Yes 1
No 2

(66)

d) How long for? (maximum) When was the last time?

	Length	Ago
< One week .	1	1
1 to 4 weeks .	2	2
1 to 6 months .	3	3
6 to 12 months .	4	4
More than 1 year	5	5

(67 - 68)

e) Does (name) like going to?
How inferred?

Yes 1
No 2
Other 3

(69)

f) Do you think behaves differently in day care to the way s/he does at home?

Yes 1
No 2

(70)

g) If yes, how? why?

Transcribe

5

4

(72)

(73 - 75)

(76 - 77)

(78 - 79)

(80)

52. Are there any special arrangements made for (name)
within day services? (e.g. special unit, extra staff, etc.)

Yes . . . 1
No . . . 2

(1)

Day Care
Ratings (1 - 4)

Most Frequently used Source

Preferred Source

Reliability	<input type="text"/>	(2)	Reliability	<input type="text"/>	(6)
Sufficiency	<input type="text"/>	(3)	Sufficiency	<input type="text"/>	(7)
Suitability	<input type="text"/>	(4)	Suitability	<input type="text"/>	(8)
Helpfulness	<input type="text"/>	(5)	Helpfulness	<input type="text"/>	(9)

Preferred option is:

53. Short-term Residential Care

Include care overnight in own home while parents are away.
Exclude hospital care for illness.

Nights per year

Form of Service

Provider	Service Facility	Family Placement	Minding	Other	
S.S.D.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(10 - 17)
N.H.S.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(18 - 25)
Voluntary	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(26 - 33)
Education	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(34 - 41)
Private	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(42 - 49)
Other	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(50 - 57)
Informal	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	(58 - 65)

(infer nights per year from existing regular pattern
OR if no existing pattern, actual nights in past year)
Specific probe on informal overnight care.

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6				4
(72)	(73 - 75)	(76 - 77)	(78 - 79)	(80)

Most recent instance (of residential care outside the home)

a) Length of stay . nights (1 - 2)

months ago (3 - 4)

b) If none, why not?

c) Have you met (any of) the staff who looked after
.....(name)?

Yes 1 (5)
No 2

d) After(name) came home (or on collecting
him/her) did you have any discussions with staff about
his/her stay?

No 1 Ask (i) (6)
Yes < 5 minutes 2)
Yes < 30 minutes 3) Ask (ii)
Yes > 30 minutes 4)

(i) Would you have liked to? Yes 1 (7)
Not bothered 2

(ii) Would you have liked more? Yes 1 (8)
Not bothered 2

e) After(name) came back from residential
care did you notice any changes in his/her behaviour?

Yes better 1 (9)
Yes worse 2
Yes different 3
No 4

5. Short-term/long-term

Transcribe

a) What changes

b) Do you know whether(name) liked the stay
or not?
How inferred?

c) What do you/did you do while(name) was away?

d) What did you feel while(name) was away?

e) Do you expect that s/he will go again?

f) Do you think behaves differently in
residential care to the way s/he does at home?

g) Has time spent in residential care caused any
difficulties in relation to any benefits which you

370

- b) Have you approached anyone from services yourself in the past three months to try and sort out particular problems relating to? (i.e. instances where the parent has initiated contact)

Yes . . . 1
No . . . 2

(24)

What problems? Who approached? Outcome?

If no, in the past twelve months? Most recent approach.

Transcribe

- c) Have they approached you about anything? Who? What? Outcome? (most recent)

Yes . . . 1
No . . . 2

(25)

- d) If you (and your husband) want to ask for help or advice about is there any particular person you would go to in the first instance?

No . . . 1
Family . . . 2
Stat . . . 3
Voluntary . . . 4
Others . . . 5

(26)

57. Other Service Ratings

	Social Worker	Community Nurse	Other Professional
Reliability	<input type="text"/>	<input type="text"/>	<input type="text"/>
Sufficiency	<input type="text"/>	<input type="text"/>	<input type="text"/>
Suitability	<input type="text"/>	<input type="text"/>	<input type="text"/>
Helpfulness	<input type="text"/>	<input type="text"/>	<input type="text"/>

(27 - 28)

(30 - 31)

(33 - 34)

(36 - 37)

- a) How confident do you feel that something will be done to help if you approach services with a problem?

SHOW CARD

(39)

- b) Is there any service or professional worker that you find particularly helpful or useful?

Transcribe

Yes . . . 1
No . . . 2

(40)

Who? What? Why? In what way?

- c) Looking back, is there a service or a professional worker that you thought was particularly helpful or useful in the past?

Who? How?

- d) Is there any service or professional that you have found particularly unhelpful? (past or present)

Who? In what way?

- e) Do you ever feel that professionals see you as responsible for his/her problem behaviour?

- f) Generally, how would you compare the services now with those you have received in the past? In particular services now, with those when the child was of school age.

- g) Did you play any part in discussions of what would happen to your child after leaving school? Were any choices suggested?

- h) How important is it to you that should attend services which will mean that s/he is integrated with individuals who do not have mental handicap?

- i) How important was it to you in the past?

-
58. a) Has (name) stayed away from home for longer periods in the past, for example, in a residential school, or hospital?

Transcribe

- b) Has any attempt to settle (name) away from home been made in the past?

- c) In the longer term have you considered the idea of living permanently away from home?

Have you discussed this with:

- (1) Family
- (2) Professional workers
- (3)(name) (if feasible)

- d) Is there any service you have used so far which seems to you a possible future suitable place for to live permanently?

- e) Idea of what would be the ideal kind of service.

- f) Have any specific plans been made?

- g) How do you see things going on in future?

- h) Is there any one particular change which you feel would make a substantial (positive) difference to your situation?

i) Is there anything else you would like to say, or that you think we should ask other parents?

Judson Score (wife)

(41 - 43)

Malaise (wife)

(44 - 45)

Judson Score (husband)

(46 - 48)

Malaise (husband)

(49 - 50)

 7

(72)

(73 - 75)

(76 - 77)

(78 - 79)

 4

(80)

Family Composition (continued from page 1)

Card 8

Relationship					In H/H?		Sex		Age	Married				Work Status (in H/H only)								
M	F	S	O	N	Y	N	M	F	Yrs	M	S	W	D	FT	PT	U/R	RET	ED	HW	SK	OTH	
1	2	3	4	5	1	2	1	2			1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2			1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2			1	2	3	4	1	2	3	4	5	6	7	8
1	2	3	4	5	1	2	1	2			1	2	3	4	1	2	3	4	5	6	7	8

(1 - 7)

(8 - 14)

(15 - 21)

(22 - 28)

 8

(72)

(73 - 75)

(76 - 77)

(78 - 79)

 4

(80)

Appendix 4

Show Card for Health Problems Mentioned by Parents

HEALTH PROBLEMS MENTIONED BY PARENTS

- | | |
|----------------------------------|--|
| 1 Angina | 11 Insomnia |
| 2 Anxiety attacks | 12 Joint Problems |
| 3 Anxious/Tense/Irritable | 13 Nervous Breakdown |
| 4 Arthritis | 14 Run down (susceptible to
infections) |
| 5 Back Problems | 15 Stomach Problems |
| 6 Chest Pains | 16 Stroke |
| 7 Depression/weeping | 17 Thrombosis |
| 8 Heart Attack | 18 Tired/distracted |
| 9 High Blood Pressure | 19 Ulcer |
| 10 Injury (by your son/daughter) | 20 Other please tell us what |

Appendix 5

Parent Interview - for families where son or daughter was no longer at home (1995)

HESTER ADRIAN RESEARCH CENTRE

District

--	--

(1-2)

Reference

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(3-5)

Line 1

SECTION 1

Structured information - question form optional

1. Family Composition (Respondent first)

Include all people in household and all siblings of the individual but not the individual.

	Relationship					In H/H?		Sex		Age	Married				Work Status (in H/H only)								
	M	F	S	O	N	Y	N	M	F	Yrs	M	S	W	D	FT	PT	U/R	RET	ED	HW	SK	OTH	
M	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(6-12)
F	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(13-19)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(20-26)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(27-33)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(34-40)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(41-47)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(48-54)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(55-61)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(62-68)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(69-75)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(76-82)
	1	2	3	4	5	1	2	1	2	___	1	2	3	4	1	2	3	4	5	6	7	8	(83-89)

Data prep - repeat codes in columns 92-97 on all lines

0	1
---	---

(90-91)

--	--	--

(92-94)

--	--	--

(95-97)

Mother figure is:**Father figure is:**Line 2³⁷⁷

Natural Mother 1
 Adoptive Mother 2
 Stepmother 3
 Foster Mother 4
 Partner 5
 Absent 6
 Other (specify) 7
 Deceased 8
 (1)

Natural Father 1
 Adoptive Father 2
 Stepfather 3
 Foster Father 4
 Partner 5
 Absent 6
 Other (specify) 7
 Deceased 8
 (2)

If Father absent, does he have any contact with?

Yes, regular 1
 Yes, occasional 2 (3)
 No 3

If YES, how often?

(How long since Father's departure? (4-5)

If a parent is deceased.....

How long widowed? (6-7)

2. Is this your own house or is it rented?

Own 1
 Rented [Council or H.A.] 2
 [Private] 3 (8)
 Relatives house 4
 Other (specify) 5

How long here (in years) (9-10)

3. Ethnic Origin

Asian (Indian) 1
 Asian (Pakistani) 2
 Asian (Bangladeshi) 3
 Asian (East African) 4
 Asian (Chinese) 5
 Asian (Other) 6 (11-12)
 Black (Caribbean) 7
 Black (African) 8
 Black (Other) 9
 White (please specify) 10

 Some other group (please specify) 11

4. For the person with learning disability is the household (usually)?:

Main place of residence (4 nights or more a week)	1	
Regular residence (1-3 nights a week)	2	(13)
Secondary residence (less than one night a week)	3	

Information about Person

1. Do you know how 's learning disability was caused. Has s/he been diagnosed as having a known syndrome or condition?

.....

--	--

(14-15)

.....

2. Has been diagnosed as having any psychiatric condition?

Don't know	1	
No	2	
Schizophrenia	3	
Unclassified psychiatric disorder	4	(16)
Depressive illness	5	
Other affective disorder	6	
Neurosis	7	
Other (please specify)	8	

3. Mobility

No difficulty walking	1	
Walks without aid but with some difficulty	2	
Walks with aids (or mobile in wheelchair) indoors and out	3	(17)
Unable to walk but can get around indoors	4	
Gets around with human aid only	5	
Immobile	6	

4. Is s/he physically fit?

Strong?	Yes	1	
Stronger than you?	No	2	(18)

5. Vision

Normal	1	
Poor	2	
Blind	3	(19)
Not sure/difficult to say	4	

6. Hearing

Normal	1	
Poor	2	
Deaf	3	(20)
Not sure/difficult to say	4	

7a. Does suffer from fits?

Unsure	0	
No (no medication, no seizures)	1	
No (controlled by medication)	2	
Occasional seizures (less often than monthly)	3	(21)
One or more major seizures per month	4	

7b. What type of epilepsy does s/he have?

.....

--	--

(22-23)

7c. If answer 2, 3 or 4

Does see a consultant to review his/her medication?

Yes, 4 times a year or more	1	
Yes, twice a year	2	
Yes, yearly	3	(24)
Yes, but less than yearly	4	
No	5	

If 4,

When was s/he last seen?

--	--

months ago

(25-26)

8. What medication is currently taking?

9. Language*Communicative use of Speech and Gestures*

Communicates regularly using varied phrases or sentences	1	
Only uses a few words, sounds/gestures as communication	2	(61)
Little or no communication	3	

10. Understanding communication (ring the *highest* number which applies only)

Understands information about things outside own immediate experience (eg stories or accounts of other people's experiences)	1	
Understands comments, questions and instructions related to personal needs and experiences (eg did you enjoy the trip to the zoo?)	2	
Understands a fair range of instructions or questions related to practical needs	3	(62)
Understands a few simple commands (e.g. come here, sit down)	4	
Understands little or nothing	5	

11. Understanding of speech by others

Clear enough to be understood by anyone	1	
Can be understood by close acquaintances but difficult for strangers	2	(63)
Difficult for acquaintances, impossible for strangers	3	
Not enough speech to rate	4	

12a. Continence

Usually fully continent	1	
Sometimes incontinent but less often than once a week	2	
Incontinent (soiling or wetting) once a week or more	3	(64)
Doubly incontinent	4	

If 2 or 3,

12b. Does s/he show deliberate incontinence: that is, wilful urination or defecation in inappropriate places?

Never	1	
Don't know, not sure	2	
Yes, isolated occasions	3	(65)
Yes	4	

13. Self care skills

Does s/he perform the following tasks?

a) Feeding

Usually does so independently	1	
Physically capable but sometimes needs supervision	2	
With some assistance	3	(66)
Completely dependent on others	4	

b) Washing

Usually does so independently	1	
Physically capable but sometimes needs supervision	2	
With some assistance	3	(67)
Completely dependent on others	4	

c) Dressing

Usually does so independently	1	
Physically capable but sometimes needs supervision	2	
With some assistance	3	(68)
Completely dependent on others	4	

15. Occupying Self

Occupies self constructively or can easily be occupied constructively	1	
Does not occupy self constructively, but cooperates in constructive activities	2	(69)
Hard to keep occupied constructively, may need one-to-one attention to keep occupied	3	
Never, or hardly ever, possible to keep occupied constructively	4	

16. Can use money?

Could go shopping and check change	1	
Can use money, but not check change	2	(70)
Realises money has value but does not use money	3	
Has no idea that money has value	4	

17a. Is able to go out alone?

Yes	1	(71)
No	2	

If so,

17b. *Does this create any problems?*

Yes
No

1
2

(72)

If yes, in what way?

--	--

(73-74)

18. **Sociability?**

What sort of young person is ?

(PROMPT if needed - outgoing? loner? likes own company?)

Has s/he changed in the last 4/5 years?

--	--

(75-76)

How well does s/he get on with other people?

--	--

(77-78)

0	3
----------	----------

(90-91)

Present Home

Line 4

I would now like to ask you about 's new home.

1a) Where is living now?

(1-3)

1b) Since when? __ / __ / __

months

(4-6)

1c) What sort of place is it?

Sheltered flat/house (Independent living less
than 24 hours staff cover)

1

Relatives home (or relatives move into own home)

2

Leave own home for (run by Mencap/SSD etc)

3

Small staffed house/bungalow/flat (2-5)

4

(7)

Larger staffed house/small hostel (6-10)

5

Larger hostel with grounds (10+)

6

Somewhere that includes work (Home Farm Trust type)

7

Other (specify)

8

1d) How far from home?

Near family home

1

(8)

Further away

2

1e) What sort of Day Service Provision is there for?

Transcribe

i) Same as when living at home

1

Provided on site - describe

2

ATC near 's home

3

(9)

College

4

Other - describe

5

ii) Suitable?

In what way?

(10)

iii) Sufficient?

Preferences?

(11)

1f) Is able to come home for visits?

)

How often?

)

Problems?

)

Transport?

)

Transcribe

1g) What are the arrangements for you to visit there?

Transcribe

Problems?

)

Transport?

)

Ask general questions (pink)

2a) **Has lived there all the time since moving from home?**

Yes	1 (ask Q4)	(12)
No	2	

If not,

2b) *How many other places has s/he lived?*

--	--

 (13-14)

3a) **How long is it since first moved from home?**

--	--	--

 months (15-17)

3b) **Where did move to at that time?**

Name

3c) *What sort of place was that?*

--

 (18)

3d) *How long did s/he live there?*

--	--

 months (19-20)

The Move

4a) **Why did move from home at that time?**

Behaviour? Crisis? Availability of place?

Transcribe

Behaviour/circumstances prior to move

Incidents specifically causing move

4b) *Who did you talk to about the move?*

The (immediate) family	Yes	1	(21)
	No	2	

The (extended) family	Yes	1	(22)
	No	2	

<i>Were you able to talk to about it?</i>			
	Yes	1	(23)
	No	2	
	Can't	3	

<i>Which professional workers did you see?</i>	<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>							(24-25) (26-27) (28-29)

4c) **Was there any professional worker or service that you found particularly helpful at this time?**

Yes
No

1
2

(30)

Who?
In what way?

Transcribe

(31-32)
(33-34)

4d) **How was the move done?**

Transcribe

Gradually - plenty of short stays first to get used to the place 1
More rapidly - a few short stays before the final move 2
Sudden move - no time for preparation 3
Crisis or other reason.

(35)

4e) **How did react to the move?**

What was like around this time?
Did behaviour change?
Before? During the transition (if there was one)?

4f) **How did you feel at that time?**

Transcribe

When the decision was made?
During the transition?

If only residence go to next section Q9

If not only residence

4g) **Why did s/he move?**

Problems?

5a) **Where did go to from there?**

Name

(If same as present address go to next section Q9)

5b) *What sort of place was that?*

(36)

5c) *How long did s/he live there?*

months

(37-38)

5d) *Did settle easily?*

5e) *Why did s/he move?*

*Problems?***Transcribe**

6a) **Where did go to from there?**

Name

(If same as present address go to next section Q9)

6b) *What sort of place was that?*
☐

(39)

6c) *How long did s/he live there?*
☐

months

(40-41)

6d) *Did settle easily?*6e) *Why did s/he move?**Problems?***Transcribe**7a) **Where did go to from there?**

Name

(If same as present address go to next section Q9)

7b) *What sort of place was that?*
☐

(42)

7c) *How long did s/he live there?*
☐

months

(43-44)

7d) *Did settle easily?*7e) *Why did s/he move?**Problems?***Transcribe**8a) **Where did go to from there?**

Name

(If same as present address go to next section Q9)

8b) *What sort of place was that?*
☐

(45)

8c) *How long did s/he live there?*
☐

months

(46-47)

8d) *Did settle easily?*8e) *Why did s/he move?**Problems?***Transcribe****Satisfaction with new home**9a) **How happy are you that has now got the kind of placement that you and s/he wanted?**

Just what we wanted

1

Close to what we wanted

2

(48)

Some of what we wanted

3

Not what we wanted

4

9b) **How much do you think your views were taken into account when the decision on where should live was made?**

Fully	1	
Partially	2	(49)
Not at all	3	

9c) *Were you able to choose the place?*

Yes	1	(50)
No	2	

10a) **How do you think that feels in general about his/her new home?**

Transcribe

10b) *Are there any problems now?* (Ask behaviour questions - blue)

11a) **How suitable do you think this home is for?**

Definitely meets needs	1	
To some extent meets needs	2	
Doesn't really meet needs	3	(51)
Doesn't meet needs at all	4	

11b) *In what way?* (Ask service package questions - yellow)

Effects on Parents life

12) **How do you feel now -**

About? *About being away?* *About your life?* **Transcribe**

What are the changes you have noticed in your own situation?

Work? *Financial?* (ask occupation - green)

Social?

Are there things that you do now that you could not do when was living here?

Health? - (ask health section - white)

13) **Is there anything else you would like to say, or that you think we should ask other parents?**

Transcribe

Thank you very much for taking part in this study

Person still living at home?	Yes	1	
	No	2	(52)
	Deceased	3	

GENERAL

1. Do you have a telephone?

(Don't ask if you rang to make the appointment)

Yes	1	(53)
No	2	

2. Do you have a car?

Family has a car	1	(54)
No car	2	

2a) Are you able to use it if needed for (name)?

Can't drive	1	
Main user	2	(55)
Can by arrangement	3	
Weekends/evenings only	4	
No	5	

2b) Are there any problems in taking(name) in a car?

Yes	1	(56)
No	2	

2c) If you drive - Can you do so

Alone?	Yes	1	
	No	2	(57)
Accompanied?	Yes	1	
	No	2	

2d) Are there any problems connected with's behaviour in using public transport?

Cannot do	1	
It can be difficult	2	(58)
No problems	3	

BEHAVIOUR

We were wondering whether shows any behaviour that staff find difficult at his/her new home. For example

A Aggressive Behaviour

1a) Do you know if s/he is ever physically aggressive towards staff or other residents living there?

Yes	1	(59)
No	2	
Don't know	3	

1b) Does s/he ever cause physical injury to anyone in any other way as a consequence of his/her behaviour? For example, by grabbing them tightly when agitated, or by throwing objects at people?

Yes	1	(60)
No	2 - go to next section	
Don't know	3	

2a) If YES (to either) In what way? Does s/he

	Yes	No	
Hits, kicks, slaps or head butts	1	2	(61)
Hits with objects eg cups, books, rams with wheelchair	1	2	(62)
Bites, pulls hair, scratches or pinches	1	2	(63)
Verbally abusive	1	2	(64)
Other (specify)	1	2	(65)

2b) Is this aggression

Intentional	1	
Incidental	2	(66)
Both	3	

3) How often?

All or most of the time	1	
Once or more a day	2	
Once or more a week	3	(67)
Once a month or more	4	
Once every 6 months or so	5	
About once a year	6	

4) Does the behaviour come and go in phases or is it fairly consistent?

Phases	1	
Consistent	2	(68)
Both	3	

5) *Does cause injury or become aggressive when s/he is*

Upset?	1	
Bored or unoccupied?	2	(69)
Both?	3	
Other (specify)?	4	

6) *Usual form of attack?*

Brief episodes	1	
Sustained attacks	2	(70)
Either	3	

7) *Who is the aggression directed to most often?*

Staff	1	
Residents	2	(71)
Other (specify)	3	

8) *What are the consequences of the attacks in terms of injury?*

	<u>Usual</u>	<u>Most Serious</u>
None	1	1
Minor injury (eg bruises) not sufficient to impair functioning for more than a few minutes	2	2
Between minor and serious	3	3
Serious injury (eg broken bones stab wounds: requiring treatment in hospital)	4	4
	(72)	(73)

0	4
---	---

(90-91)

B Destructive Behaviour

Line 5

1) Do you know if s/he breaks, destroys or damages things as a consequence of his/her behaviour? (Includes accidental/clumsy)

Yes	1	(1)
No	2 - go to next section	
Don't know	3	

2) Type of damage?

	Yes	No	
Own property	1	2	(2)
Staff's personal property	1	2	(3)
Resident's personal property	1	2	(4)
Small household objects	1	2	(5)
Damage to furniture	1	2	(6)
Damage to fabric of building	1	2	(7)
Other (specify)	1	2	(8)

3) Is this damage

Intentional?	1	
Incidental	2	(9)
Both	3	

4) Does cause damage when s/he is

Upset?	1	
Bored or unoccupied?	2	(10)
Both?	3	
Other? (specify)	4	

5) How often?

All or most of the time	1	
Once or more a day	2	
Once or more a week	3	(11)
Once a month or more	4	
Once every 6 months or so	5	
About once a year	6	

C Self Injury

1) Do you know if s/he injures, or attempts to injure, her/himself?

Yes	1	(12)
No	2 - go to next section	
Don't know	3	

2) In what way? Does s/he

	Yes	No	
Self-biting pinching or scratching	1	2	(13)
Hitting self	1	2	(14)
Hair pulling,	1	2	(15)
Pulling hair out	1	2	(16)
Finger or hand mouthing	1	2	(17)
Other (specify)	1	2	(18)

3) How frequently does any form of self-injurious behaviour occur?

All or most of the time	1	
Once or more a day	2	
Once or more a week	3	(19)
Once a month or more	4	
Once every 6 months or so	5	
About once a year	6	

4) Does the behaviour come and go in phases or is it fairly consistent?

Phases	1	(20)
Consistent	2	
Both	3	

5) Does self-injure when s/he is

Upset?	1	(21)
Bored or unoccupied	2	
Both	3	
Other (specify)	4	

6) What are the consequences of this behaviour?:

	<u>Usual</u>	<u>Most Serious</u>
No physical injury	1	1
Minor tissue damage	2	2
In between minor and life threatening	3	3
Life threatening injury or permanent impairment	4	4
	(22)	(23)

D Other Difficult Behaviours

1) Do you know of any other behaviour/habit that staff or other residents find difficult to live with or handle? (Examples if needed, pestering, overactivity, stripping, making noises/faces).

Yes	1	(24)
No	2 - go to next section	
Don't know	3	

2) What does s/he do?

	Yes	No	
Refuses to cooperate, sits down and won't move etc.	1	2	(25)
Temper tantrums	1	2	(26)
Stealing	1	2	(27)
Stripping	1	2	(28)
Wandering, running away	1	2	(29)
Overactivity	1	2	(30)
Interferes with activities of others	1	2	(31)
Pestering	1	2	(32)
Smearing faeces	1	2	(33)
Making noises	1	2	(34)
Pulling faces	1	2	(35)
Messy behaviours, splashing water, emptying drawers etc	1	2	(36)
Dangerous activities	1	2	(37)
Unacceptable sexual behaviour (specify)	1	2	(38)
Other (specify)	1	2	(39)

3) Does behave like this when s/he is

Upset?	1	
Bored or unoccupied?	2	(40)
Both?	3	
Other? (specify)	4	

4) How often does s/he do this?

All or most of the time	1	
Once or more a day	2	
Once or more a week	3	(41)
Once a month or more	4	
Once every 6 months or so	5	
About once a year	6	

5) Is physical injury or danger to

Usually or often a consequence	1	
Has happened at least once	2	(42)
Could be a consequence if not controlled	3	
Not a likely consequence	4	

Overall questions about challenging behaviour

Changes in Behaviour

1) Do you think that 's behaviour has changed substantially in the last 4 years

Yes	1	(43)
No	2	

2) Do you feel that on the whole 's behaviour has improved, stayed the same or gone worse?

Gone worse?	1 (ask i)	
Stayed the same/unsure	2	(44)
Improved	3 (ask ii)	
Changed	4 (ask i and ii)	

i) In what way

	Yes	No	
New behaviours present	1	2	(45)
Episodes are more frequent and longer	1	2	(46)
Episodes are more frequent	1	2	(47)
Episodes are longer	1	2	(48)
Other (specify)	1	2	(49)

ii) In what way

	Yes	No	
Behaviour no longer present	1	2	(50)
Episodes are less frequent and shorter	1	2	(51)
Episodes are less frequent	1	2	(52)
Episodes are shorter	1	2	(53)
Other (specify)	1	2	(54)

3) Is there one aspect of his/her behaviour that causes you most concern?

Yes	1	(55)
No	2	

What?

Why?

Transcribe

1a) Has an assessment of needs been done for?

- | | | |
|-------------------------|---|------|
| Yes, currently | 1 | |
| Yes, in last year | 2 | (56) |
| Yes, more than year ago | 3 | |
| No | 4 | |
| Don't know | 5 | |

1b) If no, is one planned?

- | | | |
|----------------------------------|---|------|
| Yes, definitely within next year | 1 | |
| Yes, no idea when | 2 | (57) |
| No | 3 | |
| Don't know | 4 | |

2a) Have you been to a case review meeting (that is a meeting with a number of professionals to discuss) in the past 12 months?

- | | | | |
|-----|---|----------|------|
| Yes | 1 | Ask (ii) | (58) |
| No | 2 | Ask (i) | |

i) If no, have you been to such a meeting in the last 4/5 years?

- | | | | |
|-----|---|----------|------|
| Yes | 1 | Ask (ii) | (59) |
| No | 2 | GO TO Q3 | |

ii) If yes, how long ago?

 years

(60-61)

 months

(62-63)

2b) Who was there? (SHOW CARD) Transcribe

(64-65)
(66-67)
(68-69)
(70-71)
(72-73)

2c) Where was the meeting held?

- | | | |
|----------------------|---|------|
| At ..'s home | 1 | |
| ATC/SEC/Day Centre | 2 | |
| School/College | 3 | (74) |
| Hospital | 4 | |
| Social Services Dept | 5 | |
| Other | 6 | |

PROBE What was meeting about? How did it go?

Transcribe

2d) *Did you feel that they wanted to hear your views?*

398

Yes	1	(75)
No	2	

2e) *Were you happy with the meeting overall?*

Very	1	
Quite	2	(76)
Not very	3	
Not at all	4	

0	5
---	---

 (90-91)

Line 6

3a) *Have you approached anyone from services yourself in the past twelve months to try and sort out particular problems relating to? (ie instances where the parent has initiated contact)*

Yes, in past 3 months	1	
Yes, in past 12 months	2	(1)
No - don't know who to ask	3	
No	4	

3b) *If yes, most recent approach*

Who approached?

(2-3)
(4-5)
(6-7)

3c) *Why?*

	Yes	No	
Benefits related	1	2	(8)
Aids for living	1	2	(9)
Services requested	1	2	(10)
Services query	1	2	(11)
Help with behaviour	1	2	(12)
Help with physical condition	1	2	(13)
Other (specify)	1	2	(14)

3d) *Were you happy with the outcome?*

Yes, very	1	
Yes, quite	2	(15)
Ongoing	3	
Not very	4	
Definitely not	5	

If 4 or 5 why?

Transcribe

4a) Have they approached you about anything?

399

Yes, last 3 months	1	(16)
Yes, last 12 months	2	
No	3	

4b) If yes, (most recent) Who approached you?

(17-18)
(19-20)
(21-22)

4c) Why?

	Yes	No	
Benefits related	1	2	(23)
Aids for living	1	2	(24)
Services requested	1	2	(25)
Services query	1	2	(26)
Help with behaviour	1	2	(27)
Help with physical condition	1	2	(28)
Other (specify)	1	2	(29)

4d) Were you happy with the outcome?

Yes, very	1	
Yes, quite	2	
Ongoing	3	(30)
Not very	4	
Definitely not	5	

If 4 or 5, Why?

Transcribe

5) If you (and your husband) want to ask for help or advice about
is there any particular person you would go to in the first instance?

Family	1	
Day service worker	2	
Social worker	3	(31)
Community nurse	4	
GP	5	
Voluntary	6	
Others (specify)	7	

OCCUPATIONAL/FINANCIAL

400

(COPY ANSWERS FROM SHEET)

1a) Would you give me an indication of your household income?
That is the total income^e coming into the house from all members
of the family (including - parents, siblings and others).

☐

(32)

1b) Do you have any worries about money or finances generally?

Yes
No

1
2

(33)

2a) What is (was) your occupation?

.....

☐

(34)

2b) What is (was) your husband's occupation?

.....

☐

(35)

Financial situation since left?

3) Overall do you feel that you are better off financially, worse off or about
the same now that lives away?

Better 1
Same 2
Worse 3

(36)

1a) How often have you and your husband consulted your GP during the last year? (I mean a consultation on your own behalf).

Wife

Number of consultations in last year (37-38)

Husband

Number of consultations in last year (39-40)

N/A = 99

1b) And, have you or your husband had to go to hospital as an in-patient in the last year?

	Wife	Husband
Yes	1	1
No	2	2
N/A	0	0
	(41)	(42)

1c) What was this for?

1d) Have you or your husband been to a hospital as an out-patient in the last year?

	Wife	Husband
Yes	1	1
No	2	2
N/A	0	0
	(43)	(44)

1e) What was this for?

2a) Over the last 12 months, have you (or your husband)
ever had to take any sleeping tablets or tablets for your nerves?

402

For each one taken, ask:

2b) Is this often OR only just now and then?

Code response in grid

		Wife		
Tablets for your nerves including tranquillisers and anti-depressants	No	1		
	Rarely	2		(45)
	Often	3		
	N/A	0		
Sleeping tablets	No	1		
	Rarely	2		(46)
	Often	3		
	N/A	0		
		Husband		
Tablets for your nerves including tranquillisers and anti-depressants	No	1		
	Rarely	2		(47)
	Often	3		
	N/A	0		
Sleeping tablets	No	1		
	Rarely	2		(48)
	Often	3		
	N/A	0		

3a) Do you feel that looking after (name) is affecting or has affected your health,
physically, or in a mental or emotional sense?

No reported effect on health	1	
Physical health only	2	(49)
Mental/emotional health only	3	
Physical and mental/emotional health	4	

3b) Do you feel that looking after (name) has affected your husband's health,
physically, or in a mental or emotional sense?

No reported effect on health	1	
Physical health only	2	(50)
Mental/emotional health only	3	
Physical and mental/emotional health	4	

3c) Cause of death (if appropriate) Mother ☐ (51)

Father ☐ (52)

0	6
---	---

 (90-91)

3d) When we have spoken to parents in the past they mentioned a range of different health problems that they suffered from at the moment or in the past. Have you or your husband/wife suffered any of these?

(SHOW CARD)

If yes, Do you think it was due to caring for?

	MOTHER					FATHER					
	Yes due care	Yes partly due care	Yes not due care	Yes D/K	No	Yes due care	Yes partly due care	Yes not due care	Yes D/K	No	
Angina	1	2	3	4	5	1	2	3	4	5	(1-2)
Anxiety Attacks	1	2	3	4	5	1	2	3	4	5	(3-4)
Anxious/Tense/Irritable	1	2	3	4	5	1	2	3	4	5	(5-6)
Arthritis	1	2	3	4	5	1	2	3	4	5	(7-8)
Back Problems	1	2	3	4	5	1	2	3	4	5	(9-10)
Chest Pains	1	2	3	4	5	1	2	3	4	5	(13-14)
Depression	1	2	3	4	5	1	2	3	4	5	(15-16)
Heart Attack	1	2	3	4	5	1	2	3	4	5	(17-18)
High Blood Pressure	1	2	3	4	5	1	2	3	4	5	(19-20)
Injury (by)	1	2	3	4	5	1	2	3	4	5	(21-22)
Insomnia	1	2	3	4	5	1	2	3	4	5	(23-24)
Joint problems	1	2	3	4	5	1	2	3	4	5	(25-26)
Nervous Breakdown	1	2	3	4	5	1	2	3	4	5	(27-28)
Run down (susceptible to infections)	1	2	3	4	5	1	2	3	4	5	(29-30)
Stomach Problems	1	2	3	4	5	1	2	3	4	5	(31-32)
Stroke	1	2	3	4	5	1	2	3	4	5	(33-34)
Thrombosis	1	2	3	4	5	1	2	3	4	5	(35-36)
Tired/Distracted	1	2	3	4	5	1	2	3	4	5	(37-38)
Ulcer	1	2	3	4	5	1	2	3	4	5	(39-40)
Otherplease tell us what	1	2	3	4	5	1	2	3	4	5	(41-42)

4a) Is there someone you can confide in or talk frankly
to if anything should worry or upset you about.....?

404

Yes	1	(41)
No	2	

4b) If yes, who do you talk to?

	Yes	No	
Spouse	1	2	(42)
Relative	1	2	(43)
Friend	1	2	(44)
Services	1	2	(45)
Social Worker	1	2	(46)
Community Nurse	1	2	(47)
GP	1	2	(48)
Other (specify)	1	2	(49)

4c) Is there anyone you confide in generally. Someone you feel close to?

Yes	1	(50)
No	2	

Give SF 36

Would you mind filling this in for me?
It is a measure of whether your health is
affecting the sorts of things you can do
in your everyday life.

It should only take 10 minutes to complete.

(SWITCH OFF TAPE)

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Appendix 6

The Malaise Inventory (Rutter et al, 1970)

For office
use only**PARENTAL HEALTH QUESTIONNAIRE**

Below is a list of general questions about your health. Can you read through these questions and circle either 'Yes' or 'No' for each one.

- | | | | |
|---|-----|----|------------|
| 1. Do you often have back-ache? | Yes | No | ----- (21) |
| 2. Do you feel tired most of the time? | Yes | No | ----- (22) |
| 3. Do you often feel miserable or depressed? | Yes | No | ----- (23) |
| 4. Do you often have bad headaches? | Yes | No | ----- (24) |
| 5. Do you often get worried about things? | Yes | No | ----- (25) |
| 6. Do you usually have great difficulty in falling asleep
or staying asleep? | Yes | No | ----- (26) |
| 7. Do you usually wake unnecessarily early in the morning? | Yes | No | ----- (27) |
| 8. Do you wear yourself out worrying about your health? | Yes | No | ----- (28) |
| 9. Do you often get into a violent rage? | Yes | No | ----- (29) |
| 10. Do people often annoy and irritate you? | Yes | No | ----- (30) |
| 11. Have you at times had a twitching of the face, head
or shoulders? | Yes | No | ----- (31) |
| 12. Do you often suddenly become scared for no good reason? | Yes | No | ----- (32) |
| 13. Are you scared to be alone when there are no friends near you? | Yes | No | ----- (33) |
| 14. Are you easily upset or irritated? | Yes | No | ----- (34) |
| 15. Are you frightened of going out alone or of meeting people? | Yes | No | ----- (35) |
| 16. Are you constantly keyed up and jittery? | Yes | No | ----- (36) |
| 17. Do you suffer from indigestion? | Yes | No | ----- (37) |
| 18. Do you often suffer from an upset stomach? | Yes | No | ----- (38) |
| 19. Is your appetite poor? | Yes | No | ----- (39) |
| 20. Does every little thing get on your nerves and wear you out? | Yes | No | ----- (40) |
| 21. Does your heart often race like mad? | Yes | No | ----- (41) |
| 22. Do you often have bad pains in your eyes? | Yes | No | ----- (42) |
| 23. Are you troubled with rheumatism or fibrositis? | Yes | No | ----- (43) |
| 24. Have you ever had a nervous breakdown? | Yes | No | ----- (44) |

☐ ☐ (45-1)