KING'S FUND CENTRE

JANE HUBERT

HOME-BOUND

Crisis in the care of young people with severe learning difficulties: a story of twenty families

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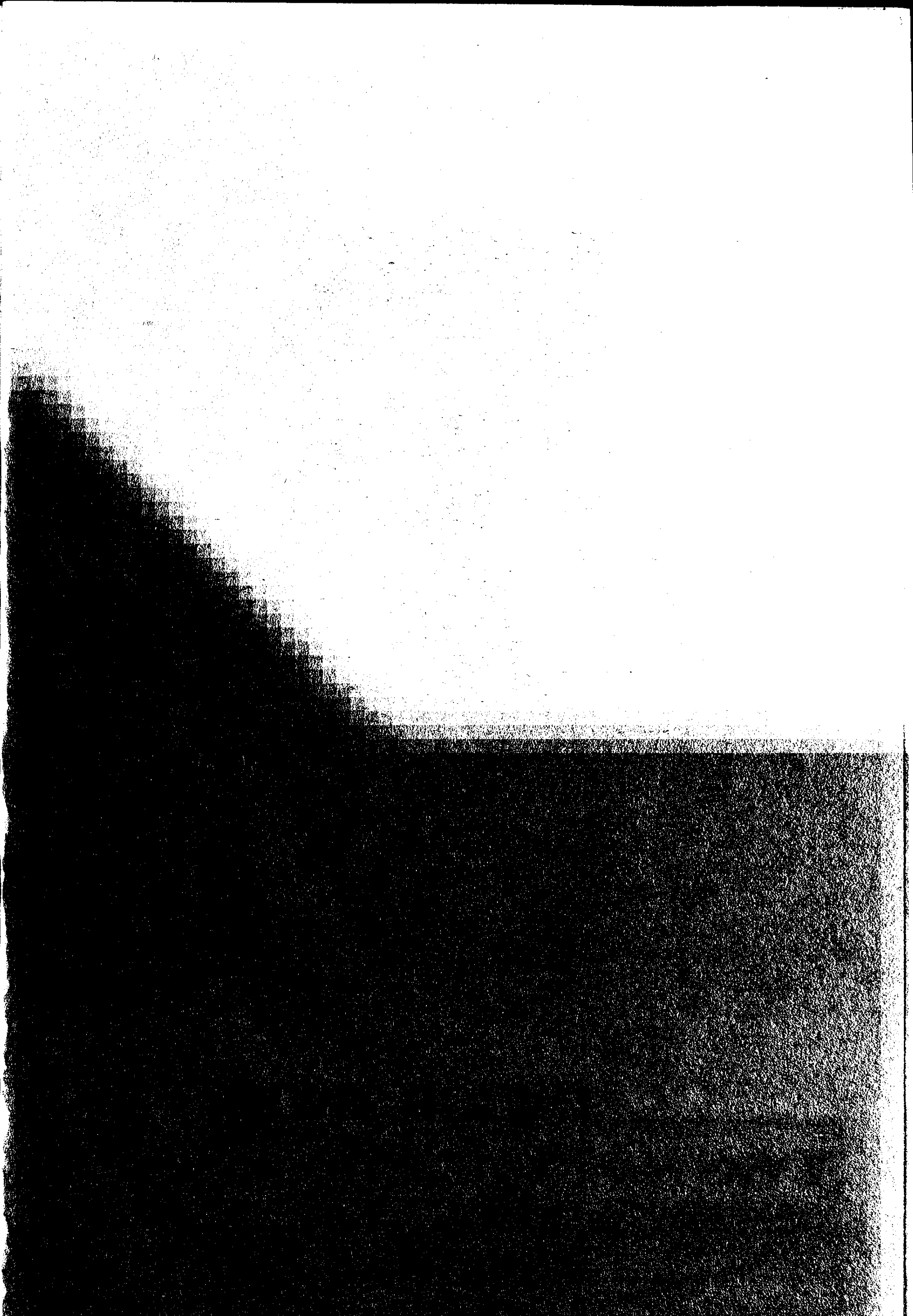

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

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Preface

The research project on which this book is based owes its existence to the experiences of one family. I joined a project, briefly, which involved spending long hours with this family, watching and filming their son, John, from the moment he awoke, through his life at home, at school and in his residential care unit until he finally fell asleep late in the evening. This was the Wain family, whose battles to keep their profoundly handicapped and self-injurious son John at home, in the face of what appeared to me to be insurmountable obstacles, made me want to find out if theirs was an isolated case, or whether, all over the country, other families faced similar problems in their attempts to obtain enough - and good enough - help and support from the local services. As a result I set up an intensive study of twenty families. This monograph is a small part of the stories these families have told me - other aspects will be covered in publications following this one.

The study was an attempt to understand the worlds of these families, and the difficulties and dilemmas they face in their relationships with the "outside" world. I visited them over a period of three years, documenting their experiences, attitudes and beliefs. I went into their houses full of my own stereotypes and expectations and found an unexpected and extraordinary world for which I was quite unprepared. I wanted to learn enough about the families to be able to describe their lives through their own eyes, not through those of the wider society. People outside such families do not usually see in the same way because there is no participation in this narrow but intense world. In many ways it is a foreign country, whose signals cannot be read without first learning the language.

In order to learn this language I visited the families many times, to carry out long, taped interviews with them, and also to participate in their daily life, in whatever ways they were prepared to share it with me. The interviews were unstructured, and covered all aspects of their lives, not only those directly concerned with their handicapped children. The strands of people's lives are too closely interwoven, and form a fabric whose pattern is too complex to be understood by analysing its single threads. As a social anthropologist I wanted to understand as much of this complex pattern as possible, not only by listening, but also by sharing the experiences of these families. Consequently, I have made many new friends, not only among the parents but also among the young people.

To a great extent this is a story about women. This is partly because the intense nature of the study inevitably meant that I, as a woman, developed close relationships with many of the mothers. Equally important, however, is the simple fact that it was the mothers who spent their lives at home caring for their handicapped sons and daughters.

Note

The texts of the case histories have been read and approved by the families involved. All names - of families and institutions - have been changed, and minor details altered throughout the text (and in the quotations) in order to preserve anonymity.

Characters and Places

Families

The Brown family: Helen, Eddy and Gary - Hamling area
The Morris family: Ella and Bryony - Hamling area
The Nicholls family: Jean, Ray and Craig - Hamling area
The Marsh family: Meg, Callum and Andy - Litchdean area
The White family: Bess, Jack and Ben - Hamling area

Residential Units

Hamling – Redelms (adult unit)
– Stafford House (adult unit)
– Hamblecot (children's unit)

Litchdean – Ashgrove House (adult unit)
– Darrow Hill (large mental handicap hospital which includes Hamling in its catchment area)

Health districts in the county

Deerminster (two families)
Gunnerton (three families)
Hamling (seven families)
Litchdean (five families)
Tramleigh (three families)

Acknowledgements

My greatest debt is, of course, to the twenty families who gave me so much time, hospitality and trust over the last few years. Neither the research nor this book would have existed without them. Nor could any of it have taken place without a generous grant from the Joseph Rowntree Memorial Trust, which has funded the project throughout. I am very grateful to the Trust, and to the members of my advisory group - Andy Alaszewski, Dorothy Atkinson, Roger Blunden, Jan Pahl, Peg Wain and Linda Ward (and also Jan Porterfield and Peter Wilcock during the initial stages of the project) - for their constant support and sound advice, and for their critical comments on various drafts of this book. I am also grateful to the professionals (who must remain anonymous) who made it possible to set up the project in the county concerned.

I am grateful to Lyn Ballard for her help and advice, and to Tom Forge, Caroline Ifeka and Rebecca Maher for

valuable comments on drafts of this manuscript. I especially thank Peter Ucko for his help, insight and constructive criticism throughout the project.

Introduction

This study is about twenty families who live in one county of Southern England. They vary in many ways - some consist of children with their own parents, others with their mother and step-father, and yet others with a widowed or divorced mother. However, all the families have one thing in common - there is, living among them, a teenager or young adult who has been classified by the professionals as "severely" or "profoundly" mentally handicapped, and who also has "serious behavioural problems" of some kind.

They are unusual families, because they are part of a tiny minority of parents who keep their severely mentally handicapped and very difficult children at home into adulthood. Throughout England, although only about half such children are in permanent care, a large proportion of those living at home will be in permanent care by the time they are adult - leaving less than a fifth of the total number at home with their families as adults.

The twenty teenagers and young adults in this study, aged from fifteen to twenty two years old, were initially identified by asking as many professionals as possible to put forward the names of those young people they considered were within the above categories. The names suggested by teachers in special schools, community nurses, social workers, psychiatrists, psychologists, residential care managers and others were carefully cross-checked with other professionals until some degree of consensus - often by no means complete - was reached.

In fact, there are considerable complexities involved in the above definitions and classifications. Professionals working in the local Social Services, Health Service and Special Education departments and schools have widely divergent opinions about some of the accepted categorisations, and at times even disagree about the same individuals. This lack of agreement is often not only about the degree of mental handicap, but sometimes also about the nature or extent - or even the existence - of behavioural problems such as aggression towards other people, self-injury, destructiveness or violent temper tantrums.

Such disagreements are partly because certain abilities and behaviour patterns may only manifest themselves in particular contexts. Young people who are intractable and demanding at home, for example, where they are used to getting what they want, may not show the same obstinacy at school, where they are expected to conform to certain rules of behaviour. It may, of course, work the other way round. In other cases the same behaviour patterns may be perceived and interpreted in very different ways, and what is seen by one person as a problem may not be by someone else. Thus, not only may the behaviour actually vary from one environment to another - and from one time to another - but even if such behaviour is the same everywhere, it may be classified differently by different people.

Whatever their "correct" designation, all the young people in this study have little or no speech and can do very little for themselves. The majority are incontinent, and most are subject to epileptic fits. Some are almost totally immobile, others highly mobile. Their "problem" behaviour, where it exists, consists of such things as punching, kicking, head-butting or scratching others; self-injury through head-banging or biting; kicking, chewing, grabbing or overturning furniture and objects, or of constant resistance to any suggested activity.

It is the parents of these young adults, especially the mothers, who understand them best. Whatever stereotypes society projects on to their children, they continue to talk to them, to watch and listen for almost imperceptible signs - and perceive them as communicative, social beings within their own shared social world.

It is the nature and meaning of these separate social worlds that must be understood before policies and service strategies can be successfully devised and put into practice for these young people and their families. Certainly, one of the most striking impressions, after three years of contact with some of these people, who are labelled as profoundly mentally handicapped, is the degree to which they are in fact able to communicate their needs and wishes to those people who know them well, and how much they actually appear to understand of what is happening around them. In a few cases it became clear that a physically very disabled young person, who at first sight seems hardly to react to the outside world, is in fact both aware and responsive. This realisation was both exciting and unnerving. It necessarily provokes that recurring nightmare - that some of those who can neither speak nor move in any controlled way, may merely be trapped inside their bodies, unable to make contact with the outside world.

The age span of the young people in this study includes two ages at which certain changes - totally external to events or developments within the families - take place. At sixteen they are transferred from children's services to adult services, and at nineteen they must leave school (a special school for children with "severe learning difficulties"). It had been thought that these would be important transitions in the lives of the families, transition times at which decisions about the future might be made, and this research set out specifically to discover the factors that influence such families in their decision whether or not to put their children into permanent care during these years. As it turned out, the ages of sixteen and nineteen did prove to be significant times, but ones which intensified rather than diminished these particular parents' determination to keep their young adult children at home.

The provision of services to mentally handicapped children is through the National Health Service, the Social Services Department and local authorities, and - until nineteen - the Education Department. If there is any further education or training beyond the age of nineteen this is supplied by an Adult Training Centre, run by the Social Services. All the young people in this study had attended school until the age of sixteen, and all but one have continued until nineteen, or are expected to do so. Of those who have left school, five attend Adult Training Centres (in Special Needs Units), five attend day centres, one attends both, on different days, and one is at home every day.

In the case of severely mentally handicapped young people who have special needs, the main responsibility is with the NHS. How this responsibility is interpreted and acted upon varies from one District Health Authority to another. In the county under study there are local Community Mental Handicap Teams in each health district. These give families access to a consultant psychiatrist specialising in mental handicap, a psychologist, a community mental handicap nurse and other professionals. The consultant psychiatrist has overall responsibility, particularly for the prescription and monitoring of drugs. The community mental handicap nurse visits the families at home - assessing problems, giving advice, making sure that doctors' appointments are kept, ensuring supplies of continence pads, liaising with other professionals, giving information about allowances, changes in benefits and so on, as well as giving advice and moral support in times of crisis. Families may also be assigned a social worker, but to a great extent their role will be to deal with familial problems not necessarily concerned with the disabled member of the family.

Despite all these support systems the twenty families, without exception, see their experiences to date as an uphill struggle, mainly because they have had to fight a constant battle to get adequate help and support from local health and social services. They feel that much of the help and support they have received has been disorganised, unreliable and thus far from adequate. At all levels, and in most contexts, these parents feel that they are fighting a battle which is all the harder because they know that the professionals they work with generally consider it to be a losing battle.

The day-to-day routine at home is necessarily very demanding, especially for mothers, and caring for the basic needs of a young adult - washing, dressing, toiletting and changing continence pads, feeding, carrying and so on - is extremely time-consuming. In many cases they must also attend to epileptic fits, wet beds and general wakefulness during the night. Other members of the family also need their attention, and any sort of crisis within the family - not necessarily related to the handicapped young adult - may upset a fine balance between managing or not managing to get through each day.

One of the most vital services, which often make it possible for parents to keep going, is the provision of regular periods of short term care in a residential unit. These NHS units are run by senior, qualified nurses, with a staff of trained and untrained care assistants. Access to short term residential care allows a disabled child or adult to spend brief periods away from home - perhaps a weekend every month or two months, or even a week a month. In addition they may go away for a week or two during the year, so that parents can have a holiday alone, or just spend time with their other children. Occasionally this care is provided in units which are specifically for people going in on a short term basis, but the majority of units are for long term residents, and contain a few beds for use by people living at home.

Only two of the families in this book do not, by choice, use any short term residential care facilities. One of these two young adults is also at home during the day - all the others are either at school or receive some form of day care for at least three days a week.

The following pages are concerned specifically with the parents' view of the nature and quality of the short term residential care available. It represents the experiences and perceptions of twenty families whose chief concern is the physical, emotional and intellectual well-being and happiness of their disabled children. There are, no doubt, alternative pictures which would be put forward by other people - by care staff, doctors, community nurses or any other professionals - but these are not the concern of this book.

Because this book is an account of the families' experiences much of it is told in parents' own words. Chapter 1 describes the experiences of two young adults (and their parents) who are officially classified as "severely mentally handicapped" and who are both very physically disabled. They represent a group who spend much of their time - at least when they are away from home - sitting in their wheelchairs. Chapter 2, on the other hand, describes the experiences of three young people who are very mobile, and whose violent behaviour results in quite different problems for them. Many of the young adults in the study fall somewhere between these two extremes, and their experiences tend to be a mixture of those that are recounted in the five case histories. In Chapter 3, many of the points which have been raised by the five case histories in the previous chapters are brought out for further examination and discussion. These are dealt with under several main themes: the quality of care - in terms of physical, intellectual and emotional care; problems involved in the transition from children's to adult care; vulnerability to accidents and injuries; the prescription, administration and effect of drugs; the effects of staff shortages and lack of training; the reliability of the short term care service and the specific problems related to severe behavioural problems. All of these themes are also relevant to the other fifteen families which form the basis of this book.

Finally, specific recommendations are made which would, if implemented, ensure a service that would come a long way towards being acceptable to parents as a short term alternative to home.

1

Vulnerable and Invisible

Many of the problems that families experience in connection with short term residential care are common to all of them.

The case histories that follow in this chapter illustrate these, and also focus on some of the specific difficulties and anxieties faced by parents of those young handicapped people who are less mobile, constantly unwell and subject - in spite of medication - to frequent epileptic fits. In a short term care situation these people are often unable to protect themselves from the vagaries of those around them, and since they cannot draw attention to themselves easily, they may become almost "invisible" to other people, and through this invisibility may be forgotten and neglected in a crowded and noisy environment.

GARY BROWN

One of these is twenty-year-old Gary Brown. His younger brother has already left home but he is still there with his parents and ten-year-old sister. He has no speech and cannot dress, wash or toilet himself. He usually wears a continence pad, although his mother, Helen, takes him to the lavatory frequently - not, she says, because she minds changing him, but because she feels that he does not like to wet himself. She responds quickly to the signals that he gives - perceptible even to people who know him less well - when he wants to go. However, he is becoming increasingly disabled, and his epileptic fits occur daily, leaving him ill and exhausted. Helen finds that his care seems to take longer and longer, and the less he is able to walk, the more difficult it becomes to carry out normal daily activities. Helen finds that she has little time left over in the day to spend with her daughter, Ruth.

Since he left school, Gary has had some form of day care away from home throughout the week, but because he is often too unwell to go out of the house he usually spends at least one day a week at home -often more - in addition to the weekends. Helen feels that she must have short breaks from looking after him through the day *and* night. Her husband Eddy works long hours, and comes home too tired to do much, though he helps Helen lift Gary, and will occasionally bath him.

Gary has had short term residential care off and on since he was a small child. In Helen's view, some of it has been good, some of it bad. Now, when Helen needs the breaks more than ever, the short term care has become less reliable, more sporadic and increasingly unpleasant.

When Gary was a toddler he was hyperactive - in total contrast to how he is now - and very difficult to manage, especially with another small child in the house as well. The Browns' GP suggested that the family should have a holiday without him, and this was the beginning of many years of carting Gary round the length and breadth of southern England in a seemingly fruitless search for somewhere that would take him in for the occasional weekend, or holiday break. The first place he went to was unable to cope with his epilepsy. The next place found him too active - constantly climbing into other children's cots and jumping up and down on sleeping babies. After short spells at three other places, seven-year-old Gary spent a week in Darrow Hill, the huge, gloomy mental handicap hospital some twenty miles away, while Helen and Eddy took their other children on holiday. When they went to fetch him at the end of the week:

> He was smothered in these big blotches, he had tufts of hair pulled out, he had a bruise on his head, bruises on his face, bruises all over his back, and he stunk. He had lost half a stone in weight and he was in an awful mess.

After that distressing episode three more residential units were tried, all of them a long distance from home, but no one would keep him after the first few weekends. He was going to school, which gave Helen some time without him, but because he was having frequent fits she often had to go and bring him home in the day.

Eventually, when he was ten - in the same year that Ruth was born - a new unit opened locally. Gary's time there was a success, mainly, Helen says, because it was run by a woman who was kind and loving. Gary went there for short breaks over the following two years, but he was becoming increasingly disabled, and he and his wheelchair were considered a "fire hazard" in the small and crowded house.

The next two residential units Gary went to were so far away that by the time they had taken him there and gone to fetch him, their weekend break was hardly worth having.

By this time Gary was fifteen, and at this point a new children's unit, Hamblecot, opened in the area. It was a long-term residential unit, with a few short term beds within it. This was a warm, friendly environment where the children were loved and cuddled, and surrounded by toys. Almost all the parents of children who have spent time at Hamblecot speak highly of it, mainly because they feel that the person in charge seemed to care about the children, however difficult they were. By this time Gary was far from hyperactive, and becoming increasingly unable to walk, but Helen Brown was happy with Hamblecot, and she felt she could trust the staff to look after Gary. "He loved it there" she said, "It was like a little family."

But Gary could only use Hamblecot for a year, because at sixteen he was no longer eligible for children's services, and being deemed adult he was sent to Redelms, an adult long term residential unit with four short term beds. Helen said it was "dreadful", and was shocked by the contrast to Hamblecot. At this point he also had to leave his school, and was transferred to a school class at Redelms - at first for only three hours, but later for normal school hours. Helen was sure that Gary disliked going into Redelms to stay the night, and said that he still gets upset when he realises he is going in:

> We have to hide his case so that he doesn't know he is going in, and when he comes back he's always in a state, shaking and everything.

One of the worst things about Redelms, to Helen, is the general standard of cleanliness:

> He always smells funny... we call it the "Redelms smell", he's always got that smell on him. I send in talc and deodorant, but whether it ever gets used I wouldn't like to say... often he's wet, that's the thing that annoys me more than anything, he's wet and he smells. We always wash him down if he's wet, but he's not washed there, and he does smell, because it *does* smell, especially as he's adult.

He is also left to mess his nappy at Redelms, something which he very seldom does at home, unless he is too ill to be moved. Helen is sure he feels humiliated when it happens in front of other people, and she is upset when the staff say they have had to "clean him up".

It is ironic that when the young people are transferred to the adult unit, they are assumed to have abruptly become adults - yet at the same time they are not treated with the respect that they deserve *as adults*. The parents, on the other hand, are aware that they are in fact both adult and child - Helen, for example, lets Gary keep his childish toys and objects, but at the same time she makes sure that he is always shaved and dressed as an adult, and that he is never left in wet or dirty nappies.

One of the biggest problems at Redelms is the constant turnover of staff, and the frequent lack of qualified staff on duty. For people as disabled as Gary, and unable to communicate their needs to people who do not know them well, this means increased vulnerability - to accidents, loneliness, assaults from other residents and some degree of personal neglect. When Helen picks Gary up the staff can often not tell her whether he has had a fit during the day, because there are periods when no one is in the room to see.

Sometimes when Helen goes to fetch Gary there only appear to be two staff with up to twenty people to look after. Thus if someone needs attention there is only one person to watch all the others. This shortage of staff means that those who have wheelchairs tend to get left in them for most of the day; nappies remain unchanged - sometimes Gary is so wet that his tee shirt is soaked up to his neck. He often comes home unshaven, and since he dribbles almost continuously, his face gets sore, and his stubble matted with dried saliva and food. Recently, when Helen and Eddy went to fetch him after a few days, they were shocked by his appearance:

> When I went in I didn't recognise him, he looked such a poor little waif... we looked in the room and Eddy said "he's not in there" and, do you know? I only recognised him by his wheelchair. I thought, gosh, that's Gary I'm looking at - it really threw me.

There is also a lack of communication between staff and parents, at least there is only communication in one direction - Helen, like many parents of children there, almost swamps staff with information, often repeated over and over again in case it should be forgotten. However, little information seems to come back with Gary. Helen, for example, has asked to be told if Gary has a major fit when he is at Redelms for the week-end, because it affects his behaviour, his eating patterns, his sleep and so on:

> It seems that whenever he goes to Redelms we don't benefit from it. I've had a couple of goes at them recently because the other week he was really strange and his behaviour was dreadful, I couldn't do anything with him. I was getting really angry with him because I couldn't cope with him. He got really wound up, and was really acting strangely... he went on the settee and he crashed out and slept for four hours, and I said "well, that's weird."

She discovered a few days later (via the escort in the ambulance that brings him home) that Gary had had a major fit at Redelms. She was upset by this, because she distinguishes between "bad behaviour" and "the post-fit thing" and felt she had got angry with Gary when it was "not his fault".

Helen feels that Redelms is the "poor old Cinderella". The more able and easier to manage people have been moved out into group homes, leaving only the ones that need a lot of care, and the more violent ones, in Redelms. She believes Gary has been less happy after the influx of long term residents from Darrow Hill, and blames a recent patch of anti-social behaviour on them:

> There were more and more difficult ones being wormed out of Darrow Hill and shoved into Redelms. He's never thrown a plateful of food across the floor until he mixed with those. He tipped his dinner and his pudding on to the table on Monday. I was really angry about that because I don't want him ending up doing things like that.

Most of them seemed to be people who were considered too handicapped or too badly behaved to live in smaller units, let alone be put out into the community:

> There's one there that just *screams*... even the staff were saying that they are really bad, you know, it's driving them mad... it's like a dumping ground. Eddy walked in and he said "My God, this is the worst place Gary's ever been in" - he was really shocked... They're awful, some of them, I mean they are so different, that sounds awful, but Gary isn't like them, they're different, you can see it - all our kids [who live at home] are different, they've got something about them, it's not nice for the ones living at home having to go in and mix with them.

Like many of the other "short term" parents, Helen and Eddy feel that the short term people should be separate from the long-term ones, at least from those who have been in Darrow Hill for many years and are very institutionalised. They regard the behaviour of the Darrow Hill people as bizarre, and quite different from the behaviour of their own children. They see their own children as total individuals, with a wide range of distinctive characteristics, and their own methods of communication - aspects which may be more difficult to see in the Darrow Hill residents.

Helen and Eddy are definite that they want Gary to go on living at home, but there have been times when the professionals who are dealing with the family seem to decide that the situation is getting too difficult for them. On one occasion, when Eddy was just about to have an operation, the consultant mental handicap specialist suggested that Gary might go into permanent care. Because Helen was worried about Eddy's health, and therefore anxious about the future, she was afraid to say "no" outright. She was told that she must decide quickly or she would lose the bed, and that there might not be a bed later if she changed her mind:

> But I said "no, he's unwell at the moment, and he doesn't seem to thrive very well when he's away from home." The doctor seemed to think if I left him there he'd be all right, if he didn't come home in between! She said "maybe it's because he's coming home that he's not settling" but I said no, I disagreed... if he was away all the time he'd be dead, I think, he'd never survive.

Helen felt that they were being pressurised to put Gary into care, since the implication was that he would be better off if he never came home at all. She felt that the doctor had no understanding of the situation. She and Eddy were going through a difficult patch at that time, and they certainly needed all the support they could get - especially short term care that they could trust - but what was needed was support to help them to continue to have Gary at home, not the opposite.

Gary's subsequent experiences at Redelms only confirmed the Browns in their conviction that Redelms was in no way a viable home for Gary. He was injured one weekend by a chair thrown across the room by Amy, another weekend resident. As a result Helen was nervous about letting Gary go in when Amy was there. This was a dilemma, because she was becoming increasingly aware of the family's need for breaks -partly because the accident resulted in Gary being at home night and day for many weeks:

> From my point of view and from Eddy's point of view if we don't have a break it's going to cause us more pressures in the family. Everything just reinforces my vow that he's not going to live there, you know, I made the right decision in not letting him live in that environment - but we still need our breaks, it doesn't alter that.

Eddy agreed - he wanted Gary at home "so long as we get our breaks".

The accident brought a great flurry of attention and statements of reassurance to the family, but when it had passed nothing had changed:

> They don't appear to be doing anything about [the accidents]... they're not taking on any more staff, what they're doing is extending the shifts that the staff are doing so that they overlap, so there's a proper takeover period.

After the accident the staff appeared to close ranks against them for some time, and the story of how the accident happened changed in various ways. It was also referred to as some sort of fluke that would or could not happen again. But Helen saw it happen again, one day soon afterwards. Amy threw two chairs across the room, narrowly missing people's heads - but still nothing was done:

> You're fobbed off all the time with what's *going* to happen, and you don't know who you can trust, this is how I feel now, I feel I can't trust anyone... it's very hard to go in there now, because I'm up against a whole wall of people that are against me, I can't do it on my own. It's very, very difficult... I'd rather not face them now on my own, I'd rather have Eddy with me.

The following year Gary was involved in a different sort of accident. One day in July, Helen, looking pale and near to tears, said that he had been given the wrong drugs - for some years he had been on a range of drugs for his epilepsy, behaviour and sleeplessness. A member of staff rang, saying she "had a confession to make"; she said she was new at Redelms, and she was afraid she had given Gary drugs meant for someone else. The doctor she had spoken to had said it would probably just make him "sleepy". Quite apart from the dangers involved in mistakes with drugs, Helen was concerned that there was no one there who actually knew who Gary was. Neither of the two members of staff on duty knew who was who. Few of the residents had any speech and were not able, as Helen pointed out, to "speak up for themselves". Helen was concerned not only about the general lack of staff, but also of qualified staff. This was brought home to her again when she rang the unit one evening, and an unknown voice answered the telephone:

> She said "hello, you don't know me, I'm a new care assistant", so I said "oh, is there anyone I can speak to?" and she said "no, there's only me and another girl, there's nobody qualified on".

Helen has often been called "overprotective" of Gary, but everything that happens merely confirms her view that she needs to be constantly vigilant and aware of possible disasters.

The dissatisfactions of parents about the quality of the services are often dismissed by the professionals as being the result of "over protectiveness". There is no doubt that most of the parents, especially the mothers, *are* extremely protective of their young adult children. However, these children *need* protection, at all levels, from their own actions and the actions of others, from the environment in which they live, and from the consequences of their disabilities, such as incontinence, inability to move and the deformity of their bodies. Parental protectiveness is vital and natural - there is little to suggest that this is *over* protectiveness.

If Helen cannot be sure that Gary is safe and happy, then she would rather he was at home under her maternal eye. She made this quite explicit when all short term care was temporarily withdrawn:

> Apparently they had five short term care ones going in every weekend and they didn't have the staff to cope. We'd all booked up ages before. You tend to think, God, those that have come down from Darrow Hill are the ones who've been away all their lives, whose parents don't bother that much, and all we ask for is the wee-end and we're not going to get it - but then I thought, well, OK, perhaps we're better *not* getting it if they can't cope.

Although she became very worn out, and was highly indignant about the lack of short term care, it was in one sense a relief not to have the continual niggling worry about what was happening to Gary when he was at Redelms. Once she did fight for the only "emergency" bed, for one particular night, because she did not dare tell Eddy that they would have to cancel an outing he had planned. Helen has to balance her anxiety about Gary against her relationship with Eddy, who is inclined to sulk. She thinks, in fact, that Eddy puts up pretty well with being treated as the least important member of the household. Helen tries to keep him happy by doing the things that he wants to do when Gary is away, which has meant that she seldom sees her mother or sisters, because Eddy would rather visit other people.

Helen knows that short term care is necessary to maintain her marital relationship (apart from giving her some much-needed rest) but that is as far as she will go. If she had to choose between letting Gary or Eddy go away permanently she is quite clear which it would be:

> Definitely Gary wouldn't go... there's no way Gary would be shoved off just to suit Eddy... I'd be so bored if I didn't have Gary. I wouldn't have anything to do, oh, I'd be really bored. My brain would just go stagnant, I don't know what I'd do. At least Gary gives me something to think about.

The ideal situation, as far as Helen is concerned, is one weekend a month of short term care for Gary, plus two weeks at some time in the year so that she and Eddy can go on holiday:

> I'd like to have decent short term care, to know that I can send him in and when he comes back he's going to be OK.

Looking back over the last few years there have not been many stretches of time where this simple requirement has been met. Helen (and other parents in the area) have now been asked by the community mental handicap team to fill in a questionnaire about their views and needs regarding short term care. Helen feels this is a good sign but, up until now, the nature of the care has caused Helen more anxiety than relief. She certainly would not let Gary go away for good:

> I worry that he's not well cared for, that's what bothers me, who would care for him? If he could speak it would be better -because he can't tell you what happens... I'd rather he died first and then I could think, well, I cared for him all the time. It's wicked, isn't it? But a lot of my friends feel the same, the ones who've got their children at home and perhaps have got sick ones, like Gary can be, we all feel like that.

This does not mean that she would not let him go if there were any possibility of an acceptable place for him to go to, but it would have to be a place quite different from the bleak and overcrowded mini-institution that Redelms had become:

> I'd like him to live in a little unit, and still have quite a lot of contact, I think that would have to be the answer. In a small unit and have good staffing; to be able to go up there and feel he's still mine, not feel that they're in charge. And I would like them to contact me when they've got any decisions to make about drugs, not just do it. You know, involve you as if you're a member of their team, not just "oh, they're only the mum"... I think on certain occasions they do let you know, but I'm sure there are times when you don't know what the hell is going on.

Even if he went to live in the perfect place she would not let him die away from home:

> I wouldn't like to think of someone else looking after him in his last days, I'd rather it was me, and if he did get very ill I'd want him brought back home, I wouldn't want him in there.

Gary's health is deteriorating quite quickly and even his doctor has said to Helen that it is understandable to want him at home, because she could not expect to have him for much longer.

Helen's stories of the hyperactive, naughty little boy have an increasing poignancy. As she speaks she strokes Gary's trembling hands, and talks to him between her sentences, rousing him when he slips into his frequent episodes of *petit mal*, and teasing him when he laughs and flashes his eyes. On bad days, after major fits, he sits or lies almost immobile, his face ashen white. On better, now rarer, days, he shouts and laughs, and even walks a little, falling and bumping into things. On these days he resists being dressed and washed, spits his food and laughs, and sits dropping shapes through shaped holes as though defying all those professionals who say he has the mind of a one year old. Like many of the other young people in this book he spends much of his time watching and listening, and the initial perception of him as a person without skills and without speech gives way, when one has the chance to observe and interact with him at home, over time, to a quite different understanding of him as a communicative and responsive young man. To a great extent this awareness of his character can only happen at home, where other people care about him as an individual person.

Elsewhere he is often treated merely as the sum of his needs, there is no time - and often no inclination - to look beyond those aspects that are so time-consuming for others.

The story of Gary's family brings out certain aspects of the inadequacies of the available short term care very clearly. One thing that is immediately apparent is the shortage of staff in the adult units, especially of trained staff. This has obviously been the cause of needless accidents to Gary, both in terms of physical injury and receiving the wrong drugs. There is also evidence of personal neglect, lack of communication between staff and parents, and general unreliability. The picture painted by Helen and Eddy is a grim one, and because of Gary's tenuous hold on life it is not surprising that Helen is constantly worried about him when he is away, and she is angered by suggestions that she is being "over protective".

ANDY MARSH

In Litchdean, some forty miles away from Hamling, where the Browns live, and in a different health district, parents report the same kinds of problems. One family there, the Marsh family, has had very similar experiences with their son, Andy, who is also very physically handicapped, and as intensely vulnerable as Gary.

Andy Marsh is 19, his face is crooked and his body and legs are small and twisted. He can use his hands, but his legs will not hold him up. He cannot chew his food, and is liable to choke on anything that is not finely minced; he is incontinent, but needs regular suppositories to open his bowels. Until recently he was subject to epileptic fits, but these are now controlled by anticonvulsant drugs.

From a distance, because he is so small, he could be mistaken for a child, but there is no doubt that in fact he is a young man, with a serious adult face. He cannot speak, so it is hard to tell how severe his mental handicap really is. With him, perhaps more than with any of the others, it is difficult not to feel that he is restricted by his body, that will not obey him, and cannot communicate what he knows and feels.

His mother, Meg, is highly protective of him, she feels his vulnerability and cannot bear to see him suffer. This intense preoccupation with her son has been the cause of many problems between her and her husband. For years Meg would not let Andy out of her sight, except to go to school, but when he was fifteen her husband

Callum put pressure on her to let him go into overnight care occasionally:

> Cal was so angry and bitter with me in that I wasn't prepared to bend a little so that we could have a life together... I had this great fear of letting Andy go away even for a night... I was prepared to give up my life totally.

After about eighteen months of continued battles between them, Callum won the day, and Andy began to go into a local unit, Ashgrove, for one weekend a month. Meg found it unbearable at first, and even after a few years finds it hard:

> I go completely to pieces when he's in, really and utterly, in case he dies... I worry every time he goes in there, like if we go away on holiday - it sounds as if I'm a very maudlin person but I'm not really - I say "mummy will pick you up next week", and I think "dear God, don't let me have an accident and let him down".

She worries that he will die, or that she will die and he will have to go into permanent care. Callum also worries about Andy when he is in care, although not to the same extreme. He is particularly worried because the staff at

Ashgrove do not always mince Andy's food, and has put a complaint into the "head of department, above the manager's head".

This fear that Andy might choke is not exaggerated. Many times Andy has stopped breathing, and Callum and Meg have had to scoop or shake a piece of food out of his throat - even at home, where they watch him almost continuously. Thus they know that when he is away there is even more chance that he will choke. Gary's survival depends on the memory, thoughtfulness and vigilance of those who care for him. In an overcrowded and understaffed unit Meg and Callum realise that these qualities can easily be swamped by the mere logistics of coping with too many residents.

In spite of his worries Callum believes it is the best thing for their marriage, and for his son, that Andy goes into short term care - and for longer and longer periods. But Meg has still not come to terms with the idea of Andy going in at all, becoming just one among twenty-five or so others, and deprived of the love and attention he gets at home. Andy appears not to want to go away either, and hangs on to the side of the car as Meg lifts him out, making it even more upsetting for her.

Meg feels that the staff at Ashgrove give him far too little attention, even at the level of basic care. Because his spine is twisted and his back all "lumpy", when he sweats he gets very sore in places if it is not wiped and washed. Sometimes he comes home with his back in an awful state, obviously not bathed the whole weekend:

> Each time he comes home with little things wrong, and they're minor things to other people... but it just aggravates me and I feel I'm doing him down by sending him back there. If I feel that strongly over it then theoretically I should say "right! That's it! That's how I feel". But you have to weigh things up, don't you? And of course, I say to Cal "here, see his back", and he doesn't say anything. He can't, can he, really, when he looks at his back covered in these spots.

They have been away for the odd week, as well as the regular weekends, but Meg does not think its worth it:

> He always comes back with some sort of problem, and it's me who nurses him back to 100 per cent - well, as near as I can get him to fairly good health, and you know I sometimes wonder if it's worth it. Cal's had a lovely break, goes off to work, and I'm left with this child who has perhaps got a very, very sore bottom... and needs to have enemas just because

> they say they had no disposable gloves at Ashgrove to do the suppositories. It's Andy who bears the brunt of their neglect.

Like many of the mothers she feels that the staff just do not care about the people in their charge:

> I do think some of the carers are really too young and immature, they don't have to have the qualifications that the actual nurses do, and the way they change staff up there I think for a lot of them it's just a stop-gap job for a few weeks... perhaps I expect too much, but there *are* some in Ashgrove that are good - and there are a lot that just do the very barest... there used to be one boy working up there, you could always tell when he'd been on a shift because Andy was spanking clean, and he comes to visit them even now he's left... but he was one in a million, really.

Meg realises that much of what is wrong with the residential care unit is the fault of the policy makers and administrators, not the care staff. Many of the parents say this, but nevertheless there is also much criticism of the way things are done on a day-to-day basis, and of the attitudes and beliefs of the care staff.

One aspect that worries Meg is the lack of attention to the dignity of the young people in the unit. She considers it important that Andy should be able to retain his dignity in spite of the "indignities" that he has to undergo. Although Andy is incontinent, Meg makes sure that he never stays in trousers that have become wet, partly for the sake of comfort and convenience, but also because she feels he would be embarrassed if other people saw:

> Sometimes when I go there his trousers are all wet. Now this annoys me so much, it really aggravates me, because he deserves his dignity and that is something they don't have up there.

Her anxiety about Andy at Ashgrove is not simply to do with the lack of care:

> Things are not right there. Andy dislikes it... his face is like thunder, and he plays them up... he makes his stress show... I don't feel there's any excuse for the basic lack of care -admittedly, it's harder when they're adults... I think it's very sad and I can't explain it, it's a deep sadness in me when I take him up there, really, because I foresee how he's going to be, and I see these sort of poor souls there... I do have a lot of guilt because I'm putting him somewhere where I know he's not happy... and I do say that if anything

> happened - if I didn't have Cal, Andy probably wouldn't go back to Ashgrove.

Meg's fears for Andy would probably exist however much faith she had in where he was. This does not mean that she is "over protective" of him, but that her relationship with him is extremely close, and to some extent she is also dependent on him. Relationships of this kind are sometimes dismissed as unhealthy, for both mother and child, and as "abnormal", and as a result it is sometimes considered better for both if the adult child were to leave home, and become "independent".

This raises two points. Firstly, the *context* of these relationships is itself "abnormal". In the vast majority of families adult children are not totally dependent on another adult to fulfil all their basic needs, nor have they been locked for many years into this almost continuous and intense personal contact and communication with another adult human being. It is not surprising, therefore, nor unacceptable, that the resulting relationship is an intense and close one.

Secondly, these parents know that there is no such thing as real independence for their children. When their other adult children leave home they take over their own lives, get jobs, go to college, get married and so on. The young adults in this book, if they leave home, will move into an environment in which they will be even less autonomous than they are now, since their needs and wishes will be less understood, and they will probably live without ever having another close relationship.

Meg believes that all the parents of children as disabled as Andy feel the same way as she does:

> All the parents, they've all got this awful fear of this permanent side to it, and, I bet you, if you could break it down, basically it's not so much you want to be possessive, it's just that the care's not as it should be. It would never be as parents wanted it, if we're honest, would it? But I think it could be a lot better, it needs more money put into it, which they're not going to give - let's not kid ourselves - that's why I think it will always be a second rate service... I think probably if they had smaller units, it could be done.

Meg, as she says, criticises Ashgrove "left, right and centre", but the alternative - the old mental handicap hospital, Darrow Hill - is worse:

> To the parents of mentally handicapped children Darrow is a bit like Dachau... I'd top me and him rather than let him go there.

Meanwhile Andy goes into Ashgrove for his one weekend a month. The staff say that he spends most of the day trundling his wheelchair round the corridors. They say that he does not like to be with the other residents: "He likes to mix with us, in the staff room or in the office". Meg is sure he looks at the residents wandering around the unit and thinks "I'm not one of them", and it fills her with sadness. She would prefer the short term people to be separate from the long term people. Like Helen Brown she considers her son to be significantly different from those who have been institutionalised a long time:

> It does grieve me greatly to think that Andy's got to be subjected to staying in an environment where people scream and do odd things, that grieves me.

Standards at Ashgrove vary according to who is running it. Sometimes there are improvements for a time - the unit may be redecorated, and as a result it "smells better". During these periods Andy comes home in a cleaner state, although he still has nothing to do there, except wheel himself around the corridors.

Meg and Callum avoid the issue between them of what is going to happen to Andy in the future. Meg does not accept that it is the natural thing for someone like Andy to "leave home" as Callum does, and the residential units will have to improve a great deal before Meg will consider any longer term care for Andy.

Meg's account of Andy's short term care highlights a number of issues. She, like Helen, is considered "over protective" because she worries about Andy when he is away, but her anxieties are not mere flights of fancy - they arise from her experience of Andy's short term care experiences, and a realistic assessment of the day-to-day risks to his life. Andy needs constant vigilance, mainly because he chokes so easily, and this has certain implications regarding staffing levels. It is clear that if there are not enough staff to watch those whose lives depend on other people to see and act when something goes wrong, then the level of care is inadequate. Similarly, when Andy comes home with sores because he is not washed in the sweaty dips and hollows of his back, this at least implies a lack of staff sufficiently trained to care for multiply handicapped people.

Most of the complaints that Meg has are double-edged. She deplores the standards of cleanliness, and the apparent neglect of wet and dirty nappies, but also important to her is the dignity of her son - and of all the others that she calls the "poor souls" in Ashgrove. This is an important issue, and reflects not only the difference between the perceptions of parents and care staff, but also the extent to which staff tend to "dehumanise" the mentally handicapped people for whom they care.

These two families illustrate many of the experiences that parents and their young adult children have in relation to short term care. In the case of Gary and Andy, their difficulties partly stem directly from their physical disabilities. These less physically able, and apparently less threatening people, tend to be left for long periods sitting in their wheelchairs - often unable to communicate their needs, or to protect themselves from others.

2 Violence and Visibility

The case studies that follow are about three young people who are mobile and physically quite able - and whose behaviour causes serious problems for the people around them. Their one advantage perhaps, in a residential unit, is that they tend to be highly visible. Far from sitting quietly in wheel- chairs waiting to be attended to, they try hard to make their demands explicit, though the nature of them may often be misunderstood. Part of their problem stems from the fact that they are considered a "danger" to other people, and hence may generate a degree of hostility or fear in others.

BEN WHITE

One boy who is unquestionably visible is Ben White. Doctors, social workers, friends and family have all suggested at some time or another that Ben should be "put away", but his parents, Bess and Jack, have no intention of doing so.

Ben has tended to attack other people most of his life, and at seventeen has grown into a very large and powerful young man. Most people are frightened of him, and will not stand up to him. Bess manages him best, by not letting him get away with anything, and Jack tries hard, but is basically too gentle a person to assert his authority over his son.

All through his life Ben has been unwelcome everywhere except at home. All his life his parents have battled on his behalf, for his right to attend school, and to have short term care, so that they can keep him at home. Until Ben was moved to his present school, (where there is one teacher who manages him very well), Bess was constantly being rung up and asked to take him home because he was so violent, until it reached a time when all the teachers were too scared to have him in their classes.

As a child he started having weekends in a local residential unit, but he was said to be "unmanageable" and was "kicked out, back to mum". He was then offered short term care in another health district, but that too came to an end, partly because he attacked other children, and partly because he seemed to hate it, "screaming and struggling" when they took him over there. For some time he was at home day in and day out without a break. His tantrums were frequent and violent, and included throwing furniture around the house, through windows, and even at his mother.

When a new children's unit opened in the area Ben was taken for infrequent weekend breaks. Like the other parents of children having short term care there, Bess and Jack found it a friendly, loving atmosphere, but there was not enough control for someone like Ben. The person in charge was kind and sympathetic:

> She cares, but she is too wishy washy to be dealing with the likes of Ben. She cares about the children, I know she loves the children, but she hasn't got the force for dealing with any sort of behavioural problem.

Because the staff at the children's unit found it hard to manage Ben, he was transferred for his short term care to the adult unit, Stafford House, before he was sixteen. At this stage the unit was run by Alice, almost the only person that many of the mothers had any confidence in once their children entered the seemingly hostile world of adult services. Bess also found her community nurse a help, especially when she wanted something from other professionals, but she got on particularly well with Alice, and felt that she "has the force behind her" that is needed with Ben.

He started going in to Stafford House for two weekends a month. Bess said that he was never given any longer than a weekend, even in the six long weeks of the summer holidays, whereas other, less problematic children, had longer breaks:

> It seems like the easier the handicap the easier it is to find places - the more difficult children tend to be pushed back to mum.

In fact Ben, at this stage, had not been away for a whole week since he was born. With him, the choice only seemed to be between living at home, with a few weekends away, or going in altogether. At one stage it was suggested to them that Ben should go away for two years, to a residential "behavioural place" somewhere a long way from home:

> They said it would be easier if they just had him for two years. We did think about that, and Jack said "I don't think we could cope after two years". After two years of living a normal life, and having no hassle... It's all right them saying he would be different, but there would also be a big build up of resentment there. And I think for someone like Ben, you wouldn't understand him any more, you wouldn't be geared up to him. It wouldn't be like your son after two

> years, would it? So we said no, that isn't what we want... I don't know if after two years we'd have been able to cope all over again. They said "oh, but he'll come back reasonably behaved", but I said, "he is reasonably behaved at home *now* - I'm not finding the problems, you are!" I've got my house in order, I've sorted my house out - I've laid down my rules and they've got to stick to them.

Bess tends to talk about Ben much of the time as though he is a relatively placid boy. She knows he is often quite the reverse, even at home - and tells vivid stories about his violent episodes - but it is as though these are something apart from his real character. The Ben who is important to her is the boy she spends many hours with every day, trying to understand what he is struggling to tell her, and including him in family life and conversations with other people.

Bess and Jack have in fact had many difficult times with Ben - but Bess can often foresee violent episodes, and feels that others could, too, if they paid enough attention to him:

> I can usually see it coming, he gets agitated and he usually paces up and down, and his eyes go quite glazed, and he can't stop. And I say come on, we'll sit

> down and have a cup of tea and we'll have a talk... you can talk usually to get him down a little bit... that's why he's so high, I think, when he comes home from Stafford, because he's not getting the talking.

This lack of anyone who will try to communicate with Ben when he is away, and the absence of anything for him to do, makes Bess annoyed:

> They're doing nothing, they might as well be dead, they're just sitting there all day long. You've got to think about the *content* of life, haven't you, when you're talking about living. I mean, I know Ben gets a lot out of life, he*likes* life, I wouldn't like to see him there, somewhere like that. Every brain needs stimulating, no matter what.

Bess's attitude to her son is very different from that of most of the other people who care for him. Bess sees him as a human being, with intellectual and emotional needs; she also realises that he is a large and energetic teenager who gets easily bored, like most boys of his age. In the unit he is related to mainly only at the level of someone who is "severely mentally handicapped" - the emphasis seems to be on his disabilities rather than his abilities. His individual needs and capabilities are not catered for, and recently the staff at the unit have just let him lie in bed "playing with himself" if he wants to. Because he is potentially violent most people do not seek his company, so they do not listen to what he tries to tell them, or ever give him the benefit of the doubt. This difference between the way Ben's family see Ben, and how many others see him, epitomises the problem that many of the young people with behaviour problems have in their relations with the rest of the world.

At least Stafford House was willing to have him occasionally, and Bess and Jack were relieved about that. As Jack says:

> We make the most of it, like he's away this weekend so we'll cram everything we can in, and the next weekend we'll virtually do nothing. He always has to be with one of us, you have to watch him all the time.

They both consider that this vigilance is lacking at the unit. They are not worried, as some others parents are, about the state of Ben's clothes, or whether his face is always clean, but they do feel that there is a disastrous lack of supervision and attention to individuals, especially to people like Ben, who are often threatening. Much of the time Bess thinks he is just trying it on, and that if people did not just back away he would give up, but sometimes even Alice, the indomitable manager of the unit, finds him very difficult to manage:

> Alice said he was like a demon, an absolute demon, and they phoned us up and said would we go and collect him. Alice had given him an injection and they couldn't do anything else with him. It took four of them to hold him, and they'd been holding him for an hour. He attacked one of the young girls up there, threw the fire extinguisher, Alice said the room looked like a bomb had hit it.

During the period when all short term care was withdrawn in the area for a few months, everything seemed to go wrong. There were other major problems within the family, and Ben was terrible:

> He was going berserk, he was hitting everybody, nobody was safe - he was going for us all the time, punching us.

Bess went to see the doctor responsible for Ben to see what could be done about his behaviour:

> She said she was going to "monitor" him. I said "well quite honestly it hasn't helped that we haven't had

> any short term care," I said, "I'm sick of him, he must be sick of me, my Jack's sick of all of us, I'm sure."

For the parents of very difficult young adults the need for short breaks from them is acute. With more physically disabled and less aggressive young adults it is often possible for the mothers to keep the problem more to themselves - often to their own physical and emotional cost - but with people like Ben, who cannot be contained, the effect on the whole family can be very great. At the same time, when there is always the possibility of violence, the anxieties about what is happening when they are away are compounded.

When Redelms started taking short term people in again, the staff situation seemed worse than ever - and Alice had left:

> We take him in there and we have to find someone to leave him with; the person he's left with doesn't know him from Adam, he's never seen *them* before, so he's totally bewildered - there isn't one single staff he recognises... not one person understood him, he was dirty, smelly, he hadn't been bathed at all because he was naughty and he was overactive and he was hard work. He was bruised where someone had been thumping him, and bruised where he was being

> restrained. Their whole attitude was to give him an injection as soon as he started and then he's like a zombie.

The situation became potentially untenable when Bess and Jack were told that there would not be anywhere for Ben to go in the day when he left school at nineteen, although he had been promised a place at an Adult Training Centre for the last five years. This meant that he would be home every day every week of the year, except for the odd weekends in the short term care unit. For Bess, it was almost the last straw:

> I shouldn't *have* to keep fighting like this. I said to Jack "I am so sick and tired of fighting the system all the time for Ben, isn't it about time we just gave up?" He said "What? Just let him go to people like that?" he said, "that can't even keep him clean for a weekend?" No, I think I'd rather kill him, quite honestly, I'd rather give him an overdose, than see him go in there. When I got home from that meeting and I tucked him in that night I thought, what is the point of keep trying to fight - he'd be better off dead. What sort of life would he have? They're not even kept clean, they stink - the whole place stinks. They're suffering there because they can't say any different.

Later that year Ben "blew up" so badly at home, that Bess and Jack were unable to control him. They tried to get help but found that the mental handicap specialist responsible for Ben, and the whole of the community mental handicap team, were on holiday. When Bess eventually saw the mental handicap specialist, some weeks later, she described what had happened, adding that since there was no reliable source of help, no decent short term care and nowhere for Ben to go in the daytime now that he had left school, the most practical thing to do would be to give him an overdose. Finally, someone took her words seriously and Ben has now been promised three nights away every fortnight, in the recently opened residential specialist unit for people with severe behaviour disorders.

Bess's predicament is a familiar one to many parents of very difficult people. Because of the extent of the behavioural problems there are few options, if any, that are open to these parents, especially when their children become adult. Short term care units tend not to want them, nor do Adult Training Centres welcome them. Thus help and support is seldom forthcoming for those families who need it most of all.

Bess bitterly resents the fact that she has had constantly to fight for everything to do with Ben. But she is even more angered by the fact that because there was no one to turn to when she needed them, she was finally pushed to the limits of her ability to control Ben - driven to a point at which, for the first time, she had to admit defeat, albeit only for a day. She has repeatedly said that if the time ever comes when she can no longer look after Ben at home, she will make sure that he has no future at all, rather than let him face a future in permanent care - where she believes he would be tranquillised into oblivion. Since she cannot rely on help even in an emergency, she is being forced into an untenable situation.

BRYONY MORRIS

Ella Morris also feels that she is being pushed into a situation that gives her very little choice of action. Her nineteen-year-old daughter, Bryony, tends to cause havoc wherever she goes, turning furniture up side down, making loud noises and at times attacking other people, including her mother. Much of the time, however, she has no malicious intent, and it is only those who accidentally come within the orbit of her riotous behaviour that may be harmed.

Ella is alone with Bryony most of the time - she was widowed when her children were very young, and now they have all left home, except Bryony. Trapped in a small house on an unfriendly council estate, Ella's attitude to short term care is that it is a necessary evil for her survival. Otherwise, apart from day care during the week, Bryony refuses to leave her side, even at night, and the only way Ella can get a reasonably unbroken night's sleep is if Bryony sleeps with her in her double bed.

After a distressing experience for Bryony in Darrow Hill, Ella refused to let her go away again for the following five years. She then spent the occasional weekend at a children's unit until, at sixteen, she was transferred to Redelms. Ella was disturbed by the lack of basic care at Redelms, as Helen Brown and Bess White were, but continued to let Bryony go there. The staff found Bryony difficult to cope with, and tended to give her injections when she became difficult. Ella was shocked one weekend when she discovered that Bryony had been given a considerable overdose of an antipsychotic drug. When Ella went to collect her she found her looking very strange:

> They said "You'll find Bryony is a bit under the weather, she's not quite herself - we had to give her

> some sedative because she was quite high"... and she was absolutely like a zombie, I mean she just stared straight ahead, she could hardly walk. I said "whatever's wrong with her? What's happened to her?" And I found out that they gave her too much and they couldn't bring her round - they had to get the doctor in... I don't know whether it was a mistake or whether they wanted, you know - I know that they gave her [ten times the highest dose] she should have had, because I went to the hospital to ask their opinion and the doctor there looked it up.

Ella was told that the drug would probably be in Bryony's system a long time, and it was:

> For weeks Bryony used to come home from school and go straight up to bed and sleep the clock round to the morning... and they said she used to sleep at school.

Ella made complaints about the overdose, but nothing came of it - she knew that there really was nothing that could be done anyway, at this stage, except to try and stop it happening again, but this seemed a hopeless task to Ella, who was well aware that the staff in the unit would continue to tranquillize Bryony when she played up, and that there would always be the possibility of mistakes being made while the unit was so woefully understaffed.

Because Ella was alone, Bryony went into short term care for a long weekend every other weekend, and for one night in the middle of alternate weeks. Just as Ella got used to this, it was cut down to one weekend a month. When she complained she was told by the mental handicap specialist that some single mothers had other children to look after at home as well. This was no help to Ella, who had visions of her life narrowing completely, and consisting of almost continuous interaction with her daughter.

When Bryony is going through a particularly aggressive stage, Ella gets covered in bruises. At one level she accepts this, because she feels that it is part of Bryony, who has always been hyperactive and aggressive. Ella's tolerance of Bryony's bad behaviour at home, however, makes her more difficult to manage in other contexts, where people are less tolerant of aggressive behaviour. This may be why some of those who care for Bryony away from home would prefer her to be in permanent care, without going home at all - as they have suggested to Ella.

Ella, on the other hand, feels that many of Bryony's worst habits have been picked up in the unit, like grabbing all the food from her plate and stuffing it into her mouth. When Ella complained the staff said that there were too few of them to give everyone the attention they need at meal times - but Ella blames it on the quality of the staff, not how many there are.

The staff complain that Bryony sometimes smears faeces all round her room when she wakes up in the mornings. Ella retorts that its no good blaming Bryony - she never does it at home. But she wakes up at about five, and needs to be taken to the lavatory quite quickly to avoid a mess. There was also trouble when Bryony injured another resident, but Ella said they should not have been alone in a room - a member of staff should have been watching.

There is thus a continual battle that rumbles on between Ella and the staff at the unit. Ella, like the other parents, is torn between letting Bryony go into short term care, which she considers unsatisfactory, and keeping her at home - limiting Ella's life almost totally. She resents being put into this position, just because she wants her daughter to live at home, and feels that it should be possible to have short term care that is acceptable, even for someone as difficult as Bryony. Meanwhile she had to manage with Bryony only going away for one weekend a month. The fact that she is told that a permanent place could be found for Bryony if she abandoned her altogether makes it even more infuriating.

It is true that if Ella was prepared to give up Bryony she would be able to get a place in the same residential unit. This seems illogical to her - if there are too few staff (as they tell her) to look after Bryony every other weekend, how could there be enough staff to look after her if she was there full time? The implication is that they do not care so much about the people who are there permanently, and that these people are therefore likely to be neglected.

Eventually Ella managed to get Bryony in to short term care again for one night a week, but the complaints about her behaviour became more serious. She destroyed some video equipment and furniture, and Ella was told by the community nurse that the short term care staff might be "building up a case" against Bryony.

> I said they hadn't better say that Bryony can't go there, because if she's supposed to be so terrible, how come that I can never get any short term care when I'm ill? I mean all those months I was really ill they didn't offer me any extra time at all. They say I'm supposed to cope at home.

She has a valid point - how do they expect her to manage alone, when they are unable to in a unit with staff who do not have to manage Bryony continuously through the days and nights? She has become increasingly worried by the thought that they expect her to "give in" and let her go.

Ella feels that life is slipping away. She wants to go out and meet people, to go to London and see life as it is led by the rest of the world. She makes endless plans, but most of them are thwarted by her life with Bryony. But still she will not entertain the idea of letting her go into permanent care - although she is sure this is what the professionals want - mainly because she believes she will just be tranquillised:

> I think they think the easiest way out of it would be if Bryony was a resident, you know, that that would probably end their problems. Because once they're a resident you've got no control over them at all, even if they say you can have them home as often as you like. For a start the drugs are out of your control, they can do what they like, you've got no say in it at all. She'd probably be heavily drugged, she'd probably go incontinent and - well, I don't know what would happen to her. I think she would just fade away or something. Bryony is really sensitive and, you know,

> if ever I thought she would have to live somewhere like that... if I had an illness or something, and I wasn't going to get over it, I'd give her an overdose.

Ella is not being unrealistic, the future for Bryony is stark, and obviously no one is going to care as much about her as her mother does. Some of the people who have known Bryony for a long time are fond of her, but it is doubtful whether anyone else thinks of her as "sensitive" - it is not an adjective that seems to be heard often in contexts outside the families of such violent young people.

Bryony's experiences reveal one of the most worrying aspects of care away from home - the apparent temptation to keep violent people sedated rather than to spend time and effort on more direct attempts to control and contain difficult behaviour. There is also, therefore, the continual anxiety for parents that too large a dose will be given - again a reflection of overstretched, and possibly underqualified, staff.

Ella's fears that Bryony would be tranquillised all the time if she went into full time care, and Bess and Jack's similar fears for Ben, are borne out by the experiences of Jean and Ray Nicholls, who eventually decided that they would have to let their son Craig go into the residential unit for "semi-permanent" care.

CRAIG NICHOLLS

By the time he was eight Craig was already proving too difficult for his parents to have at home all the time. No local schools or short term care units were prepared to take him, so he was sent out of the county to boarding school. During the holidays his mother, Jean, "climbed the walls and went on to valium". Craig throws furniture, attacks his younger sisters and brothers, has frequent temper tantrums and is highly disruptive. He was moved from school to school until mid-1987, when he was brought home and left there because no one could cope with him. He was eighteen by this time, and started going into Stafford House for day care, and for the odd weekend, but Jean could not manage him without far more support. She decided that he would have to go into permanent care, although his father, Ray, was reluctant to let him go at first:

> To be honest, we were very fast approaching the end of our road, where I didn't want to come home, and Jean didn't want to come home. Then the social worker called to say did we want long term care for Craig? We said, well, not really, we've still got a responsibility for him and we love him... OK, he's a handful but there's no use getting away from the fact that we love him. But they said that the short term

> care might disappear - and its the short term care which makes it tolerable.

Jean and Ray knew that they could not survive without more short breaks from Craig, and so when Stafford House offered to take Craig "semi-permanently" - that is, that he would be away from home most of the time - Jean was relieved, and Ray resigned himself to it.

Craig came home at week-ends, and they became increasingly worried about the amount of drugs he was being given to control his behaviour. When he came home he tended to be "very, very tired", and wanted to go straight to bed. Ray was very concerned:

> He's dopey, and sometimes he gets high so they give him an injection to knock him down a bit. To be honest it leaves us a little bit powerless... you don't know whether the medication he's being given on a long term basis might damage his health, or how its blocking his development. Why are they increasing it to such an extent as they have done? Lots of questions, no answers. And the staff change there so often that you never get time to develop a rapport with anyone... sometimes there aren't any staff there when you take him back, or even when you pick him up.

Ray says they have not signed anything handing over responsibility for Craig - "there's no way I'd sign a legal responsibility over to someone else" - because he is afraid that if they handed him over legally he might be put into a mental hospital, and this is something Ray would not tolerate:

> There are certain lines that I wouldn't go over, and I don't think Jean would. It would probably devastate us to have him home but there's no way he would ever go into a mental hospital.

He was worried about the sort of treatment Craig was having at Stafford House, and Jean was anxious too:

> Neither of us are happy about it, but, saying that, neither of us are capable really of looking after him, it just wears you down too much. But we'd just like him to be somewhere that's better, a much better situation for him, much more planned out. All we can hope is that we outlive him... and with the drugs and that, you know - I can see the drugs basically tending to kill him off, the long term effect on him. They make him dopey - some are supposed to calm one side of his brain down and the others to uplift the other side, and the other ones he takes are supposed to counteract the side effects that they have. So, if you can believe that you can believe anything!

Six months later the situation had got much worse. Their fears that Craig would be continuously "doped" seemed to be fulfilled. Ray was now highly critical of Stafford House, and had become angry and upset by the effect of the drugs that were being given to Craig:

> He comes in now and walks straight into that wall... and he's dropping things, and he'll bend down to pick it up and completely mis-time where it is... and he's got hand tremors, and they said he was asking to go to bed at six at night - you don't find many twenty-year-olds going to bed at six... so we complained about it, and they gave me all manner of excuses. It's still an ongoing battle, to be honest... the head of Stafford House said she had no control over what drugs he was taking. And there were other things, he wasn't being looked after properly, his nails weren't being cut, his hair wasn't being washed or cut, and his teeth had very thick plaque. We refused to take him home one Friday because of the way he was dressed, or not dressed. And he had an air of neglect about him and, you know, you get angry at seeing one of your children being treated like that.

Ray feels that the staff look after and pay attention to the ones that need the most help to do things - which is the opposite view from the parents of the very dependent young adults, who believe that the more mobile and difficult ones get all the attention. Both are undoubtedly biased views - but the most likely picture is that neither group is getting the care and attention that is necessary and desirable.

Ray complained and a meeting was called with the relevant professionals, at which he expressed his concern about the level of care at the unit. He feels that his complaints have had some effect on what happens to Craig, but is quick to point out that although this is good for Craig it is wrong in principle, because it means that there is little hope for those whose parents have abandoned them, or are already dead.

But their battle over the drugs continues. They took Craig off them one weekend at home, and the result was extraordinary:

> When he was small his eyes used to glow, it was an outstanding feature, these glowing eyes, and in the last couple of years they've dulled, but all of a sudden he had these glowing eyes again. It was like having him back with us - it sounds ridiculous I know... and he was happy - its the little things, the stupid things - I hadn't seen or heard him laugh, not for a long, long time. That weekend he was home, not only did his eyes start glowing, but he started laughing.

Ray and Jean cannot manage Craig at home, their problems with other children and the very size of their family have precluded it. But their experience of longer term care has borne out their worst fears. Not only has their son's physical care been inadequate, but he has become a "walking zombie" as a result of the high level of drugs he is given.

In spite of Ray's efforts to find out why Craig needs so many drugs he has been given little information. The staff in the residential unit have proved unhelpful, and disclaim responsibility since they are not responsible for the prescription of the drugs, only for their administration. There is evidence, in Craig's case, of inadequate monitoring of the effects of the drugs he has been given, and of the interactions between them.

The experience of Craig and his family has borne out the fears of all the other parents whose adult children are violent or difficult to manage. It is unlikely that anyone will have the time or inclination to control their bad behaviour by any more time-consuming method than drugs. Throughout their lives their parents have had to fight almost continually to get the help and support that they need, and without their parents there to watch and fight for them as individuals the future for these young people is bleak.

3 Views and Values

As we have seen, the provision of short term residential care is one of the most important services to families who have a severely mentally handicapped child at home. Some parents have indeed made use of short term residential care for many years, but in many cases the decision to make use of this service - if it is offered at all - is not made easily. Parents quite often feel guilty about sending their child away, even for a night or two. They may feel that they are shirking their duty as a parent, or that they are admitting to the world that they cannot "cope".

In some instances the extreme vulnerability of their children makes it hard for parents to let them go away for a night, even though they have become used to them going to school in the daytime. But the situation at home may reach a point when a number of different factors combine to make a short break necessary. Meg Marsh, for example, only gave in when her husband forced the issue. In other cases it is increasing tantrums, or lack of sleep, or the demands of other children in the family, that tip the balance.

The transition to adult care

In the particular geographical area that concerns this study, children and adults have separate residential units for both permanent and short term care. The parents speak highly of many of the children's units, though there are notable exceptions. At the age of sixteen the young people have to leave these units, and the transition to adult units is often traumatic and distressing both for the young people, and for their parents. Parents feel that as their children become adult they need increased help and support, whereas the provision of services seems to become haphazard and uncoordinated.

Because these are adult units, and those who live there are decreed to be adults, they are frequently deprived of those comforts and displays of affection that they may still need - but which are no longer considered appropriate. "Age appropriateness" appears to be considered more important than individual needs and desires, as though it is better to sit without anything at all, than to hold a toy that moves and rattles, and can be squeezed and thumped and chewed. Because a person enjoys these sensations does not imply that this is the sum total of their intellectual and physical needs. As we have seen in the case histories, parents recognise the complexity of their children's abilities and disabilities, and the various different "ages" that they are at any one time. Thus many parents are critical of professionals, including care staff, who do not appear to recognize this complexity.

Most parents feel that if there has to be an administrative change at all, the transition to adult care, as it is done at present, is too abrupt, and that a gradual move from one unit to another would be better. Sixteen is usually considered too young, anyway, for the transition - few feel that their sixteen-year-olds are ready to be plunged into an adult world, especially into residential units full of older people who have been institutionalised for most of their lives. In fact, parents would prefer their adolescent children to stay with their own age group - preferably moving with the same children that they were with in the children's units - and to be separate from the people who have been in permanent care for many years. Ideally, the children would not have to move into another residential unit of this kind at all, but move into small home units. This has, in fact, been the official policy in one health district in the study area for some time, although it has not yet been put into practice.

Almost all the parents are dissatisfied with the quality of adult residential care provided. Some even feel that in any context other than that of mental handicap (and perhaps of the elderly and infirm) such low levels of care would provoke a major scandal. It only confirms their belief that the services for mentally handicapped people are, as one of them suggested, the "Cinderella" of the services.

There is a great deal of bitterness about this. All the parents need breaks, but they also want the breaks to be relatively free from stress and anxiety, so that they can gather their strength for the coming weeks or months. As it is, these days of freedom - incredible though it may seem - are often more anxiety provoking than normal days with their children at home. They know that their sons and daughters will probably spend most of the time doing nothing except sit in their wheelchairs or, if they are mobile, will either be left to wander about aimlessly and, if they are difficult to manage, will probably be given extra medication.

In reality, the number of demands that parents make of the short term residential care services are very few, and most of them are aspects of the same thing, *quality of care*. This is the basic issue, and it is dependent on a wide range of people and policies at all levels - from national policy makers down to the care staff themselves.

Part of this care is obviously physical care - the provision of adequate and appropriate food, warmth, rest and such things as cleanliness and comfort, which may involve constant vigilance and work with people who, as we have seen, are incontinent or who are unable to move, or who dribble continuously. But equally important, from the parents' point of view, is to know that their sons and daughters are receiving emotional care - affection, understanding, company, communication and also protection from harm of any kind. This last factor is one that often looms large, for these young people can seldom protect themselves from others, whether the threat be from other people's aggression, or from mistakes made by those who are responsible, in such things as preparing food for those who may choke, or the administering of drugs. In an environment where there are many people to be cared for, each with very individual needs, parents are aware that mistakes are easily made, especially when there are too few staff. An acceptable level of care therefore presupposes adequate staffing levels, and employment of staff who care about (as well as for) the people they look after.

It is also essential that there are enough beds to provide regular - and emergency - short term care as frequently as individual families feel they need it, so that they can continue to keep their young adult children living at home for as long as they want to.

Parents also need to be able to count on a *reliable* short term care service. As we have seen, the success of the continuation of the families in this study has often relied upon a fragile balance between overstretched physical limits and negotiated arrangements between husband and wife. For the balance to succeed, a reliable contract with the service agencies is essential. Sudden gaps in availability, changes in frequency or abrupt changes in dates, inability (for whatever reason) to continue to provide regular short term care without withdrawing it for considerable lengths of time, are a threat to the very essence of the continuing fabric of the families concerned.

All these factors are necessarily interconnected and are not easy to disentangle. Almost all the families complain about the inadequacies of the adult short term residential care system, and its implementation. They are aware that it is not all the fault of the care staff themselves, but of the policy makers and administrators. Nevertheless, there is also a great deal of criticism of the way things are done on a day-to-day basis, and of the attitudes and beliefs of the care staff.

Such anxiety and criticism has even resulted in two families choosing not to make any use at all of available short term care services, in both cases because their experience of them in the past has been distressing, and they are unwilling to inflict the experience on their children again.

There is one Litchdean family that seems to be consistently content with the short term care unit that their son uses. The mother's view of this unit as a "small, homely run, friendly place" clashes with that of the other three families who use the same unit. She does not worry very much about her son when he is not at home - she says she has no idea what he does when he is away - but as long as he is happy to go there she is happy too. She compares the unit with the old mental handicap hospital nearby, which she knows well through visits to an older member of her family over many years. By comparison the unit can indeed be called a "small, homely run, friendly place".

It is an established, and obvious, fact that human judgement and comparison are always based on available knowledge. Such things as cleanliness, orderliness - even happiness - are all relative concepts.

Cleanliness and comfort

One of the most common causes of sadness and anger among the parents is the level of physical care in the adult residential units. Relative or not, it is clearly unacceptable that people should be left sitting in urine, and even faeces, whatever their mental or physical status. As we have seen, this appears to happen most often to those who are confined to their wheelchairs, and are less able to draw attention to themselves and to their needs. As suggested earlier, these people are thought by their parents to be ignored for long periods, especially when there are few staff - who may be busy controlling and attending to the needs of those who are more mobile and more demanding.

Although many parents are aware that the units are short staffed they still consider prompt nappy-changing and cleaning up to be an essential need of their adult children. At one level they are self-evidently correct - sitting in wet and dirty nappies causes rashes and sores - but it is also uncomfortable and unpleasant. After all, just because these particular young people cannot make specific complaints it cannot be legitimate to forget that their skins are at least as sensitive as anyone else's, that the sensation of a squelching nappy, the smell of urine and faeces and the feeling of wet thighs and legs are unendurable to anyone - so why should it be assumed otherwise for these youngsters? Not surprisingly, therefore, the parents, who treat their adult children as ordinary people who just need extraordinary care, cannot bear to think of, or witness, their children suffering in this way. Indeed, nothing could be more disheartening for a mother than to hear from her daughter's carer that if she wanted her daughter to be looked after "the way I look after her, then I should look after her myself - they said my standards were too high."

Parents feel that there is no excuse for low standards of care, and it is difficult not to agree with one mother's view:

> He was sitting in a wheelchair, soaking wet and dirty, still wearing the same clothes he went in on Friday. He'd messed himself, and he was sitting in it, and he was sopping wet - and the girl said "oh, I'm ever so sorry" she said "we're so short staffed" - but that's not the point, is it?

One of the things that upsets parents, and supports their view that their young adult children tend not to be treated as individuals, is the way that their clothes are often boiled, bleached or shrunk in residential units, and are frequently interchanged and lost. This may seem a minor point, but in fact is far from being so to parents. Quite apart from the considerable costs involved in replacing clothes week after week - none of these parents being able to afford to spend money in this way - it is a question of respect and dignity that their children, of whatever age, should appear well-dressed and clean.

One parent from Tramleigh, for example, whose income is very low, tries hard to dress her daughter well, although it is clearly an uphill struggle. She resents the fact that her daughter sometimes comes back looking like an orphan:

> She'd been away for a week, and oh, my God - you should have seen the sight of it! She went with a case full of clothes and she came back with a skirt right down to her ankles, and a jumper what would fit someone twice as big.

For these parents, when their children return home from residential care in other people's clothes it is, for them, just another insult. They rightly claim that if a person can say "that's not my sweater" as it goes over their head, or is able to ask where their own clothes are, or to go and find them, care staff would make an effort to try to sort out clothing, to read the carefully stitched-on name tapes, and dress people in their own clothes. Not so with these residents.

As we have seen, parents often feel guilt in any case about consigning their children to periods of short term residential care, and when the care provided by these units falls so far short of the kind of care that they want for their children, and which they give them at home, the situation is compounded. One mother says that when her son comes home she has to bath him, and herself - and even hose down his wheelchair - in order to get rid of the pervasive "Redelms smell" that clings to everything. Her reactions are not atypical:

> The next time he was due to go in I was in a terrible state, I didn't know whether to send him - I couldn't sleep the night before, tossing and turning, wondering what to do. I was so desperate for a rest that I took him in and I was crying my eyes out because I felt guilty... I felt so guilty, it was like I'd sent him to his death.

This feeling of guilt is a common one among the parents in this study. The few days of "rest" are hardly worth it. It is only the desperate need for physical and emotional respite that forces the parent to send a teenager away even when, as one mother said despairingly, they return "cold, stinking and hungry".

Feelings

Many parents speak of the need for their sons and daughters to be able to retain their dignity in spite of the undignified procedures they have to undergo, like having nappies or sanitary towels changed, and in spite of the visible consequences of their disabilities, such as wetting and soiling, or dribbling in public. The parents know that the older and more adult their disabled children become, the fewer the people who will want to look after them. Changing nappies on babies and young children may be part of the normal caring "package", but with adults this may well be a smellier, bigger, more difficult task, and not one that other adults normally have to take on.

Parents often feel that care staff do not respond to the changes that are taking place in their children as they grow up, but continue to respond to them at the level of their physical needs. As these young disabled people get physically older there is no reason to believe that they are not getting intellectually and perceptually older, or that their adult emotions are not developing, including sexual awareness. This does not mean (as discussed earlier) that they should be deprived of those comforts and playthings which are not considered "age-appropriate", but that carers, in their daily task of attending to the personal needs of these young people, must take account of feelings such as pride, embarrassment and humiliation. Thus they should act on the assumption that those they care for do not want their incontinence made public, that they would prefer not to have nappies changed in front of other people, or by someone of the opposite sex.

At an age when we would assume for others that they would need *more* understanding, *more* respectful and sympathetic treatment, those who care for these particular people appear to be *less* concerned with emotional needs, respect and understanding, than were those who were responsible for them at a younger age.

Parents also want their growing children to have intellectual stimulation. One of the Gunnerton mothers, who has few other criticisms of the short term care her son receives, feels that he is given little opportunity to use his brain:

> He was banging his head backwards and forwards on the floor, he was bored. I walked into that room and they were all sitting round like a load of cabbages, with no music on, no television, but the helpers were sitting drinking cups of tea and talking. Of course the youngsters are going to get withdrawn if they're not

> made to get their minds working and occupied - people give up on them too easily.

The problems in the residential units include not only undeniable shortages of staff but also deficiencies in staff attitudes; the carers who really seem to "care" stand out among those who appear not to care very much at all. Some of the parents are aware of the problems, and are sympathetic towards the young staff who, for example, are presented with the task of changing and cleaning up large, and often intractable, adults. One mother, who complains bitterly about the treatment of her son, nevertheless understands how they might feel:

> When people get adult they're different - even their body smell is different isn't it? I mean, if he dirties a nappy it sometimes smells terrible; it takes a lot for me to be sick but a couple of times I've, you know, *bwak*! A couple of times I've changed his bum and I've thought "oh, gosh, I can't", and it's easier to throw him in the bath. The trouble is he's mature, you know, and it all sort of sticks to him. I don't mean to be crude, but it's like glue - it's terrible!

It is not only that the task itself is unpleasant, but also the fact that people feel differently about adults, as one mother pointed out:

> Everyone loves them when they are babies, but when they're older its a different matter - no one wants to change them when they're all messy when they're sixteen or eighteen or whatever. I should think you've got to be quite dedicated to do it. I mean, although I do mine I don't know if I could go and tend to other boys as old as him - so I can understand, you know, I can understand that people perhaps wouldn't want to do it.

Nevertheless, none of the parents really excuses the overall situation in the adult residential units. They may not blame individual staff -except in a few cases - but they do blame the system that makes it possible, or even necessary, either to employ staff who do not care about the people they are looking after, or to run such units without enough staff.

Injuries and accidents

One of the greatest causes of parental anxiety about overnight absences from home is the vulnerability of their young adult children to attack from other residents in residential units. In some cases such anxiety has been shown to be fully justified. Parents feel that safety, above all else, should not be an issue in a system which is supposed to be about "care" - and believe that it must be possible to provide enough supervision to prevent injuries. When a weekend away results in cuts and bruises they feel even more guilty sending their children into short term care:

> She knew she didn't like it there, and when I went to leave she followed me, and took hold of my hand and wanted to come home with me. Now that girl can't speak, and she's classed as severely retarded, but she knew that she'd got hurt there, and I felt terrible leaving her. They should be watched more closely. I know they're short-staffed and they've got a difficult job, but my daughter didn't go there to get thumped, and she can't defend herself.

This instance illustrates the dilemma that parents are forced into when they desperately need short breaks, but are aware that their child may come to harm. In this case the mother kept her daughter at home for many months - with serious effects on her own physical and mental health, and consequently on the whole family. Lack of short term care, in this case, meant lack of sleep every night, because of her daughter's frequent epileptic fits. Without any overnight breaks the situation became almost intolerable, and her relationship with her husband deteriorated. When she burst into tears in front of her doctor he did nothing to sort out the problem, but merely prescribed Valium. Eventually, after five months without any short term care, she was forced to compromise, and let her daughter go in for short breaks, in spite of the risks.

This case emphasises two points. Firstly, that it is essential that there are sufficient staff to keep violent people away from others and secondly, that when one form of help for a family breaks down, for whatever reason, alternative forms of support should be made available.

There are, of course, all sorts of accidents which occur in residential care units which may not be avoidable - they occur at home as well. However, at home, the parents are there to watch, and influence, whereas when their sons and daughters are away they can only sit and worry about what may be happening.

Drugs

Because the majority of the young people in this study are epileptic, and have additional problems of different kinds, the prescription and administering of a range of drugs is an important aspect of their care. In fact, only two of them are on no regular medication of any kind. Three quarters of them are on some kind of anticonvulsants, the majority on more than one. Many also have additional medication at night, for sleep problems, and some also have antipsychotic drugs to control their behaviour. In some cases further medication is prescribed to counteract the more obvious side effects of the drugs, such as Parkinsonism, and drugs or enemas to deal with severe constipation.

Parents are often concerned about the number of drugs their young adult children are prescribed, but apart from this general anxiety one of the most worrying aspects of care away from home is the possibility of unacceptably high dosages of drugs being given - whether deliberately (for example to suppress violent behaviour) or by accident.

Such accidents do happen (as we have seen in Chapter 2) and they are rarely adequately explained to parents. One mother was surprised to hear, when she rang the unit late one afternoon, that her daughter was still in bed:

> They said “oh, she’s still sleeping”. I said “well, she never does that at home” and when I went over to get her I found out what had happened... her eyes

> were all rolling... she was drugged out of her mind, really... she was conscious but it was like she was asleep but awake, and making funny noises.

Another young person was seriously affected by a mixture of drugs given to her at the residential unit, where she had gone in order to "sort out her medication" - as a result she is now kept at home altogether:

> She couldn't move her facial muscles or her arms and legs, and when I went to meet her she didn't really know me, she was like a zombie, shuffling along.

The whole question of the prescription and administration of drugs to severely and profoundly mentally handicapped young people is fraught with difficulties. Many of the prescribed drugs have medically acknowledged side-effects and interactions. Apart from physiological effects on bone and muscle some drugs are known to have other effects - such as nausea, ataxia (shakiness and unsteadiness), blurred vision and confusion.

It is possible that the known side effects of anticonvulsant and antipsychotic drugs are largely disregarded by many professionals in the case of people who are unable to communicate their feelings and fears. The effects of high dosages, and mixtures of different drugs, may not always be recognised as such. For example, some of these young people seem reluctant to walk, in spite of being physiologically able to do so. It is possible that this is not through "obstinacy" or "laziness", which are sometimes postulated as reasons, but may be caused by a fear of falling down, or a sense of confusion - or may be the result of blurred vision.

Normally only the parents of these young people have the intimate knowledge to distinguish between their "normal" and "abnormal" behaviour, whether caused by drugs or whatever. In residential care units, staff have little time to notice such differences, and in any case, *expect* abnormal behaviour from these young people, but they cannot really know what is "abnormal" or "normal" for a particular, virtually unknown, individual. The parents are right to be concerned about the consequences of their children's inability to express or complain about their feelings and fears.

Parents (whether they - or the professionals - know why it is happening or not) see their children becoming gradually less able to walk or to control their movements, become clumsy, shaky, and apparently fearful of walking outside the house, even into the garden. The result is that parents become even more worried and protective, and their determination to care for their adult children themselves grows, as their anxiety about what may happen to their children when they go into short term care increases.

Staff problems

It is abundantly clear, from all that has been said so far, that the number and quality of staff working in residential units are of vital importance to the well-being and safety of the young people who stay in them.

Parents worry about the fast turnover of staff. The continually changing staff sometimes have no time to learn even individual names, let alone the needs and preferences of short term care people, whom they see so infrequently. Similarly, the young people do not have time to get to know or trust the care staff. Some parents firmly believe that staff who come and go in this way are merely doing the odd few weeks as a stop-gap, without any dedication to the job.

At Ashgrove the staff situation has often been very bad. At one point it seemed to parents that there were hardly any staff at all:

> At the moment Ashgrove is going through an almighty shake-up, they've lost...ten staff in a month, ten resignations, so you don't know who you're going to get in their place, and there's constant changes... they put an advert in the paper for ten and only three turned up for the interview and none of them was suitable, so what happens now?

Another result of continually changing staff is that in cases where a parent is trying to accustom a young adult child to living away from home, little progress can be made, as this Deerminster mother found out:

> She comes across so many people who don't know her, all the time, because of the changes in the staff, and so we have to go back to square one so many times. If it was the same people she was with all the time it would be a lot different - not new people having to get to know about her, and her having to get to know them.

Parents often reported that they could not find any staff when they arrived at the unit to collect or deliver their children:

> It took me quarter of an hour to actually find anybody to leave him with - all the residents were sitting round

> the room, and anything could have happened. The only bloke I could find was an electrician doing a job, I shouted, I ran up and down stairs but I couldn't find a soul.

One parent, returning to one of the Tramleigh units to collect some pills, could find no one around:

> We walked all round that house and couldn't find no one in charge - she was right down the staff room having a cup of tea and there was children right by that door that could have gone out in the road, or anything, and she said to me "oh, we're short staffed..."

In some cases this lack of vigilance has led to young people walking out of open doors, and wandering away into busy streets. There have also been a few instances of sexual assault, incidents which might have been prevented if there were adequate numbers of staff.

But it is not only understaffing and rapid turnover of staff which is the problem. Pay for care assistants is low, and it is thus not surprising that posts in adult residential care units are not considered premium employment, and therefore there is no reason to expect quality of service.

Nevertheless, it is quality which, as we have seen, is not only demanded by the parents, but is essential. Thus, if care staff do not bother (or are not trained) to be friendly and interested when parents take their children to units for the first time, the results may be both long term and destructive.

One mother's experience of an uncaring and slapdash approach is not unusual:

> It seems such a strange place, you don't see anyone there, they didn't introduce me to anyone. I haven't looked round it or anything. You just get someone come out and take him off, you know. I don't know who she is and you just feel awful. I came back and I was in tears because you just don't know what he's going through, and you're not familiar with the place, you don't know where he's sleeping, or what... they didn't ask me anything about him, his drugs or anything, whether he can speak - I just find it so slapdash, and you think if that's the way they organise it, how the hell are they looking after him? I mean, he can't chew things, no one has asked me about his food. I don't know whether its because they think, oh well, they're adults and they've survived this long, just shove them a cup of tea and something to eat, you know, they'll be all right.

When such apparent inefficiency is combined with a lack of knowledge about the individual needs of a particular person, it can become dangerous - as in the administration of drugs or in the preparation of food for those who do not chew their food - or even fatal.

This situation arises not only because staff are constantly changing, but is also the result of lack of communication between staff and parents. Not surprisingly, the importance of the quality of individual staff is continually stressed by parents. Yet many go to immense pains to retain dispassionate judgement, as this father does:

> You're bound to get a change over of staff. How do you expect a person to go and work under the conditions that they do work under for about £60 a week? It's daft, isn't it? If you want the best out of anything then you've got to pay the best... it's back to the old money bit... the system is running on people... that are doing their job because they like to do it and would continue to do it even if they got *less* money...
> if that's reckoned as being OK by the DHSS then what they should do is start a new order of nuns, and get it for nothing, because that's what they're doing isn't it? We're going back to the Middle Ages... the [best people] are doing it because they want to do the job anyhow, they're not doing it for what they are

> getting out of it, because they're not getting sod all out of it.

Yet at the same time he acknowledges that the efficiency and personality of the person in charge of a residential unit may be all-important. The influence of a good manager has been strikingly illustrated in previous chapters in the case of Alice, the nurse manager in charge of Redelms for a few years, and highly approved of by parents. She was friendly, efficient, knowledgeable and understanding of the young people and their families. The parents knew that if they could get hold of Alice she would at least listen to them. Even the parents of the most difficult young people appreciated her because she knew how to manage difficult residents without losing her nerve or her cool.

It is vital to parents that they feel they can trust the staff who care for their children. Although some carers may be trusted on the strength of their individual qualities most parents emphasise that carers also need to be suitably trained - for those young people who are multiply handicapped, epileptic or ill it is felt that there must always be trained nursing staff on duty. Parents also feel that many of the problems that arise with their difficult children, whether at school, Adult Training Centre or short term care unit, could be avoided if staff had been trained, not only in methods of control (other than the administration of drugs), but also in strategies to avoid the occurrence of violent episodes.

Apart from specialised training of this kind parents also consider that care staff need to be taught basic caring skills, including such things as respect and understanding, how to develop communication with people who have no speech and to encourage emotional and intellectual development.

Breaks in the provision of short term care

As seen at the beginning of this chapter, it is of fundamental importance to the parents that they should be able to count on the reliability of the breaks offered by short term residential care. There are many instances of dates not being adhered to, but a far worse situation is sometimes caused by the complete withdrawal of short term care for all families (through closure of units - temporarily or permanently - or lack of adequate staff) or the withdrawal of care from individual families, for whatever reason. Although to the professionals the idea of six months or so without short term care probably seems to be no time at all, for the families concerned it seems a lifetime. When short term care was withdrawn in one area, while a unit was being reorganised, one mother felt she was reaching the end of her tether. Her appeal for help was met with the suggestion that she might consider getting private care:

> I said, "where am I going to get the money to put her into private care for the weekend?"... you've got to laugh or go under, haven't you?

For some of the parents these months without a break are almost impossible to get through. As one mother said, it is easy enough for the professionals in the services to write a letter saying "sorry, there'll be no short term care", but for some of the parents it was almost the difference between being able to cope, and going under. None of the families did, in fact, "go under", but this was because they somehow pushed themselves even harder than usual.

In the Tramleigh area, two of the three families were without short term care for long periods, one for a year and the other for two years. In the latter case the nineteen-year-old concerned had proved too difficult for the staff in the local residential units. Since she is totally dependent for all her basic needs, has frequent fits and episodes of violent aggression her mother's life has had to totally revolve round her. When her mother was finally offered some short term care for her in a newly opened unit - which proved to be excellent - she almost refused it because she was afraid that her daughter would find it too hard to adjust to a strange place after so long:

> The last time she went she hadn't been away for nearly twelve months and she got very upset being away from home, she wouldn't eat and she wouldn't sleep, she wouldn't do anything.

Other parents say the same thing - there comes a point, after a certain length of time without any short term care, when parents feel it is almost not worth going through the worry and anxiety of starting it again. Certainly, if part of the aim of the professionals is to prepare parents and their adult children for future long term separation, such gaps in the provision of short term care defeat the purpose.

In Litchdean, there is a young woman whose tantrums are so violent that she is liable to injure herself, throwing herself around the room. Normally she has a week a month in short term care, and her mother cannot manage without these breaks from her. She needs to know that she will get them regularly, otherwise, she says, "one day I'll 'flip'!" Asked what she meant by this she said:

> I mean I could kill her... I *have* felt like that. I mean, last night she threw a wobbly and I thought, "I will not interfere, I'll just let her get on with it." [She bursts out laughing] But I can't leave her - I'm frightened she's going to hurt herself! I say "come here, calm down"... and I take her out into the garden..

This year she has been told that there will be no short term care for three months in the summer. She has complained to her community nurse, who is extremely supportive, but since the resources are apparently not there to be drawn on, there is little that the community nurse can do. This mother will probably get through somehow - as she has in the past.

However, just because these remarkable parents have survived, professionals should not disregard the effects of sudden or prolonged breaks in the provision of short term care. One mother, for example, was pushed to her limits when her sixteen-year-old son was somehow left in limbo between the children's services and adult services, and was without any short term care for six months:

> No one sort of came to see me about the fact that he's sixteen, or ask if there are any problems or anything. You think, Oh God, perhaps I'd just better resign

> myself to the fact that you are not going to be going anywhere any more, you know? But then you've got nothing to look forward to, and it was getting so depressing, I was saying to the kids "we won't be able to go on holiday or anything."

Although very physically disabled her son is highly destructive, and has to be watched every moment:

> You can't leave him for two secs really, because he'd hurt himself. That's where the strain is - if I want to go to the *loo* I've got to plan it, I've got to get someone in to sit and watch him while I go to the loo, that's how stupid it is. And I can't even walk down the road with him - he dribbles so much that he's frozen before you even get down the bottom of the road.

She feels she needs time without him, to give her a chance to gather her strength:

> When they're younger you don't seem to need it so much. It seems the minute you tend to need it, it's gone. I just sit back, sort of tensing myself, waiting for the next blow to come. I just don't know what to expect next. All of a sudden he's sixteen and no one prepared you for this - that they are not going to do anything. Sometimes you feel they're pushing you to

> say “well, I just can’t cope any more”. It’s as if they’re making it so difficult that you’ve got to admit defeat - you have to actually crack up or something, physically or mentally. Either you just keep him at home and suffer, or they take him away and you suffer - they don’t seem to want to make it easier for you so that you can keep him at home but still have a bit of a rest.

This example illustrates the dilemma that many parents find themselves in. They need short term care to enable them to have their young adult children living at home, but when for some reason this service is withdrawn they are afraid to cry out too loudly, in case the professionals decide that they can no longer cope with their children. Many of the parents feel that this is just another example of the professionals' insufficient knowledge and understanding of their feelings, perceptions and priorities.

The parents who have the most problems seem to be the ones from whom services are most often withdrawn. In some cases parents even grow to believe that they are being manoeuvred by the professionals into a situation in which they will be forced to put their children into permanent care.

Ideal care

The picture painted in this chapter may be a gloomy one, but there are chinks of light, and the scattered examples of praise and admiration by parents should not be overlooked.

Bess White, for example, whose son Ben (as seen in Chapter 2) has tended to leave a trail of scared and helpless professionals in his wake, recently found a group of people who were prepared to offer him affection and companionship - albeit only for seven days.

For the first time, Ben was given a week's holiday (arranged by Bess's community nurse) at a "holiday home" - a small house near the sea. It was a week organised for young adults who need special care of some kind, and there were fifteen staff to look after seven young people. Bess had to pay £35 for it, but it was worth it - the young people were treated as individuals and as friends, rather than as "residents". Great efforts were made to communicate with them, and to involve them all in exciting activities. Altogether it was the kind of care that all the parents in this study would consider ideal:

> It was splendid. I've never seen anything so well organised - in fact they could learn a lot up here by going down to see that organisation. They came actually out to greet us, "Hello, Ben, come on in, come on Ben, you must be thirsty after your long drive"... a man came from up the corridor "Oh hello, Ben, you've got your bucket and spade, good. Come on then, I'll show you where you're going to sleep"... he was as good as gold all week - they said he was hard work, but no tantrums, no trouble. He was so happy, and he was so well cared for. I was impressed - and it takes quite a bit to impress me!

The first few days Ben was away Bess kept ringing up to make sure everything was all right. Every moment she and Jack expected a telephone call asking them to come and take Ben away. But the telephone did not ring, and gradually, for the first time that they could remember, Jack and Bess relaxed.

The significant elements of care in this case were firstly, sufficient staff, and secondly, staff who established a relationship with the young people they were working with.

The importance of these factors became clear the following year, when Ben went again to the same holiday home. His parents happily left him there, expecting another stress free week - but the people in charge were different this time, and there were fewer of them. Ben was reported to have "behaved badly" and the week was not a success for anyone.

Many parents stressed the importance of the number and quality of staff. As another parent said:

> It's a fallacy to assume that money alone will make a good home... it doesn't matter whether the carpets are old if the child gets lots of cuddles... its the people who are there that are far more important than the kind of building they're in.

And another:

> It isn't actually the place or the building which counts, it's the people, isn't it? These things are only as good as the people working in them... the kind of people who sort of take them on board... who come into work and consider the people they work with as part of their second family, that kind of attitude.

A vital part of ideal care is this commitment to the people being cared for. Of course there must also be *enough* staff, so that there is sufficient time and opportunity to demonstrate a caring and sympathetic attitude.

There is currently no *adult* unit in this area that could be described as ideal, but there is a *children's* unit in Deerminster which approximates quite closely to most parents' ideal model of care, at least within the context of residential units.

Their are various different aspects of this Deerminster unit that combine to make it highly acceptable to parents. They include the fact that the person in charge of the unit, and her staff, are extremely sympathetic and understanding both towards the children in their care, and towards parents; there are separate units for children receiving short and long term residential care, and only four to six children in each; parents are encouraged to visit the unit, and to take part in its activities, and have regular meetings with staff and other parents; each child has a key worker who spends the majority of his or her time with the child; problems that arise regarding the child are immediately discussed with parents (and with teachers at school) and any programmes initiated either at home, at the unit or at school (such as behavioural interventions) are carried out in all three settings; the unit is clean, cosy and as "home-like" as possible.

Although none of the adult units in the area come up to these standards, some of them had some of these qualities some of the time. It is significant that parents usually related the onset of a "good" period to the appointment of a different person in charge.

However ideal the Deerminster residential unit may be, it is still a residential "unit". Most parents would prefer their children, of whatever age, to stay in small, purpose-built flats or bungalows - with two or three other short term people, preferably familiar to each other - run along the lines of a domestic household, rather than a small institution.

One step even further towards "home-like" care is the provision of short term care in the homes of other families: short term "family placements", or "family-based care". A few of the families in this study were asked whether they would be prepared to try this, but no host families were actually found. Many parents - especially those with very physically handicapped and vulnerable children - could not envisage this short term fostering as a viable alternative to residential care, unless "substitute" parents could be found who had suitable qualifications or experience. Other parents, whose children were aggressive or destructive, did not expect to find any family to take them on, even for the odd weekends. The fact that their children were already young adults was thought to be a problem - parents believed that other families would only want to take on younger children, and that it was now too late for theirs.

On the whole the idea of family placements was thought to be good - but only if host families were experienced enough, and prepared to make long term commitments to the young people concerned. Even then, the shadow of the future, and of possible institutional care, still tended to remain.

One of the major difficulties faced by families in their struggle to obtain adequate services is undoubtedly the lack of co-ordination between the various sources of possible services - Health, Social Services, Education and voluntary agencies. One of the reasons, for example, why few of them had received information about family-based respite care, which is provided by the Social Services, was that their main contact is with NHS-based community mental handicap nurses. Ideally, the latter would act as channels of information from all sources, but in fact were often either insufficiently informed themselves, or did not think to offer unrequested information. Thus parents sometimes only heard by chance, from other parents, about sources of help, or about allowances they might be eligible to claim.

In the context of respite care this need for one designated person to serve as a link to all available services is vital. It may be that such a "key" or "link" person of this kind should not be directly connected with the *provision* of the services, but be free to act solely on behalf of the families. It is not often possible for parents with disabled young adults living at home to do anything more than just keep going from one day to the next. There is seldom time or energy left over to form pressure groups, to take up issues with unsympathetic authorities or to risk upsetting the unstable equilibrium in which many find themselves. Most families would welcome someone to act as a kind of "family advocate" - not only to give them all the information they need, from all sources, but also to take up their causes, and help them fight for a range and quality of services for their children and for themselves.

4 Conclusions

This account of the provision of short term residential care services to twenty families and their young adult children has revealed a sad state of affairs. It has also exposed a dilemma that many mothers feel they are in - whether or not a weekend "break" is worth it when it causes them so much anxiety. But the pros and cons are like a ton of feathers and a ton of coal - they may weigh the same but they have nothing else in common. It is difficult for mothers, especially, to balance their own needs for sleep, for time alone or with their husbands, against their disabled child's needs for love and comfort, familiar faces and clean nappies.

It is significant that all except two do currently make use of the short term residential care service, and would like to have more. In fact, most of the families could not do without it now, and when it is withdrawn life at home becomes almost unbearable.

Ironically, although it is the short term care that makes it possible to continue to keep their adult children living at home, it is their experience of this residential care that makes them determined not to let their children go into permanent care. This determination leads three quarters of the mothers to express the hope that their children will not outlive them, and in a few cases this hope is even a statement of intent. Whatever actually does happen in the future, this is clear evidence of powerful emotions, and cannot, and should not, be lightly dismissed.

At this age and stage in life it might have been expected that the families would have been making plans for the future, for the time that they themselves will be old and less able to cope with a disabled and difficult adult. Instead, many of them felt unable to contemplate the future, because they believe that it is only by living at home that these young adults will continue to receive the love and the physical care which they need. They cannot see any viable alternative.

As long ago as 1979, the *Report of the Committee of Inquiry into Mental Handicap Nursing and Care* (The Jay Report) stated:

> The first question to be asked must always be "How can we provide support which will allow the child to continue to live with his own parents and his own brothers and sisters, in his own home, in his own community?"

Ten years later the mother of a severely handicapped sixteen-year-old in Hamling asks:

> What is the point of keeping them alive until they are sixteen if all of a sudden nobody is going to help you and nobody cares about them except you? What's the point if they're either going to be put away or you keep them at home and you just become a prisoner? If they're going to keep them alive, and look after them when they're children, then its got to be for ever. You can't just give someone a life limit of sixteen...

In 1988 Sir Roy Griffiths told Government in his *Community Care: Agenda for Action* that:

> To translate broad community care objectives into action for individual people, those arranging public services must:
>
> - have systems which enable them to identify those who have need of care and support in the community;

- assess those needs within the context of the individual's own situation;

- taking account of the views and wishes of the person to be cared for, and any informal carers, decide what packages of care would be best suited needs, whether provided directly or indirectly;

- arrange delivery of the services decided upon;

- keep under review the delivery of that package of services, and the individual's needs and circumstances.

The quick and full implementation of these recommendations by Government is the only spark of hope for the twenty young adults in this book - and for their parents, who have so clearly and consistently expressed their dissatisfaction with the current provision of services.

The recommendations which follow attempt to translate the general sentiments of the Griffiths recommendations into *specific actions* relevant to the categories of parents and young adult children described in this book, and to the provision of one service - short term residential care. Although care in residential *units* may not be considered the most suitable form of respite care, the recommendations apply particularly to these since, for the families in this study – and for many others – this is currently the only type of respite care available. As the foregoing pages have shown all too clearly, the exceptional nature of the problems confronted by such parents and their children are unlikely to be met by more general strategies and intentions - they demand specific action.

5 Recommendations

RESIDENTIAL SHORT TERM CARE

1. Residential short term care should be available *by right* to *all* severely and profoundly mentally handicapped people who are living at home.

2. If short term care is to be in residential units, these should provide short term care only, and be of a size and design that will minimise the contrast between home and residential care.

3. If a transition from children's services to adult services is necessary for administrative reasons, this should take place:

   - at the age of nineteen or older, and be preceded by a comprehensive assessment;

- over a period of at least a year, so that there is no abrupt change of people or place;

- with a familiar adult for the initial stage of the transition and, where possible, with the same group of children through adolescence and into adulthood.

4. Residential short term care units should be adequately and appropriately staffed to ensure that:

   - parents are able to make use of the units as often as they wish in order to enable them to continue to have their adult children living at home;

   - the needs of those young adults who are ill, or profoundly disabled, are adequately catered for;

   - the needs of those who have serious behavioural problems are adequately met;

5. Residential care units should be inspected without prior notice by independent inspection units.

6. Service managers should recognise the unique experience and information that parents have regarding their young adult children, and ensure that they:

- are fully informed of the various short term care options that are available to them, and are fully involved in discussion and decision-making with regard to the most suitable type of care for their young adult child;

- are invited to provide information about needs, preferences, fears and preferred occupations etc. This should be entered in writing and be accessible to all carers;

- are encouraged to visit the unit at all reasonable times;

- have access to a named carer, who has special responsibilities for their adult child;

- are consulted before additional medication is given, or if medication is changed, and informed at once if any crisis arises, or if medical help is sought for any reason;

- are involved in a written exchange of information (in the form of a book or folder) between the providers of short term care and the home regarding health, disturbed behaviour, sleep problems, accidents, eating problems etc. This should always accompany each individual as he or she moves from one environment to the other;

- are given, as far as possible, the dates they request for short term care, and that these, once agreed, are not normally altered.

7. Service managers should ensure that all carers:

- carry out personal tasks such as the changing of continence pads, undressing, bathing, etc. in privacy, and, whenever possible, restrict such tasks to people of the same sex;

- are aware of the medical, personal and social needs of each individual in their care;

- are trained to treat the people in their care as individuals, and to respect their individual needs, preferences and dislikes.

Further Reading

Ayer, Sam and Andy Alaszewski (1986) *Community Care and the Mentally Handicapped: Services for mothers and their handicapped children*. London: Croom Helm.

Brechin, Ann and Jan Walmsley (1989) Eds. *Making Connections: Reflecting on the lives and experiences of people with learning difficulties. A reader*. London: Hodder and Stoughton.

Glendinning, Caroline (1983) *Unshared Care*. London: Routledge and Kegan Paul.

Griffiths, Sir Roy (1988) *Community Care: Agenda for Action*. London: HMSO.

Hicks, Cherrill (1988) *Who Cares: Looking after people at home*. London: Virago Press.

Oswin, Maureen (1984) *They Keep Going Away*. London: King's Fund & Oxford University Press.

Pitkeathley, Jill (1989) *It's My Duty, Isn't It? The plight of carers in our society*. London: Souvenir Press.

Richardson, Ann and Jane Ritchie (1989) *Letting Go: Dilemmas for parents whose son or daughter has a mental handicap*. Milton Keynes: Open University Press.

Robinson, Carol and Kirsten Stalker (1989) *Time for a Break - Respite Care: A study of providers, consumers and patterns of use*. An Interim Report to the Department of Health. Bristol: Norah Fry Research Centre.

Robinson, Carol and Kirsten Stalker (1990) *Respite Care - the consumer's view*. Second Interim Report to the Department of Health. Bristol: Norah Fry Research Centre.

Ryan, Joanna with Frank Thomas (1987) *The Politics of Mental Handicap*. London: Free Association Books.

Shearer, Ann (1986) *Building Community with People with Mental Handicaps, Their Families and Friends*. London: Campaign for People with Mental Handicaps and King Edward's Hospital Fund for London.

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HOME-BOUND

JANE HUBERT

Home-Bound describes the experiences of twenty families who have, living at home, a teenager or young adult with severe learning difficulties who has been classified by professionals as 'severely' or 'profoundly' mentally handicapped, and who also has 'serious behavioural problems'.

Home-Bound documents the lives of these families, and the major, uphill struggle they have to keep their children at home, often with little or no support from the health and social services. Short-term 'respite' care, considered by parents to be the most vital service, is provided in residential units which fall far short of any ideal level of care.

The experience of these parents can shock - "..quite honestly, I'd rather give him an overdose, than see him go in there'.

Jane Hubert, a Senior Research Fellow at the University of Southampton, is an anthropologist who visited and talked with the families over a three-year period. She found an unexpected and extraordinary world, and documents this with graphic accounts from the families themselves.

Home-Bound is a moving story which should be essential reading for all those connected with services for people with severe learning difficulties. It provides a valuable insight for those who plan, manage or deliver services to this client group, whether through the health service, social services or voluntary agencies. Students of social service and anthropology will find the book to contain a rich and disturbing account of family experiences.

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