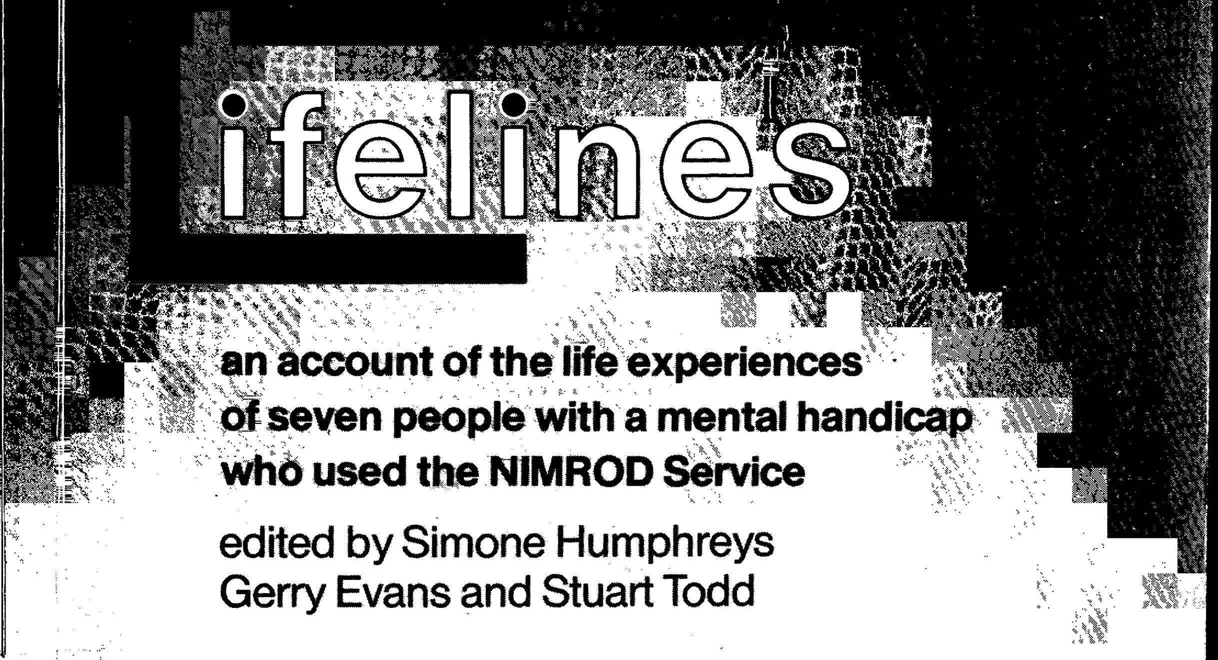

Lifelines

an account of the life experiences of seven people with a mental handicap who used the NIMROD Service

edited by Simone Humphreys
Gerry Evans and Stuart Todd

King Edward's Hospital Fund for London

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The Mental Handicap in Wales – Applied Research Unit was established in 1975. The Unit conducts research with the aim of achieving effective, comprehensive community-based services for people with a mental handicap in Wales. This research is directed at promoting services that are capable of encouraging the development of skills and the provision of opportunities to enable mentally handicapped people to lead normal and valued lives.

A major component of the Unit's work in recent years has been the long-term evaluation of the NIMROD Service in Cardiff, an evaluation supplemented by a series of short-term studies. The Unit is, also, embarking on the long-term evaluation of the All Wales Strategy for the Development of Services for Mentally Handicapped People.

The Research Unit is based in Cardiff and is part of the Department of Psychological Medicine, University of Wales College of Medicine. The Unit is funded by the Welsh Office and Department of Health and Social Security.

A bibliography of Unit reports is available from The Mental Handicap in Wales – Applied Research Unit, St David's Hospital, Cardiff CF1 9TZ. Telephone Cardiff (0222) 26188.

APPLIED RESEARCH UNIT STAFF

Director	Roger Blunden
Research Officers	Simone Humphreys Gerry Evans Stephen Beyer
Research Assistants	Kathryn Lowe Siobhan de Paiva Stuart Todd
Secretarial Staff	Yvonne Emanuel Pamela Collins

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INTRODUCTION

MEETING THE PEOPLE

This publication presents an account of the lives of seven people who live in the west of Cardiff, South Wales. They have all, at some stage in their lives, been labelled as having a mental handicap or have received specialist services for people with mental handicap. In 1980, the area of Cardiff in which they live became the setting for a new experimental scheme – the NIMROD Service – which was one of the earliest British attempts to provide a range of support services to people with mental handicaps in their own communities. Today, however, such policy initiatives are becoming increasingly commonplace, with community-based service provision being government policy for a number of client groups. In the late 1970s, such initiatives were viewed with deep scepticism; in particular, residential provision in ordinary housing for people with severe handicaps was frequently seen as being idealistic and misguided. In 1980, the seven people described here became eligible to receive NIMROD services.

The authors first encountered the seven individuals in their role as evaluators of the NIMROD Service. Because of the innovative nature of NIMROD, a long-term research evaluation of the scheme was commissioned by the Welsh Office and the DHSS. The evaluation of the NIMROD Service in its early days concentrated on examining changes in the behaviour of all individuals receiving the new Service, on examining changes in their activities and relating such changes to the way the NIMROD Service was developing. The results of the evaluation were aimed primarily at an audience of academics and service planners. As the evaluation proceeded, it became apparent that the life stories of the people who were 'subjects' of the research held insights which could be valuable to a much wider audience – namely, service deliverers, service users and, also, people who had no direct involvement. Another major aim was to provide some much needed detail and individual perspective to complement and supplement the data of the long-term evaluation which, by its nature, related to major groupings of people with mental handicaps in 'communities' or residential settings. This, therefore, is the origin of the content of this book.

The information for the book was obtained by the authors spending time with the individuals in the range of places they visit, by talking to them and to the other people in their lives. It was also important just to stand back and spend time in the environments in which the individuals spent their time. In addition, records and documents were consulted to develop pictures of their backgrounds and life histories. This process of information-gathering took place over a period of approximately six months during 1985.

The original intention was to give an indication of the impact of the NIMROD Service on the lives of the individuals. However, it became apparent early on that the descriptions of the people gave much more than a view of their involvement with a relatively new specialist mental handicap service. They also gave a picture of the situation of handicapped people in present-day society. While every description is very individual in nature, issues such as the struggle for basic rights as citizens can be seen from each account. One of the most striking features, common to the seven people, is the lack of control they have over their own lives and that their lack of autonomy is frequently unrelated to their handicap.

Another striking feature is the wide range of different, individual life experiences; the individuals were originally selected to illustrate the experiences of people of different ages, degree of handicap and living situations. Indeed, these are but seven of the 150 people who have been identified as NIMROD clients and, of course, their real names have been changed to protect their identities. Liam Roache is one of the three men who live in NIMROD's only group house; Victoria Adamson and David Stevens are two of the 32 adults living in NIMROD staffed houses; Robert Griffiths and Pauline Davies are two of NIMROD's 49 clients who live in long-term residential care in hospitals or hostels (nine of whom live outside the county of South Glamorgan); Michael Collins and Carl Wilson are school-aged NIMROD clients who live at home with their families. In all, there are 69 such clients, 25 of whom are school-aged children.

Michael Collins's experiences are also an account of the struggles of his family. The impact of mental handicap on family life has been well documented and this story highlights the struggles which children with handicaps and their families still face. This account illustrates, in particular, the determination of parents, a feature which is common to a number of the other accounts. It also reflects that many of the struggles which service users face are a direct result of the actions of the service providers and the services which were designed to support such individuals.

Carl Wilson is a young man reaching school-leaving age – a time school students look forward to as an indication of increasing maturity. And, at times of full employment, when they have been able to assert their financial independence from their family. However, for Carl, everyone closely associated with him sees it as a very challenging time, and one which is not full of optimism. For Carl the options are very few and the chance of being able to earn a reasonable wage to support a more independent lifestyle is, at present, very unlikely.

One of the fundamental principles underlying the NIMROD Service when it was established was that community living is an option that should be available to every person with a mental handicap. The number of individuals exhibiting very challenging behaviour is a very small proportion of people with mental handicaps. Robert Griffiths has some very severe communication difficulties which have been accompanied by loss of sight. For any person, the experience of losing one's sight would be traumatic and for Robert it has been yet another difficulty on top of many others. The behaviour he exhibited was probably the most challenging any service would have to try to respond to. The account of Robert's life, and particularly his experiences with the NIMROD Service, reveals the dedication of service providers who tried every avenue to support Robert but who, despite this, have had to resort finally to hospital provision – a very unhappy option for all those involved.

The ultimate form of segregation people with handicaps often face is that of being admitted to an institution. The reasons for such admissions can vary from a family crisis to a gradual process of reduction in a family's ability to cope with supporting an individual. Whatever the reason, the admission of an individual to a hospital or hostel is nearly always viewed as a last resort and an indication of service failure. Pauline Davies had lived in the community for 37 years, leading an active and productive life. For nearly 35 years she led a life in which no reference to a mental handicap was made. Within five years she had been admitted to a mental handicap hospital and is still there 13 years later. In the account of her life, the contrast between her early life and life in an institution with its deprivation and loss of control is particularly striking.

David Stevens was admitted to a hospital at a very young age because of the inability of his parents to support him at home. For nearly 20 years he lived in a hospital, leading a very deprived life and experiencing a harsh regime. In 1981, David was given the opportunity to move to a staffed house in the community and, as reflected in the staff accounts presented, he has come into close contact with people who genuinely care about his future. The individuals he has met, however, are paid to be with him and his experience of community life reveals that moving people to ordinary housing is probably the easiest part of developing community-based services. Helping people to participate in community life is a much greater challenge.

Victoria Adamson and Liam Roache have both avoided long-term accommodation in institutions. Victoria moved from a close and supporting family to a NIMROD staffed house and has now moved on again. She has successfully participated in activities for people with handicaps. The account, however, reveals the low demands which are made of her in her work and the overwhelming mundaneness of her life in her day setting. A similar picture emerges from Liam's story – namely, his disillusionment with his day setting and his rejection of being congregated with other people with handicaps. The impression gained from Liam's life story is one of a person who, to a large extent, is present in the community but who appears to be a lonely person.

The accounts presented here illustrate a factor which is common to any discussion about people with handicaps. The focus of such discussions usually centres on the differences or dissimilarities of people with handicaps in comparison with those who have no apparent handicaps. The accounts serve to provide a picture of individuals with mental handicaps as members of society who, despite their handicaps, and frequently despite the additional handicaps imposed as a result of the way in which services are organised, are attempting to lead ordinary lives in their communities. They also, unfortunately, illustrate the long way we have to go before we can effectively provide the types of flexible and individual support needed by the individuals described. The detailed and honest descriptions of the lives of the people as presented in this book do, however, reveal the contribution that an examination of the lives of individuals can make to increasing our understanding of the directions in which services need to develop.

MICHAEL COLLINS

by Stuart Todd

Michael Collins is the youngest of the seven people to whom you will be introduced. This portrait can therefore be used as a yardstick to detect shifts in attitude towards mental handicap over the years when compared with the early lives of the other six individuals. In this way, many aspects of Michael's story are disappointing, in that they show that little has changed over time, particularly the limited perspectives with which some professionals apparently continue to view mental handicap. Another aspect of this study is the description of the experiences of the family of a young child who has a mental handicap, and the way in which services intervene in attempting to deal with them, focusing on the response of the local education authority and the NIMROD Service to the needs of a child and his family.

This case study, however, would not be complete without describing Michael who, like other children with a mental handicap, has been perceived as a problem from the earliest months of his life. Some attention is given to describing his lifestyle, and his educational and leisure experiences. However, given Michael's youth, this story is just as much a reflection of the attitudes of society towards mental handicap, and the effect on a family of bringing up a child with a mental handicap, as it is a study of a child's individuality.

Michael is ten years old and, like the majority of children with a mental handicap, lives at home with his family. There is little doubt that his life has been affected by changes in service provision for people with a mental handicap over the last 20 years. He attends school and is expected, in adulthood, to live in the community rather than in an institution. However, other aspects of what might constitute a valued and normal life have yet to be considered as realistic options for Michael's future. He is fortunate, though, in that his future will be in some way shaped by the potential successes of the All Wales Strategy.

Michael's home is situated in the centre of the NIMROD catchment area, about a mile from the city centre. He lives at home with his parents and elder sister. His father, John, is 39 years old and works as an engineer for British Telecom. His mother, Anne, is 35 years old and is a friendly and active woman who has worked hard to ensure that Michael has received the services he needs. His sister, Rachel, is 15 years old and attends a secondary school a few miles from home where she is preparing for her 'O' level examinations. The family is an active and outgoing one. John is keenly interested in sports, and is involved with the Scouts and the Special Olympics. Anne is involved in a great deal of committee work: she is a member of the NIMROD consumer group; she is the parental representative for the voluntary sector on the South Glamorgan County Officers Group, and is also a founder member of the Support Group for Integrated Education in the Cardiff area. Rachel is a Venture Scout and, like other girls of her age, enjoys youth clubs and fashion. The family have lived in their present home for just over seven years and previously lived in the north of Cardiff. They are well known and liked in their neighbourhood, and Michael benefits from the family's network of neighbours and friends.

In the words of his mother: 'Michael is a nice-looking boy and has a nice body'. She also describes him as active in things which she views as inappropriate; for example, dismantling the gas fire or standing on the gate and rattling the latch. He has little general interest in toys but has some preference for musical ones. Like other children of his age, his taste in food is for crisps and fizzy pop. He enjoys playing games such as water-play and rough and tumble. He also likes swimming, riding in cars, playing in the park, kicking a football and listening to music. He is ambulant and has full, effective use of one arm; the other is slightly rigid due to his epilepsy. He uses a few Makaton signs which, together with some other non-verbal expressions, are used to indicate his needs and emotions. He has no speech but he does interact, albeit awkwardly, with members of his family and a few others who are close to him, but he does not engage in any type of group activities. He appears to show no interest in major events such as birthdays and Christmas, and does not appear to be disappointed if expected visitors fail to arrive. He has no friends outside the family, other than the NIMROD staff who spend time with him and are paid to do so. Although he has opportunities to meet other children, he apparently has no interest in doing so. He also engages in repetitive routines and stereotyped behaviour, constantly flicking his fingers, for example, and turning knobs. On occasion he is destructive and overactive.

His vision and hearing are normal. His major difficulties appear to be his lack of interest in his social environment and his epilepsy. The severity and nature of Michael's epilepsy has varied over the years, and has received considerable attention and treatment. It has been viewed by some as his major and only outstanding problem, and is as much under control as is currently possible. Presently, Michael has one major seizure during the day, and usually a minor seizure at night. A major seizure will last anything from two minutes to twenty minutes if he has repetitive seizures, but he usually recovers well afterwards.

The ways in which parents react to the discovery of handicap has been the subject of considerable attention and documentation. It is often an experience which parents recall vividly and, even after a considerable time, with a sense of pain. Michael was born in hospital in Cardiff on 12 December 1975. It was a normal birth with no complications or problems. At the age of five months, while in the house, his mother noticed that: 'Suddenly his limbs became rigid, his head turned up and his eyes rolled back. His appearance totally changed.' She took him immediately to a child clinic and was advised to go to her GP who witnessed Michael having a major seizure and admitted him to hospital

He was to remain in hospital for seven weeks, an agonising and confusing experience for the family. During this period, Anne stayed at the hospital, returning home only to take Rachel to school and to be with her at home for a little while in the evening. It was an 'exhausting and emotional time'. During the fourth week of Michael's stay, Anne was approached by a consultant who informed her that, given the type of epilepsy Michael displayed, he would 'more than likely be left retarded'. The consultant, who was accompanied by medical students, then said: 'I'll leave you now. I expect you want a little cry.' The doctor then left.

The initial experience of being informed about a child's handicap and the way that this is carried out by staff is one that parents often relate with a sense of anger and frustration. For John and Anne the following months were a difficult period. As Anne stated: 'I couldn't share my feelings with anybody, not even John. I'd cry and stop when he came in. I wanted to cry with him, and share it, but neither of us could. It was a shame. It was like mourning and I was angry at the way the specialist told me. I just thought I had to help Michael. I only knew a little about mental handicap. A girl in my school was "backward" and she was teased.'

As time passed, the family started to adjust to Michael's mental handicap and their concern turned towards finding help and support. They felt a desperate need for information and advice about Michael's handicap, rather than having to rely on their own assumptions about mental handicap. It was during this period that Anne's commitment to fight for better services for Michael and for other children with a mental handicap was shaped. 'I assumed a lot in those days. I didn't ask people to repeat the things I didn't understand. I thought Michael would just lie there, his limbs becoming permanently rigid, as they were when he had a fit. So I worked on him. I was determined. Michael is Michael and I had to help him.'

Over a period of time, Anne and John gradually began to express their need for help. To a large extent the need was for information on the availability of services. The health visitor advised the family to contact the home advisory service for information on the Portage programme. Just before Michael's first birthday, therefore, he received skill teaching at home from the home advisory service and he also started to attend a playgroup, within a general hospital, for children with all types of handicap. The playgroup leader suggested that Michael wear a crash helmet for his own protection. 'He was turning things over in those days – everything had to be upside-down. He would bump into things and hurt his head.'

Michael has attended a special school for children with a mental handicap since he was three years old. There was, from that time, a feeling of parental concern that, despite staff reassurance, Michael had other problems which had not yet been identified. People who worked with or were parents of autistic children started asking Anne if Michael was autistic. A friend of the family who had a child who attended a special school for children with language problems mentioned some similarities between Michael's behaviour and that of her own son. This prompted Anne to read about autism and this helped her to make sense of some of Michael's behaviour. She approached his headmaster and inquired about the possibility of Michael's transfer to the more specialised school for children with language and behaviour difficulties which, at that time, was known as a school for 'autistic' children.

Anne was told by teachers and medical practitioners that it would not help Michael to be 'labelled' further, that she should accept him as he was, and that his major problem was his severe epilepsy. At this stage, Anne was not thinking in terms of Michael as autistic, but recognised that recent advances in teaching children with autism might benefit him. She persisted in seeking expert advice on the nature of Michael's condition, and eventually he was assessed and sent to the specialist, independent school for children with language and behaviour difficulties. After one term, an assessment carried out on Michael concluded that he: 'did not make the standard, and his major problem was his epilepsy', and that his 'understanding and functioning was at a low level'. The educational psychologist who had assessed Michael prior to his entry to the school appeared not to understand the reasons for his withdrawal from it.

During the period that Michael attended the school, Anne felt that he had started to show signs of improvement in his behaviour. He was becoming more responsive to social contact and his parents attributed this to the structured and intense nature of the school environment. However, he was not accepted by the school and he returned to his former special school the following term. Here, Anne felt, Michael was allowed to do as he pleased, which was usually conducting repetitive stereotyped activities and engaging in free play for long periods. 'I continued asking questions. It was still nagging me. I wanted to do all I could to help.' The issue of whether there existed, an as yet unrecognised, extra dimension to Michael's handicap was taken further when in assessment, the NIMROD clinical psychologist (Michael's key-worker) observed that Michael had 'autistic tendencies'. 'During my assessment of Michael, I noted that his scores on certain items were variable and some were surprising. He didn't look at other people or pick up their emotions and he engaged in repetitive activities. On some items he was quite skilled. I looked into his educational notes and noticed that the word "autistic" had been used by the educational psychologist to describe Michael. I gathered information on autism and shared it with Michael's mother. She read her way through a number of text books.'

Anne next pursued the possibility of having Michael formally diagnosed. The need for a diagnosis was part of her commitment to understanding the various aspects of Michael's behaviour to ensure that he received the services that best suited his needs. Giving him an additional 'label' was not, to her, the main focus of her struggle. It was 'a weapon to use against the education department, to ensure that Michael's educational requirements could be met more adequately and appropriately'. Anne and the NIMROD clinical psychologist attended a professional conference on epilepsy and afterwards talked to the speaker about the possible cause and nature of Michael's epilepsy. They were told that infantile spasms can be the result of a viral infection and, although Anne had not mentioned the word 'autism' in her question, that it could lead, in some cases, to autistic behaviour. Following the conference, Anne took up the issue of diagnosis again and Michael was referred to a psychiatrist at the child assessment centre. 'I presented him with up-to-date information on autism – information that he hadn't heard of. He then admitted he wasn't an expert on autism.' The psychiatrist contacted the NIMROD clinical psychologist and Michael was sent for assessment to the Centre for Autistic Studies in London.

The outcome of the assessment was that Michael's main problem was identified as severe epilepsy. In addition, it was formally recognised that Michael had 'atypical autism' and the need for a more highly structured form of education was emphasised. This need was recognised by the education department and they have agreed that the NIMROD clinical psychologist should participate in developing Michael's educational programme. In the words of the psychologist: 'We know enough now about what Michael requires to compensate for his communication difficulties, so it's been valuable. There are techniques which have been applied successfully to autistic children which could be applied to Michael.' The family are content to accept this decision, but are prepared to take up the issue again if Michael's educational needs are overlooked. It seems that the argument surrounding Michael's educational needs will be a long one, since there still exists some scepticism as to whether the rhetoric will be put into practice. This struggle typifies Michael's parents' determination to understand the nature and extent of his difficulties and to obtain the services he requires. In the words of his mother: 'I just wanted to know why he didn't respond, to understand his behaviour. I still accept Michael for what he is. I don't need a formal diagnosis.'

The NIMROD Service

NIMROD has had an important influence on the family, both in meeting needs and in allaying anxieties concerning Michael's future, particularly his future residential needs. His mother commented: 'I didn't want him stuck in an institution – I dreaded it ever happening. NIMROD offered a much better alternative. A small ordinary living place rather than an institution. I really thought he'd end up there one day.'

The family home is near the administrative centre of the NIMROD Service and this closeness has, in itself, served as a support to the family. It has provided a friendly base with which to identify, a place where help, information and advice is readily available, and where strong links have been fostered between the Service and the family. Michael and his family have received considerable support from the Service, as typified in the efforts of the NIMROD clinical psychologist over Michael's educational needs. From the inception of the Service, Anne was optimistic and enthusiastic about NIMROD's alternative model of care. 'It was a wonderful idea; we needed help to allow Michael to continue living with us.' Her early involvement with the NIMROD consumer group, a small core of active parents who feed ideas and criticisms into the Service, has continued over the years.

The family has had regular and continued contact from one of NIMROD's community care workers (CCWs) for over four years. The CCWs are responsible for providing support and skill teaching to NIMROD clients who live at home. In

Michael's case, this consists of two sessions a week, one formal session of teaching and one social session where Michael and the CCW go shopping, to a cafe and practice kerb drill. These activities are planned in consultation with Michael's parents. The formal teaching sessions are aimed at increasing Michael's attention and concentration. Over the years, the CCW's main success has been: 'getting him to sit in a chair for two minutes; to sit at a table for half an hour'. The more informal sessions take place in the late afternoon of a school day and are aimed at helping Michael 'to behave like other children and appropriately when he's out'. When visiting shops, he will occasionally lie on the floor, take off his socks and shoes and kick out. While walking along he will often drag his feet. The visits to shops and cafes are also aimed at giving Michael the opportunity to experience normal, daily-living routines and to interact with others, usually adults, and to participate in some activity – for example, buying sweets more competently and as appropriate to his age.

The CCW and the family have formed a partnership which involves consultation and mutual agreement on the content and nature of Michael's teaching sessions. Such a partnership is not, however, without it's difficulties and dilemmas. Anne is eager that Michael should be allowed to take risks more often – for example, walking down the street without holding hands – with the eventual aim that he might be able to play in the street outside the house. For the CCW, however, 'letting go' is difficult and the need to take risks is measured against professional responsibilities and concerns. In addition, there is a need to maintain a balance between being a source of support to the family and helping Michael. It seems inevitable that the CCW, who has so much contact with the family, will become a major source of support to them.

Michael's return home from school is a difficult period for the family. He needs to be occupied during this time which places a strain on Anne who is busy preparing tea, and on Rachel trying to study for her 'O' levels. However, with support from NIMROD, the family has successfully applied for and received help from a 'flexicare worker', who spends time with Michael on his return from school three days each week. This is one of the services funded by the All Wales Strategy.

The NIMROD Service has been successful in providing the family with practical support. The key-worker has proved to be of considerable help in providing information on the nature of Michael's problems and in trying to organise services to meet his very individual needs. The community care worker has developed strong links and a good working relationship with the family by providing a regular source of support and by working with Michael on a one-to-one basis over a four-year period. The success of NIMROD's intervention is clearly demonstrated when set against the 'endless battles' which parents often experience in their relationships with services, as demonstrated in Anne's experiences with the education authority. NIMROD, in the words of the CCW, have provided another 'batter' behind the parents. The service has undoubtedly been a major force in enabling the family to lead a normal life with a large degree of freedom. The impact of the Service in meeting Michael's needs is, however, less clear. There is little doubt that providing support to the family has indirect and worthwhile benefits for Michael in that it has contributed to their ability to look after and support him.

Michael

Michael is invariably described by those who know him as 'a nice looking boy'. His CCW speaks of him as: 'a lovely boy; he laughs and chuckles'. At home, Michael has his own bedroom, and the front room displays a selection of his favourite toys which, like most other households with young children, are scattered throughout the room. Michael is well dressed in fashionable and age-appropriate clothes, and he has few outward signs of handicap.

At home, Michael will sometimes, with considerable prompting, help to set the table for tea and attempt to clear and wipe the table after the meal. He is also beginning to show improvements in his level of understanding. His family is learning to use Makaton and teaching him to use signs more frequently. He will not always use signs but does understand the signs for drink, toilet, Mum, Dad, house, car and school. Over the last 12 months, he has been using signs more spontaneously. For example, he told his father in sign language that, 'the cat wanted to come in', and in a cafe made appropriate signs for 'the baby is crying'. On another occasion, Michael's mother was signing, 'where – sister?'. After a few attempts Michael pointed 'upstairs'. He is encouraged by his parents and the CCW to shake hands with people he meets, which makes him establish eye-contact with people more often. He is also becoming more responsive to his parents and will now seek cuddles from them. Given his parents' concern about his communication and social difficulties, these improvements are welcomed with pride and encouragement.

Michael's parents have decided, in recent years, to make his bedtime a less elaborate routine. No individual member of the family is delegated the task of taking him to bed. When it is his mother, she will cuddle him on top of the bed and sometimes sing to him. When it is his father, he puts Michael to bed and asks: 'What have you got for Dad?'. Michael responds by putting his arms around him and giving him a kiss. He is usually in bed between 9.30 and 10pm. He often wakes in the early hours of the morning because of his epilepsy, but will return to sleep after reassurances from his father. He has to be wakened for school in the morning and has breakfast in bed. He is then given a bath and dressed, and will play in the front room or wait by the front gate for the school bus to pick him up at 8.30am. He returns home from school at 3.40pm and plays with his toys or the gas fire. Sometimes he will listen to music on his cassette recorder or will go for a walk with his sister or the 'flexicare worker'.

On a Monday, after tea, Michael's father takes him swimming to a pool at the local mental handicap hospital. On a Thursday evening he attends a youth club for children with a mental handicap run by a voluntary organisation. On other evenings there are no set events or activities. He may push his BMX bike around or play in the house. Recently, his parents managed to enrol him in the Cubs, which he attended for about six weeks. However, as this clashed with swimming evenings, he was given the choice of going swimming or to Cubs. By his response it was apparent that he preferred swimming to Cubs. On weekends Michael may go out shopping with his family or for a drive in the car. His only regular activity used to be attending a local Gateway club for swimming, outings, or organised indoor activities. He no longer attends Gateway, however, and instead his father takes him to a gymnastics club for children with a handicap which is held in a further education college.

Michael receives short-term care in a home run by a voluntary organisation, The Sisters of Nazareth. Residential care for handicapped and non-handicapped children is provided, as well as a day nursery. Six residential places are set aside for short-term care for children with a mental handicap, and there are usually between two and ten children there at any one time. The family is also part of the family link scheme organised by Barnardo's. Short-term care is provided by a 'link' family, with whom the handicapped child can stay for periods agreed between parents and 'carers'. Michael's 'link' family is an older couple, in their fifties, who have grown-up children. They live nearby and have occasionally visited him at home. This is a new service for Michael and is in its early stages. His parents see it as beneficial in providing Michael with new and varied experiences and contacts outside the family.

School

The special school which Michael attends is situated on the other side of Cardiff to his home, in the grounds of a local authority residential hostel for adults with a mental handicap. The school has 16 classes, with class sizes ranging from 6–16 pupils. There are 120 handicapped children in the school, their ages ranging from 3 to 18 years. Michael is in a class of six children, all of similar age but of mixed ability. The class activities range from shape sorting, having stories read, singing and painting. Michael will sit with other children in his class but will not respond to or interact with them. He frequently interrupts lessons with screeching noises or will walk over to the window and play with the locks and handles. One of the school's aims is to improve each child's ability to interact with adults and non-handicapped children who make up their social environment. In addition, it is hoped that by the end of this schooling they will have experienced many of the activities they are likely to meet in daily living or occupational situations.

Initially Michael's parents had not considered that he would benefit from attending an ordinary school. However, as Anne became more involved in committee work she was exposed to alternative ideas about service provision. Anne and John discussed the possibility of Michael attending a local primary school. Their home is situated between a state nursery school, and a primary and infant's school, a situation which Anne finds increasingly ironic. John was unsure about the benefits of Michael receiving an integrated education and felt that he might not fit into the school. However, as Anne said: 'It was worth a try. Until Michael goes to an ordinary school, we never know whether he will fit in or not. The opportunity should be there. It's a basic right for all children.' A request was therefore made for Michael to attend the local primary school, but this was turned down by the headmaster. As the key-worker reported: 'Mrs Collins was all for Michael receiving integrated education and for getting a support teacher for him. The headmaster of the local primary school, however, turned it down because he didn't have a special unit, and he had to think of the other children. The request for Michael to attend an ordinary primary school has also placed a strain on the mother's relationship with the special school. The opportunities for integrated education within this country are very limited.'

Michael's parents have changed in their attitudes towards mental handicap over the years: 'They're not separate people – they're us. If the school aims to help children with a mental handicap to develop ordinary life skills then the place to begin with is the school.' Anne now belongs to a group of parents who meet regularly to discuss how pressure can be brought to bear on local authorities to consider making integrated education a priority for children with a mental handicap. 'It may be too late for Michael, but there are other children for whom it is important now.' So although John and Anne feel that it is too late for Michael to benefit from a full-time integrated education, their thoughts have now turned to getting Michael into an ordinary school for a few hours or a few days a week.

The future

Michael entered the 'service world' from a very early age; a world that to a large extent has systematically segregated him from contact with non-handicapped peers. At school, Michael is educated with other children with a mental handicap who have similar difficulties to himself. Therefore, there appear to be limited opportunities for age-appropriate interaction with non-handicapped children. Placing Michael in an ordinary school with non-handicapped children may seem unlikely to achieve much, since his lack of social responsiveness may discourage other children from interacting with him. However, it has been shown that non-handicapped children can successfully engage handicapped children in play, an experience that will inevitably lead to social gains for the handicapped child.

Michael's leisure time is also spent, on the whole, with other handicapped children. Although both parents and the CCW recognise the need to expand his social interaction in ordinary settings, planned interactions seem only to be taking place with non-handicapped adults rather than children. Michael's current experiences of living in a handicapped world can be seen as preparing him only for a similar role as a young handicapped man – a role in which any future non-achievement or inability to lead a normal life will be attributed to his handicap. Although there are many people supporting and developing Michael's emerging skills and individuality, its purpose is limited by the expectations of 'handicap': that is, living a more independent life in a 'handicapped' world.

Michael's family and NIMROD staff are beginning to become aware of a different set of problems now that he is growing in physical strength and becoming more forcible. As Michael's mother describes it: 'I realise he is going to be a young man soon. It's hit me about services for when he is older.' Her concerns about Michael's future are more marked than they are for his sister: 'The future for mentally handicapped children is so noticeably different. There are fewer people for me to identify with, as you can with the parents of non-handicapped children. There's more apprehension in me.'

The family looks towards NIMROD's residential service for meeting Michael's future housing needs. The houses are staffed 24 hours a day and have four to six adults with a mental handicap living there. The family is anxious that, come that time, there may be no places left for Michael, given the demand for residential care. Fears about institutional care come to the surface but are met with optimism about the future success of the All Wales Strategy. As for the family's concern over post-school provision for Michael, there is no concrete idea of what he might require, only that there should 'be some sort of day care, a variety of services that we can consider, and with someone else's help, decide what is best for Michael'.

From past experience, there is little doubt that Michael's family will not accept provision simply on the basis of 'what exists' and will continue to demand services that are aimed at meeting their son's individual needs. The NIMROD Service, through the 'individual planning system' has already discussed, on a long-term basis, Michael's future housing needs and considers that he should receive care in one of its staffed houses. As far as his future day-care needs, the options seem to be limited to what already exists. Although NIMROD has proved to be invaluable in providing practical support to his parents, the real challenge of helping Michael to lead as individual and as independent a life as possible within the community still faces them. Michael's key-worker captures this sense of uncertainty. 'As Michael becomes older – the problems become bigger.'

CARL WILSON

by Siobhan de Paiva

'The doctor didn't break it to us gently. He clapped his hands and said, "It's no good messing about, beating around the bush. There's only one way to tell you this. Your child is a mongol. He'll never be able to do anything for himself. You will always have to help him. He's mentally handicapped and will never amount to much. It's just one of those things. No one knows why it happens." That's what we came away from the hospital with. I came out and I thought to myself, he's not going to be a cabbage. That was in my mind from that moment on.'

Two weeks previously, on 10 November 1967, after a long and difficult labour, Louise Wilson had given birth to her first child. She was 17 years old. Her husband, Richard, was 18. They had only been married a few months. The moment she saw her son, who was later named Carl, Louise knew instinctively that something was wrong. He looked different from the other babies on the ward and was refusing to feed. She was also aware that the nursing staff kept trying to push him on to her. However, nothing was said until Richard came to take Louise and Carl home. Just before they were ready to leave, they were told that the doctor wished to speak to them. They went to his office and the above exchange took place.

Louise and Richard went away from the hospital in a state of shock, not knowing what to expect. Their housing and financial worries didn't help. They were living in Cardiff in a furnished flat, three storeys up, and were told just after Carl was born that they would have to move as the landlord would not accept children. In addition, Richard had recently become unemployed. Fortunately, Louise's mother was able to sort things out. She knew some people who lived nearby who had a house for rent, and so Louise, Richard and Carl moved there soon after. Two weeks after leaving hospital, Carl was readmitted with jaundice. However, his stay was very short. He continued to have feeding difficulties until he was four months old, during which time he had to be fed every half-hour throughout the day and night. Louise had to sit at the end of the bed and flick his feet in order to keep him awake. He never cried to be fed. He lost weight, became dehydrated and was readmitted to hospital for two weeks to regain his birth weight. It was a very frightening time for Louise, not knowing whether he was going to survive or not. After four months, however, Carl discovered the pleasures of eating and made a meal of anything in sight.

With a first child, it is often difficult for parents to judge whether or not their child is making the progress that it should. For Louise, it was even more difficult because no one had any expectations of Carl at all. She didn't have any contact with services until a health visitor called when Carl was three years old. She had no one to turn to for help or advice. Fortunately, she had kept in touch with two women she had met and become friendly with on the maternity ward in the hospital. Carl was slower to make progress than their children. She would see what they were doing and would then know the next step that Carl should be taking. She would measure Carl's progress against that of the other children and realise that really he wasn't that far behind. This was a great source of encouragement to her as Carl was growing up. She pushed and encouraged him, determined that he would do the same things as any other child.

During this time, Louise's mother was a great source of support to her. She lived locally and came every day to help with Carl. The three of them went everywhere together. They took him to the swimming pool and to the beach, determined that Carl should not be shut away indoors. They discovered that Carl had a great affinity with water and he learned to swim competently when he was still very young. Louise had always been a keen baseball player and she continued to play, taking Carl along with her to the matches. The other team members all accepted him. He became a part of the team. No one felt sorry for him. Everywhere that Louise went, Carl went too. Louise recalls: 'I had all the energy in the world with him because I was only 18. We grew up together. I never had any problems with people accepting Carl. Maybe I didn't notice. I only saw what I wanted to see.

It was just me and Carl. At 18 I was very outspoken and if I wanted him to do something he did it. I was determined that he wouldn't miss out on anything just because he was handicapped.'

However, such individual attention, while being of great benefit to Carl, inevitably became detrimental to Louise and Richard's marriage. Richard barely spent any time at all with Carl. He pretended that nothing had happened. Even his closest friends knew nothing about his child's handicap. He was also jealous of all the attention that Louise was giving to Carl. Louise reacted by shutting him out of family life more and more. She, her mother and the baby went everywhere together. Richard went everywhere on his own. Arguments between them increased. He blamed her and she blamed him. Neither could understand what was happening to them. They grew further and further apart and within a year of Carl's birth, they were living separately. They eventually divorced in 1973, when Carl was six years old. But throughout the separation Richard kept in touch regularly with both of them.

Shortly after this time, Louise and Carl moved into another house close by where they continued to live for the next 12 years. The neighbours in the street got to know and accept Carl very quickly. Louise made a point of enlisting the help of everyone around, and telling them not to treat Carl any differently from any other child. Carl was very happy there and made many friends, and although he has since moved, he still goes back to visit them regularly.

Louise's mother continued to visit daily to help with Carl who was growing up to be an energetic, mischievous child who required constant attention. When he was two years old, he began to attend a local ESN(s) school. This provided his mother with some much-needed relief during the day, as well as providing Carl with the opportunity to meet other children of his own age. This was something which he hadn't done very much before, having spent most of the time with his mother or his grandmother. He settled into school very well. He loved going there and Louise could see that he was benefiting from it. In his early years at school, his teachers reported him to be a popular, confident and helpful pupil, if at times mischievous and strong-willed.

Shortly after he started school, Louise began to suspect that Carl had hearing difficulties. She spoke to a number of doctors about this but they refused to take her suspicion seriously. Eventually, one of the teachers at school took the matter further and Carl was admitted to the local ear, nose and throat hospital for tests. He was found to have a fluctuating hearing loss and began to see the teacher for the deaf at school. Carl's hearing problem has never really been satisfactorily solved, despite undergoing an operation when he was about nine years old. He now wears hearing aids in both ears in school, but he removes them at home because with two young children in the house, he finds that it is too noisy. Although his speech is poor, he is able to communicate fairly efficiently with other people, using a combination of speech, sign language and gesture.

The school also provided Louise with contact with a health visitor for the first time. The health visitor was a very good source of information for Louise and she would phone her at school if she needed anything. Through her, Louise found out about the Rowntree Trust which provided a new washing machine and paid for her to have driving lessons. It was also through the health visitor that short-term care for Carl was arranged for the first time when he was 11 years old. Louise had broken her leg while playing baseball. Richard was working in Jersey at the time and there was no one else available who could look after Carl on a full-time basis. He was being particularly mischievous, taking full advantage of the fact that his mother couldn't run after him! It soon became obvious to Louise that she wouldn't be able to cope with the situation. In desperation, she contacted the health visitor who suggested that she use short-term care for Carl. Louise contacted the hostel, a purpose-built facility run by South Glamorgan Social Services Department and situated approximately ten miles from Cardiff, which provides residential, short-term and emergency care for up to 21 mentally handicapped children under the age of 16. A place was immediately made available for Carl, and he stayed there for a week. Louise found Carl's absence difficult to cope with. She missed him terribly, couldn't sleep, and felt the need to phone every day just to make sure that everything was alright. Carl, however, returned home having thoroughly enjoyed his stay at the hostel.

For Louise, short-term care 'was the start of something I wish I had known about years before'. The years of bringing up Carl single-handedly had taken their toll. She had barely had an evening out socially with her friends since Carl was born. He used to hold his breath if he didn't get his own way and she had been afraid to leave him with anyone else in case they could not have coped. Over the years, she had lost her ability to socialise and mix with other people. Eventually, Louise had come to believe that she couldn't go out in the evenings. Her whole life was centred around Carl and her mother. She recalls that her twenty-first birthday had been spent watching television with Carl on her lap because there was no one to look after him.

Until he was 16, Carl continued to have regular weekend stays at the hostel approximately every two months. He also spent a fortnight there each summer. Although Louise took a while to get used to the idea, she found that short-term care was not only beneficial for her but for Carl also. As she said: 'Short-term care was really the beginning of Carl's independence – of being away from me – and he loved it. I didn't like it much at first, I must admit, but then I found that I could go out and not have to worry. So I started going out with my friends again. I started having a life again. I knew that Carl was happy and it took the strain off me. It was lovely to have him back, but it was lovely to know that if I wanted a night out I could phone them or, if I was ill, I didn't have to think, "Oh God! Who's having Carl?" The pressure was off. If I needed someone they were there.'

Not long after this, in 1979 when Carl was 12 years old, his parents began to live together again; in 1981 his brother Roger was born, followed by Clare in 1982. Louise had always wanted Carl to be part of a larger family and to have brothers and sisters. Right from the beginning, she encouraged Carl to help care for his new brother and sister. He was very gentle with them and loved to help and still does. He wasn't at all jealous of them. In fact, Louise recalls that before they were born he had been very attention-seeking. However, once they were born, he diverted his attention to them.

Contact with NIMROD

Due to the increase in the size of the family, the Wilson's moved to a bigger house about half a mile away in 1981. It was also in 1981, when Carl was 14 years old, that he had his first contact with the NIMROD Service. The Wilson's home was situated in the first of the NIMROD 'communities'. They had been contacted by the Service in the autumn of 1980, had liked the idea, and so Carl had his first 'individual plan' (IP) meeting in the spring of 1981. He attended with his mother but his father didn't go along. As a result of this and subsequent IP meetings, he began to receive visits from a community care worker (CCW). It took a while for this component of the Service to get going on a regular basis, but since the middle of 1982, he has been in regular weekly contact with his CCW. This is his main link with the NIMROD Service.

To date, Carl has had three different CCWs, including his present one Luke who has been working with him for 15 months – the longest length of time he has worked with the same CCW. Luke remembers that he had some difficulties when he first started to work with Carl who would constantly 'test him out' in various situations. But things quickly settled down and now they get on very well together. Carl is said to respond much better to male company than to females and he now looks upon Luke as his 'best friend'. Equally, Luke looks forward to his sessions with Carl. They are of a similar age group and, on a personal level, they have a lot of interests in common.

Carl's programme of work with the CCW has changed considerably over the years, as has that of most CCW clients. There has been a shift of emphasis away from skill teaching towards social activities and general exposure to the local community. At the moment Luke is concentrating on teaching Carl how to use buses on his own so that he can travel independently. He has also been learning to tell the time and to write his name, as well as following educational programmes on the computer in the NIMROD Centre which he thoroughly enjoys. He is now getting a computer of his own. However, much of the time that Carl and Luke spend together is in following leisure pursuits. Sometimes they go for a swim at the local leisure centre or go into town to do some shopping and have a cup of tea in a cafe. Occasionally, in the evening, they have a game of pool in a local pub and one evening a month they go to the Bluebirds Club – a club for people with mental handicap in the area.

While they are 'out and about', Luke makes a point of incorporating elements of 'teaching' into the activities. For example, if they go into town shopping, he will work on helping Carl to recognise the various toilet symbols that they encounter and also on helping him learn to cross the roads safely. Although Luke maintains some links with Mrs Jones, Carl's teacher in school, he views his relationship with Carl as being very different from a teacher-pupil one, and they have rarely worked together on goals that have been set for him. Luke sees this separateness as an advantage and feels that he is helping Carl to put into practice the skills he has learned about theoretically in school. However, Mrs Jones would like to see Luke having more contact with the school and perhaps going out on trips with them occasionally as Carl behaves differently in a group than he does in a one-to-one situation.

Luke has a good relationship with Carl's mother and they often sit down and have a chat about his progress. He also acts as an important link between Louise, the key-worker at the NIMROD Centre, and Carl's teacher, and frequently passes information between them. This is particularly important as, with two young children to care for, Louise isn't able to go along to the school or to the NIMROD Centre very often. Luke also introduced Carl to his current NIMROD volunteers – a young couple who are close personal friends of his. They take Carl out occasionally on an 'ad hoc' basis and help to extend his use of leisure facilities. This informal arrangement suits Louise and Carl well. Previously, Carl had a regular NIMROD volunteer, Chris, who used to take him out every week. He had also been to stay with Chris and his family for a couple of weekends. Everything worked out very well for about a year and then suddenly Chris stopped coming without giving any reason. Louise asked NIMROD what had happened to Chris, but no one there seemed to know anything either. Carl was very upset for quite a long time afterwards and kept asking when Chris was going to come back again. After that, Louise decided that she didn't want to have a volunteer on a regular basis again.

Although Luke is the Wilson's most regular contact with the NIMROD Service, they also have contact with a key-worker, as do most other NIMROD clients. Carl's key-worker is Jenny, one of the NIMROD social workers. Jenny has helped Louise a lot in sorting out Carl's entitlement to various benefits. She has also helped to arrange periods of short-term care for him because when Carl reached the age of sixteen, he could no longer use the children's hostel for short-term care. Jenny helped Louise to make alternative arrangements with a local voluntary organisation who provide short-term care for four mentally handicapped adults at a time in an ordinary house in the community. The aim of the house is for people to develop relationships in a friendly, homely atmosphere and, at the same time, to give the person with mental handicap and their family a break from each other. Since then, Carl has been spending weekends at the house on a regular basis.

Carl loves going to the house for weekends. He is very sociable and gets on well with the staff and other people staying there, although he hasn't developed any real friendships with the people he has met. He tends not to mix with the other handicapped people staying there, preferring to socialise with members of staff. This may be due to the difficulties Carl has in making his speech understood or because he does not like to be associated with other people with a mental handicap. Staff feel that his stays there benefit him mostly by allowing him to exercise his freedom of choice, and there are many opportunities for him to pursue his favourite leisure activities, his love of music in particular. He loves to perform, and as well as listening to his favourite bands on the stereo, he also enjoys making rhythms on the Casio keyboard and singing while accompanying himself on the guitar. He also does pretty good impersonations and has got the mannerisms of Shakin' Stevens and Cannon and Ball off to a tee! In the evenings he enjoys visiting a pub, going dancing or watching a band play in the local arts centre. He has 'endless energy' and always finds something to do. Louise feels that he benefits enormously from his stays away from home and recognises that 'as much as anyone else, he gets sick of the same four walls – the same routines. The more places he can go the better. He's learning something all the time.'

A transition period

Carl is now 18 years old. He has grown into a confident, reasonably capable young man who enjoys being able to do things for himself. Although he can be stubborn and headstrong, he shows a lot of determination and is always willing to have a go at something new. Like many 18 year olds, he is in a period of transition. Changes inevitably have to take place and important decisions about his future must be made.

He continues to live with his family and everyone, Carl included, is very happy with this at the moment. A new baby is expected later on in the year and Carl is looking forward to this with great excitement. The possibility of Carl moving away from home is raised regularly at his IP meetings. Although Carl is happy now, Louise recognises that one day he may decide that he would rather live somewhere else. Having seen the kind of residential accommodation that NIMROD has provided for other people, she feels that Carl could cope quite easily living in a staffed house one day, if a place were available. Although she would hate to see him go, she would give all the support she could if this was what he wanted to do.

However, the most immediate decision facing Carl and his family at the moment is what he will do when he leaves school next year. At the moment, he is a member of the 'extension unit' at the local ESN(s) school which he has attended for the last 16 years. Mrs Jones is responsible for the running of the unit and receives part-time help from the deputy head. There are 13 students in the group. Mrs Jones's course has been in existence for just over a year and aims to provide a 'first-aid kit' for community living to those students who will be leaving school over the next two years. The ultimate aim of the course is to forge links with local employers which, it is hoped, might lead to job opportunities for some of the students in the class. Although tentative approaches have already been made to local shopkeepers, the scheme is still very much in its early stages. The current emphasis of the course is on gaining useful practical experience by going out into the local community and by finding out about and using public services. For example, students have been on trips using local trains and buses. They have visited the local airport, fire-station, road-safety centre and a number of public libraries. Whenever opportunities arise during such visits, students are encouraged to learn any new words or signs that they come across. By putting students in a real-life situation, Mrs Jones feels that their learning becomes much more relevant and is not confined to the classroom. They are also encouraged to extend their leisure skills by learning new sporting activities, such as indoor bowling or youth hostelling, which they may like to take up after leaving school. Personal hygiene forms another important part of the course. A local dentist and chiropodist have come to the school to give talks. Discussions on such topics as 'The importance of being attracted to the opposite sex' and 'What kinds of food are good to eat and what are not' also take place within the classroom. Cookery sessions form another important element of the course. The youth employment officer has also made a number of visits to the unit and has had individual talks with those students about to leave school as well as informal talks with the group as a whole. Summing up the course, Mrs Jones explains: 'The course is all about students meeting people in their community. It's good for other people to come into contact with them. That, I think, is most important because a lot of people don't know how to react and the first thing they do is turn away. It's good from that point of view. We can only scratch the surface, but by providing a "first-aid" kit for survival and by using the resources available to us, we can at least go some way towards preparing our students for leaving school.'

Mrs Jones's aim for Carl during his final year at school is that he will learn to understand that all his actions have consequences. He is already reasonably well-equipped in the area of self-help skills and can dress and wash himself. Also, unlike some of the other students in the class, he is quite independent and has a lot of contact with the local community. For example, he cycles to the local supermarket and buys provisions for the house and goes to Cardiff City football matches on his own. However, he can be impulsive and doesn't always look for the dangers in situations. His behaviour in school has often presented difficulties. His greatest difficulty is in relating well to the other students in the unit. He tends to 'force himself' upon the others in attempting to gain their friendship and acceptance. Mrs Jones feels that 'he almost tries too hard' to get on with the other students, with the result that they tire of him very quickly and often merely 'tolerate' his presence. His efforts to make friends can often appear to be aggressive and he has, at times, hurt other members of the class, although not in a deliberately malicious way. He loves to be the centre of attention and if there is any confrontation, Carl will always be in the middle of it all. He is always getting into trouble but doesn't understand when he has done something wrong. He resents being reprimanded and cannot be reasoned with. For these reasons, Mrs Jones would like to see him placed in more situations where he would have to share responsibility, and she feels that youth hostelling trips would be a good way to encourage this. Carl has already spent a week with the group at a youth hostel in Pembrokeshire and he enjoyed himself very much.

The future

At the moment, the future for Carl after he leaves school is uncertain. Possibilities, such as college courses and MSC schemes, have been discussed regularly in his IP meetings since the beginning of 1984. However, as the time draws closer when final decisions have to be made, it is becoming clear that few choices actually exist. As Carl's teacher says: 'It's very difficult for me to define a goal because what is there for him? This is the big problem – not just for Carl but for all youngsters with mental handicap. The anomaly lies where you have education and social services all going along parallel lines. Neither seem to converge. Surely this is at an age when education and social services should come together to help these groups of young people of sixteen-plus.' It is a fact that at present most young people with mental handicap follow a direct path from an ESN school to an adult training centre or social education centre. This is also the case for most NIMROD clients who are in their late teens and early twenties because a day-care component is not included in the NIMROD 'package' of service components. For Carl's mother, his teacher, his CCW and his key-worker, this situation poses a number of dilemmas, given their commitment to his leading an ordinary life in the community.

Academically, Mrs Jones feels that Carl would not be able to cope with either of the further education courses currently being offered to young people with mental handicap in the county. She also believes that an adult training centre would meet Carl's needs more appropriately as he is an active young man who enjoys being out and about. Although as yet nothing has been finalised, it is envisaged that during next year Carl will start to attend his local ATC for one day each week. There is also a possibility that he may be able to gain some limited work experience through contacts which have been made by the school with local employers.

Luke, Carl's CCW, in conjunction with Mrs Jones, has recently arranged for him to attend Cardiff City Farm one day a week. It is hoped that, as a result, Carl will begin to understand the responsibilities that having a job would entail. Luke is hopeful that, should Carl eventually go to an adult training centre, then at least he would not have to attend for five days each week.

Jenny, his key-worker, feels that his local ATC is changing and that it now has a lot to offer young people in terms of acting as a bridge, for about a year, between school and some form of work. She feels that, for Carl, the ideal would be to find a college-like environment for a few years where he could carry on learning and developing, followed perhaps by some work experience. In her opinion, the ATC could fulfill this role. To this end, Jenny has recently been taking Louise around a couple of the ATCs in the area so that she can see for herself the kind of activities that go on there. Given that Carl has not expressed a preference, Louise is prepared to consider all the options open to him. However, she is adamant that he must enjoy what he does and that he must be doing something useful. As she says: 'All I want is for him to be happy. As long as he's doing something useful. He's got to enjoy what he's doing – like you or I. If you don't like what you're doing, it's twice as hard. I want to see the places he's going to. There's no way he's going to put candles in a box all day. I'll keep him at home first.'

Throughout Carl's life the greatest force behind him has been his mother. Her commitment to him and her belief in what he can achieve has already overcome many obstacles. With the right kind of support who knows what might be achieved. As Jenny says: 'If we can't do something for this young man, then we can't do it for anyone, especially with the guidance and support of his mother and with all the freedoms that she's offering us.'

ROBERT GRIFFITHS

by Roger Blunden

Robert is a young man who, despite his many problems, is described affectionately by most of the people who know him well. He also shows a great deal of affection to those around him and has created a strong sense of loyalty and concern in many of the people who have lived and worked with him. Robert's parents explain that he has always been a very loving boy, who enjoys a cuddle and gets a great deal of satisfaction when he successfully communicates with others. 'He can be very demanding, but he can also be very lovable. He can have you going up the wall all day long and then he'll do something he's never done before. Then you'll forget all about the horrible day you've had, when he's kicked you and scratched you and bit you and done everything else – because he's done something that he's never done before.'

Robert is his parents' first child and was born prematurely in December 1964. His mother contracted german measles before becoming pregnant. Although she was told at the time that this would not affect her pregnancy, it soon became apparent that Robert had difficulties. A cataract was found on one of his eyes when he was about three weeks old and later his other eye was also found to be affected. By the time that Robert was two years of age, it was confirmed that he had little or no hearing. In spite of various operations for his cataracts, he has very limited sight.

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When Robert was three, he went to a local school for children with hearing impairments. However, after about a year, the school decided that it was unable to help 'rubella-damaged' children because of their additional visual handicaps. He was also assessed by a special school catering for children who were deaf and blind, but it was concluded that Robert had additional mental handicaps and could not be helped by them. 'They told us that he was mentally handicapped. That was the first time that anyone had told us that he was mentally handicapped. We'd put it down to the fact that he couldn't hear and couldn't see very much, so how can you make yourself known and do things if you have these problems?' Robert was then transferred to a special school for children with mental handicap situated on the other side of the city.

When Robert was three a brother was born and the two played together, although needing a watchful eye kept on them. In spite of his considerable handicaps, Robert's parents received little advice or practical assistance. 'Nobody told you anything. The less you asked, the less you got.' When he was aged 14, his parents found out about the availability of short-term care at a local hostel and Robert started going there occasionally at weekends. Apart from this occasional break, they coped alone with Robert at home, with him attending the special school during the day.

Robert and his parents developed a set routine, from getting up in the morning to going to bed at night. His clothes and personal belongings were kept in particular places so that he could find them with his limited vision. In spite of his vision and hearing difficulties, Robert showed a great deal of 'common sense' while living with his parents. He enjoyed manipulating objects such as Lego and bricks and had a well-developed sense of balance. However, his inability to communicate caused him a great deal of frustration. He would sometimes take off his shoes and socks, or undress to avoid having to go out for a walk. He also developed violent temper tantrums, throwing objects, breaking windows, kicking and scratching his parents, and mutilating himself. This had become a major problem by the time Robert was 16 years old. He was admitted for emergency short-term care to the local mental handicap hospital and, for the first time, drugs were used in an attempt to control his violent outbursts. Robert continued to attend the hospital for emergency short-term care from time to time. On occasions, the hospital staff were called out, sometimes in the middle of the night, to help deal with his problem behaviour. In spite of his increasing temper tantrums, Robert's parents stress the positive aspects of life at home. 'We've had some laughs, mind. They bring a different aspect to your life altogether.' The also wonder how much of his supposed 'mental handicap' is caused by his vision and hearing problems and his difficulty in communicating with others. 'The trouble with Robert is that he knows what he wants but he can't make us understand.' However, they admit that 'whatever you do, Robert will always get the upper hand'.

Living in a NIMROD staffed house

In 1981, Robert's parents were approached by the NIMROD Service and the possibility discussed of him moving into a staffed house that was to be opened. Initially they accepted NIMROD's domiciliary services but declined the offer of a place in a staffed house just around the corner. They felt that there would be continual problems if Robert lived too close to their home, since he would always know that he was in the vicinity and would want to go home. However, they eventually decided to accept residential care for Robert and opted for a 'shared care' arrangement, whereby Robert would return to their home at weekends. By this time, the two NIMROD staffed houses nearest to Robert's family were fully occupied. Because of Robert's problem behaviour, it was felt that he could not be accommodated along with some severely physically handicapped residents in the next house to be opened. However, it was agreed that he could enter NIMROD's fourth staffed house, serving the NIMROD 'community' adjacent to his home area. It took about a year for the house to become available and, during this time, Robert's care was divided between his parents' home, the hostel and the hospital. In July 1982, NIMROD residential care staff started visiting Robert and bringing him to the NIMROD Centre. He eventually moved into the staffed house in October 1982, and was one of four residents who moved into the house.

During the period leading up to Robert's move to the house, NIMROD care staff had an opportunity to get to know him. A report, written later, stated that:

> 'We found a young man of 17 with the stature of a 13 year old who spent most of his time twirling or playing on a swing. We learnt from carers and parents about Robert's strong sense of territory and time, and the nature of the problem behaviours which made his care in the home so difficult. In a temper sparked by deviations from an established routine, or demands that couldn't be interpreted or met, Robert would be capable of physical aggression towards people (scratching, butting, hitting and, in extremes, biting), and towards objects (windows, furniture, ornaments, etc). Outside of a close relationship with his parents, and getting on well with his teacher, Robert had developed into something of a "loner".'

The staff discovered Robert's like of bright lights, plastic shapes, Lego and a swing and arranged for these to be available to him at the house. They found that the light from an overhead projector was a powerful reinforcer for him, and used this as a basis for developing a range of activities. Once moved into the house, Robert settled very well. Staff engaged him in play activities, for example Lego, 'rough and tumble', and playing on his swing in the garden. The staff reported a number of occasions when Robert collapsed with laughter after these activities. He became more cooperative, would wait patiently for a bus, carry his plate to the kitchen, and learned not to enter other residents' rooms.

However, a worrying trend was also developing:

> 'On Thursdays and some Fridays, particularly at night and, for no reason that we could fathom, Robert became steadily more disruptive. The behaviour would begin as (often creative) mischief, eg, tipping furniture over, upsetting sanitex bins, entering and disrupting other residents' rooms, blocking washbasins with towels then turning taps on and leaving them to overflow. Efforts to keep tabs on Robert and restrain or contain this behaviour would then often lead to more serious disruptions involving broken windows, cups, tearing of curtains and so on.'

This behaviour had a serious effect on the other residents, the staff and the neighbours. The problem was particularly acute at night. Indeed, a member of the night staff left after several traumatic nights with Robert. He developed a very erratic sleeping pattern and did not seem to require a great deal of sleep. The house was terraced and the neighbours on both sides were complaining about the noise at night. Considerable damage was also being done to the house and all windows had to be fitted with strengthened glass. On a number of occasions, Robert set off the fire alarms in the house, resulting in fire engines arriving in the street. He also managed to flood the washing machine, causing considerable disruption.

The house staff were extremely concerned about this situation, but also determined to persevere. They developed strategies for dealing systematically with the disruptions. On occasions, day staff worked 24-hour shifts so as to provide extra night-time support for Robert. Medication was also prescribed at this time, including 5 mgs Mogadon, as necessary, to help him settle at night. There is some evidence that Robert had his first epileptic fit during this period while on a regular weekend visit to his parents.

From January until October 1983, the staff made considerable progress with Robert. They devised ways of communicating with him, using the Makaton sign language and various objects. His disruptive behaviour became less frequent and be began to learn a number of new skills, including signing, dressing and preparing breakfast. Robert developed a set routine and became much more compliant and cooperative. He laughed a great deal. Although he did not have a great deal to do with other residents, he developed a strong rapport with staff. Temper tantrums were very infrequent and the use of medication prescribed to be administered 'as necessary' decreased dramatically. However, Robert's health became a major concern during this period, with incidents of unsteadiness and loss of balance. Various medical examinations were carried out without identifying any cause of the problems.

In October 1983 Robert's behaviour again gave serious cause for concern. He became intolerant of new or relief staff, uncooperative in the mornings when setting off for school, and aggressive towards staff and the other residents. On one occasion he threw one of the other residents across the room, and on another, hit a member of staff on the way to the bus pick up point. He also began a pattern of frenzied jumping, tearing his clothes, head butting and other forms of self-mutilation. These problems were again particularly acute at night.

The consultant psychiatrist was again involved, together with the NIMROD clinical psychologist. Staff kept careful records of Robert's behaviour and his sleeping patterns. Various drugs were prescribed in an attempt to sedate him, but seemed to have no effect after a 'honeymoon period' of about ten days. At various times, Robert was prescribed Largactil, sodium amytal, haloperidol and 'cocktails' of haloperidol and Valium. On occasions, he was receiving up to 1000 mgs of Largactil in a day, and local GPs were called in, day and night, to administer drugs.

Staff persevered with a number of strategies for dealing with Robert's problem behaviour, including organising a consistent regime for him. For example, attempts were made to contain him in his bedroom at night, but had to be abandoned because of disturbance to the neighbours. The lounge, which was originally upstairs, was moved downstairs, where the vibration of his jumping on the floorboards caused less disturbance to the neighbours. Various rearrangements to mealtimes and bedtimes for Robert were tried in an attempt to produce a regular sleeping pattern. A 'baby alarm' was installed in his room so that staff had early warning of his movements. Staff report that Robert's parents were particularly supportive at this difficult time. However,

> '... despite all these strategies, Robert's behaviour continued to get worse. So far as the quality of life in the house was concerned, this not only had a direct effect on the other residents, but also an indirect effect. Staff energies became more and more absorbed in strategies for Robert and house repairs necessitated by his behaviour. Leaving the house became more and more difficult, it being highly undesirable (and dangerous) for one staff to be left alone with Robert for any length of time.'

At the beginning of June 1984, staff began to notice a deterioration in Robert's sight and an appointment was made for this to be examined. Before this appointment, Robert apparently 'woke up blind' one morning and was extremely distressed.

> 'The most vivid and horrifying sight for staff working that morning was of Robert feeling his way along the hall and tumbling down three steps that lead to the dining room, laughing in confusion and desperation as he picked himself up.'

> 'As might be expected, Robert found the loss of his partial sight an extremely traumatic experience, and the behaviour that resulted from it amounted to the worst we had encountered – especially the self-mutilating aspects of it: continuous falling to the floor, banging his head, scraping fingernails and teeth on concrete of the backyard, scratching himself very badly.'

It is difficult to imagine what the impact of this loss of sight must have been on Robert. He already had no speech or hearing and relied heavily on what little vision he had. It is perhaps not surprising that he developed more violent and dramatic means of attempting to communicate and of expressing his anguish and frustration.

In spite of these problems, staff were determined to persevere. The house records of June 1984 state that:

> 'Robert is to stay here, behaviour permitting, until the results of eye tests and referrals, etc, are known.'
>
> 'Extra staffing is to be found to prevent Robert's current condition from disrupting the lives of other residents (and from wearing out staff)'.
>
> 'Maximum pressure is to be put on the consultants Robert sees to deal thoroughly with the possible physical sources of his problems.'
>
> 'Can everyone be gentle with Robert, especially over bedtime, dressing, undressing, etc.'

At this time, the staff felt that it was important that thorough investigations be made of any possible medical causes of Robert's problems. However, he could not be persuaded to cooperate with any medical examination. For one eye examination, eight staff accompanied Robert to the general hospital. Eventually, a general anaesthetic was given, and Robert remained in hospital for two days, with NIMROD staff present throughout the period. It proved impossible to conduct an EEG examination on Robert, since he needed to be conscious and relaxed for this. Staff sometimes went to considerable lengths to obtain medical examinations for Robert. On one occasion, after a period of head banging, they took him to the local casualty department and claimed that he had been concussed, in the hope of having his skull x-rayed. Staff also made their own visits to the local mental handicap hospital to seek advice and help.

At the end of June 1984, Robert was admitted to Ely Hospital for a period of observation and assessment. This was with the aim of reviewing his medication (he was receiving increasingly large doses with little effect), to ensure his safety, and to give the staff and other residents in the house a break. While he was away, the staff planned for his return. They contacted the Rubella Association and learned about finger-spelling and other communication techniques from the headmistress of the local school for blind/deaf children. They planned routines for evenings, nights and mornings and arranged for night staff to 'double up' for one month in order to implement a night-time policy of confining Robert to the area of his bedroom.

Robert returned to the house at the beginning of August 1984. However, the problem behaviour and disturbance to neighbours and other residents continued. The eventual state of affairs was described by NIMROD's clinical psychologist.

> 'At the time, we were working on a programme to help Robert to stay in his room at night. If he came out of his room, he was to be gently turned round by a member of staff who was standing in the corridor and encouraged to go back into his room, but not forced. We wanted him to stay in his room because he tended to try and drag the other residents out of bed, or get in with them and people didn't want locked doors in the house. On one particular occasion, it was 3 o'clock in the morning and I'd gone to the house to check on the programme and the consistency of the staff in following it. We had a psychologist and two night staff standing in the corridor. One resident was crying in his bedroom and another was screaming downstairs. Robert was being encouraged to go back into his bedroom. He was pretty cross and the staff were on the

> point of giving up because he was determined to come out and was starting to injure himself. The neighbours' lights were on (new neighbours had just moved in with small children) and they were knocking on the wall from the other side. At that point the fourth resident got up to go to the loo. I looked at her and she looked at me – a psychologist standing in the corridor in the middle of the night with two night staff, screaming and crying – and I thought, this is not my idea of community care – we must do something.'

In September and October 1984, NIMROD staff, in conjunction with Robert's parents, began to explore alternative arrangements for Robert's care in the community. They also established contact with a representative of 'SENSE', an organisation particularly concerned with rubella-damaged people. (Robert's parents had been involved with SENSE since its inception.) They also visited a residential facility for rubella-damaged people. However, it appeared that Robert was presenting greater problems than most people who had been rubella damaged, and no ready solutions were apparent. In order for Robert to be cared for in the community, the staff concluded that:

> 'Robert needs 5 day a week care.'
>
> 'Robert's parents wish to continue caring for him at home at the weekends.'
>
> 'The ideal premises would have: solid floors; strengthened windows; understanding neighbours; safe back garden with swing and play area; fewer, or no other residents, so that objects can be left in the same place.'
>
> 'Type of care at home – staffing. Robert needs night and day attendance. This could be maintained with one person at a time (but probably for short shifts) if regular nearby phone-in back-up service available. At night he needs to be allowed to get up and move around if he wishes. Staff should be prepared to sleep in his room.'
>
> 'Type of care at home – handling. Confrontations to be kept to a minimum. A short-list of important things, eg, getting dressed to go to day care will be kept, and other training and leisure opportunities tackled when Robert is receptive (a great deal of the time in fact).'

> 'The above conclusions only involve ordinary day-to-day care. Discussion of staffing needs for a special intensive enterprise will be discussed at another meeting.'

During this period, NIMROD staff were actively pursuing alternative premises and staffing for Robert, including the possibility of housing association property. In October 1984, Robert was again admitted to Ely Hospital for short-term care for two weeks. However, after his return to the house, he was clearly very distressed. He cried and screamed and clung to staff. He also became extremely angry at times, pulling down curtains, smashing lights and cutting himself with the glass, and put his head through the one window which had not been fitted with strengthened glass. After two weeks of this, he was readmitted to the hospital, and has remained there ever since.

Living in a mental handicap hospital

Robert is still living in Ely Hospital, on a ward for 24 men who are described as severely mentally handicapped. The ward is divided into two halves, with a locked door connecting them. Robert lives and shares a dormitory with a group of 15 of the more severely handicapped residents. He still goes home to his parents, for varying periods of time, at weekends.

NIMROD staff were concerned that Robert was losing some of the skills he had gained while living in the staffed house. Therefore, since March 1985, they have arranged for an additional person, paid for under South Glamorgan's flexicare scheme, to work with Robert on a one-to-one basis, for five hours each weekday. With support from a NIMROD community care manager, and the agreement of the hospital, the flexicare worker spends time on the ward with Robert, works with him in a small room which has been made available and takes him on trips around the hospital grounds and outside. The following account by the flexicare worker summarises Robert's day on the ward.

> 'Upon waking at about 7 am, Robert rises immediately and goes to the toilet independently. He insists on having a bath as soon as he rises, or he becomes aggressive. Prior to bathing, he undresses, partly by himself, partly helped by

ward staff. He enjoys water play in the bath but will not wash himself. He displays disappointment when his bath is finished, but accepts this reasonably well without becoming aggressive. After being dressed by staff, he wanders around the ward until breakfast time (between 8 and 8.30 am) mainly occupying himself by "twirling".

'At breakfast, Robert will sit at any table and wait patiently for the few minutes it takes for the meal to arrive. If the meal is delayed, he will wander off. However, as soon as he knows the meal has arrived, he wants to eat immediately and if denied becomes aggressive. He becomes aware of the arrival of the meal, sometimes by smell, sometimes by touching the food trolley which he will occasionally "look" for.

'After breakfast, Robert will clean his own teeth if given a loaded toothbrush. Then he will start "twirling" or, if it is a sunny day, he sits indoors in bright sunlight. For at least half an hour, he resents any form of contact from members of staff or myself. He becomes more approachable as time passes until around 11 o'clock when I take him to his room and open his toy drawer. He will handle all the items indiscriminately for 15 to 20 minutes, and will then select a small number of things to take with him around the ward. During this period, from 11 to 12 before lunch, he spends his time wandering around the ward apparently aimlessly, frequently "twirling", but will occasionally seek me out to accompany him to the courtyard or to his room.

'At lunch, plate guards are used inconsistently, because they are often unavailable. Robert will occasionally look for me because he realises that I will return food from the table to his plate and also sometimes help him load the spoon.

'After lunch Robert searches for me to take him out. He might also occupy himself during this time by "twirling" or by standing or sitting in the sun.

'Between 1 pm and 2 pm, I attempt to take Robert out of the ward. I try to vary the afternoon for him: a visit to the WRVS canteen with a "piggy back" on the return journey; a ride in the car for its own sake; a car journey to the park or beach; a swimming trip; a walk around the grounds or a trip to the local park. I often take Robert out for a second trip later in the afternoon, if his mood permits.

> 'During the afternoon, Robert and I will often spend time in the courtyard, if he is willing. Sometimes he is unwilling to go out and sometimes he quickly becomes bored outside. Other times, however, he will spend 15 minutes or more playing on the see-saw, receiving piggy backs or running, all of which activities necessarily require my presence. He also enjoys some time alone on his swing.
>
> 'During the daytime Robert often engages in mild head-banging, sometimes for stimulation, and at other times for attention. If it is for attention he will continue until interrupted by a member of staff, or will stop and seek out a member of staff himself. The headbanging does not become violent unless Robert is prevented from doing something, for example, breaking a window or leaving the room. One day when I prevented him from breaking a window, it took three people to restrain him in order to administer a tranquilliser by injection. Self stimulation also takes the form of eye poking and waving his hands in front of his eyes.
>
> 'Robert has very few areas of choice, so has very little decision-making to do in his daily activities. As a result, he passively "allows" most things to happen to him. His physical environment is very bland, and as he doesn't interact with other residents, he receives very little stimulation. Consequently, his passivity would appear to be increasing, and he is sometimes violent and aggressive when called upon to make a decision. Robert is very independent and resents intrusions upon his time, so making it very difficult to work with him except for short periods. These need to be enhanced and prolonged to prevent any deterioration.'

In addition to the input provided by the flexicare worker, NIMROD workers continued to work closely with the hospital staff in the care of Robert. Until May 1985, someone from the staffed house visited Robert daily. Once the flexicare worker was fully established, these visits became less frequent but considerable contact is still maintained between NIMROD and the ward, with staff still visiting Robert and taking him on trips off the ward. At first, some of the ward staff opposed this extra attention to one of their residents, arguing that it was unfair for one person to get more attention than the others. However, they are concerned that Robert will regress without the extra attention which one-to-one staffing makes possible, and a good relationship has now been established between NIMROD and the hospital staff. Indeed there have been occasions when ward and medical staff have approached the NIMROD community care manager and clinical psychologist for help when they have been in difficulty over Robert. Robert is widely known as one of the most problematic residents in the hospital.

The future

At the present time, Robert's future is uncertain. Initial plans to move him into a specially prepared house with special staffing have not so far borne fruit. South Glamorgan's flexicare budget is stretched, and the time available for a flexicare worker for Robert has now been reduced to ten hours a week. In addition, the hospital asked that Robert's status, originally as a short-term care patient, should now be categorised as an informal, long-term admission and this has now happened. As a consequence of this, it may be difficult for NIMROD to justify allocating any of its residential staff resources to Robert.

One future for Robert would therefore be for him to remain in hospital, with a reduction in the amount of extra staff available to him, and the continuing use of medication to restrain his violent behaviour. Most people agree that this is unsatisfactory. Robert's parents, NIMROD and the hospital staff are concerned that he will adapt to the day-to-day routine of the ward, which demands little of him and allows few opportunities for independence. The hospital staff would like to use the small side room in which Robert carries out table-top activities as his own bedroom, but this is not possible at present because the room is not heated. A key concern is to teach Robert to wait (for a bath, for meals, to go out) without violent or self-mutilating episodes. There is also concern to find somewhere away from the ward for Robert to go during the day.

In retrospect, it is perhaps not surprising that Robert had so much difficulty in adapting to life in the staffed house. He had developed a routine at home over 19 years where his belongings were always kept in one place and the household routine was centred on him. Robert's parents explained that he had never slept for long periods and would often get them up early in the morning to have a bath. He was also never confined to one room and was able to move freely about the house. He was not accustomed to other people being around and generally had his own way in the house. Robert's parents feel that the move to the NIMROD house must have been a massive upheaval for him, added to which was the major trauma of his sight loss. They also wonder whether some of Robert's problem behaviour might have been caused by his drug regimes and possibly by withdrawal symptoms when his massive drug doses were changed.

Robert's parents are very appreciative of the efforts which continue to be made by NIMROD staff. They share a concern that, without an individual worker and additional stimulation, Robert could quickly lose the skills and independence that he has learned. They wish that some way could be found to channel Robert's energies in a more productive direction. 'If you could get his will to work for him rather than against him he'd be streets ahead.'

NIMROD staff have identified Robert's needs in three key areas:

> 'Robert needs an environment where everything is kept consistently in one place, eg, household articles, personal possessions, clothes, etc. In neither the hospital ward nor the staffed house is it possible to leave items in one place, so that Robert can easily locate and use them.'
>
> 'Robert needs a regime which can effectively contain his violent and self-mutilating outbursts. The presence of neighbours and other residents in the house, together with the extreme nature of Robert's problem behaviour, caused unprecedented problems for staff. In the hospital, these problems can be contained more effectively, but still at the expense of the staff, Robert and the other residents.'
>
> 'Robert needs enthusiastic teaching of new, useful skills, and the opportunity to use these. In particular, the house staff have identified communication as an area requiring major development. Opportunities are limited on the ward, by the numbers of other residents, staffing levels and the restricted availability of everyday experiences and objects.'

There is still a strong desire to find an environment and the support for Robert which will meet these needs, and in which Robert will be content without a return to the major distress resulting from his stay in the staffed house. It remains to be seen whether the skills and resources necessary to provide for Robert, and people with similar problems, will become available.

DAVID STEVENS

by Gerry Evans

David Stevens is now in his early 30s and is known as 'a bit of a character'. People who know him well find him endearing, although he takes great delight in teasing others and testing them out. Most people comment that his sense of humour is particularly apparent. In examining the life experiences David has gone through, the fact that he has retained a strong sense of humour shows particular resilience on his part.

David Stevens was born on 9 June 1955 in Cardiff. The house in which he was born was his grandparents' home, and in addition to his mother and father, his aunt and a number of lodgers lived in the house. He was born in the front room of the house, with his mother being attended by a nurse. David was Mr and Mrs Stevens's first child and the birth proved to be very long and difficult. It is thought that lack of oxygen to the brain at birth resulted in David's mental handicap.

Mr and Mrs Stevens were concerned about David from birth, although nobody had told them that he was in any way handicapped. As he grew older the concern grew, particularly when they realised that he was unable to support his own weight and seemed to lack balance. His mother took him to a number of hospitals in the Cardiff area but failed to get any real advice. 'They just looked at him and looked at me and didn't say anything or do anything.' His parents described how they 'eventually took him to the City Hall where we were taken into a dark room where a lady gave David a number of tests. They did all sorts of intelligence tests on him – putting pegs into holes and that sort of thing. But he wouldn't do it, he didn't seem to have the inclination.' Following the tests they were told that 'he was an imbecile and would never be any different'.

It appears that in the following years there was no help or advice given to Mrs Stevens. 'Nobody came to see us to talk to us. In those days everybody had their problems and looked after their problems.' David was very late in learning to walk and his mother had to push him around in a pushchair until he was six or seven. 'I would push him around until the wheels dropped off the pushchair and then I'd buy a new one.' His parents say he was a very happy child but lacked any close friends. The girls next door used to come in and play with him but he couldn't talk to them. 'He used to eat from seven in the morning until he went to bed at night. He'd eat and drink all day. He would also spend a lot of time sorting out clothes in cupboards and drawers. We bought everything to amuse him, but toys – he didn't want to know them.'

Once David learnt to walk, a whole new set of problems arose for his parents. His grandmother occasionally had to stop the traffic on the main road outside her house while Mrs Stevens used to try to catch David. 'We used to be terrified sometimes.' They moved to another house for about three months but eventually had to leave because the fences at the back were so low that David used to run away to other people's gardens.

When David was about six years old, he began attending a special pre-school centre. His mother used to put him on the bus in the morning and then meet the bus at about 4 pm. 'He used to be dressed like a gentleman in the morning, but he'd come home with his clothes all ripped. He should have had therapy when he was young but they did their best for him. There was a "mongol" child there and David pushed her and she bit her tongue, but they said as long as I could cope, they could cope.'

After moving back to Mrs Stevens's mother's house, the family had to share one room. David used to pull his sister's hair and eventually they took some of the hair to the medical officer as evidence to try to get a house. When they moved into the house, a new set of problems arose. 'What we found difficult was that when he was in the front room of the house, children used to come and pull faces at the window and that used to make him miserable. He also used to make a noise out the back of the house after we moved. I had to lock the door or he would be out – so he rattled the door in the morning to get out. The neighbours tried to get us evicted.'

Over time, Mrs Stevens was becoming 'run down'. 'It was like claustrophobia because I was always locked in with him. My husband used to leave for work at seven. I was on my own to cope with the two girls and David who used to play me up. If during the day I had smacked him I would kiss him when he was asleep because I was sorry – but he was such a belter, he was hard.'

A number of doctors were consulted. 'I went to the doctor to ask his advice about David. He didn't want to know. He just told me to talk things over with my husband. Another doctor came to see David one day, a lovely doctor. He said, "Mrs Stevens if you don't have something done about the boy, you'll be in the cemetery. He's getting too strong. I advise you to put him into a hospital so people can look after him".' Mr Stevens was reluctant to agree to David's move to the hospital because he thought he would be blamed. It was Mrs Stevens's decision. 'I had to think of the other children – he'd tipped up his sister's pram. I had to think of the other girls – he'd pushed his sister downstairs. I'm sorry for David but there was nothing I could do – very sorry for him.'

At the age of ten, therefore, David was admitted to Ely Hospital. Referring to the day he was admitted, Mrs Stevens said: 'It was the worst day of my life. I cried all the way home.' After he was admitted, his father used to ride his bike up to the hospital every evening to look over the wall and see how he was. 'I couldn't shout out – there was a lump in my throat. We did our best for him but there was no more that we could do.' They used to bring David home every weekend, but they found that he was unsettled. 'He didn't know where he wanted to be. We eventually had to nail the windows down because he kept trying to get out.'

At first, his parents were reluctant to talk about the time that David spent in Ely Hospital. 'I'm not saying anything about the time he was in Ely – I can't say a lot about that. There were things I didn't like but they said "If you don't like what you see you can take him home with you". Although he was only a boy he was on a ward with 40 men, all wetting themselves. They were always short of clothes. I used to take clothes out there and they pinched them and put them on anybody. He didn't go out anywhere, just sat in a chair all day.' Referring to the time of the Committee of Enquiry into the hospital, Mrs Stevens said: 'It shook them up and a lot of people got the sack for speaking their minds, but they didn't say half of it – half of what they saw'. In summing up the time David spent in the hospital she said: 'He had a hard time there – if only he could tell you'.

Moving out

In December 1981, David moved to a NIMROD staffed house situated in the same road as the house in which he was born. His parents were pleased to see him move and have noticed major changes in him. 'There's a difference in him – he's more quiet, more grown up and has put weight on. He's smart and got nice clothes and nicely shaven. After all is said and done, David's been through a lot. He's a lovely old kid – but he's been through a lot. He used to crawl around until his hands and knees were bleeding. Nobody knows except him how hard he's tried. But now he's enjoying life.'

David moved into the second of the staffed houses to be opened by the NIMROD Service one week before Christmas in 1981. The house is a large, three-storey terraced house which has been purchased by Cardiff City Council for use by the NIMROD Service. The ground floor of the house comprises a dining-room, a lounge and a kitchen with a small conservatory at the rear. The other room on the ground floor is David's bedroom which he shares, currently, with Peter, having first shared it with Alan on moving into the house. Although the room is quite large and has its own washing facilities, it still appears small for accommodating two people. The first floor of the house has three single bedrooms and a toilet and bathroom. The top floor is not used as sleeping accommodation because of fire regulations, but is used as office space.

The inside of the house is well decorated, furnished and carpeted, although in common with many houses of its kind, can be quite dark even on bright, sunny days. The only internal features which markedly distinguish the house from ordinary domestic housing are adaptations made to comply with fire regulations, such as fire doors and a fire alarm system. The outside of the house has recently been repaired and decorated although it is apparent that more work needs to be done. There are small gardens to the front and rear.

The house is located approximately one mile from Cardiff city centre on one of the main routes linking the north and west of Cardiff with the centre. The terrace in which the house is situated is representative of the type of housing in the area. The area is primarily residential, although, because of the size of the houses, two private homes for elderly people have been established in the terrace and there are two children's homes nearby. A major shopping centre is within half a mile of the house, and local shops, a post office, pubs, bus stops, arts centre and cinema within a quarter-mile radius. There are also large areas of parkland and playing fields within five minutes walking distance.

David moved into the house with four other men who had been living in the local mental handicap hospital and one who had lived in a social services hostel. One of the men who moved into the house with David was readmitted to the hospital after approximately four months, primarily due to a clash of personality with the other residents. The five remaining residents had originally come from the locality of the house or had relatives living in the area.

David was 26 years old when he moved into the house and had been living in hospital for approximately 16 years before moving. At the time of the move, David was described as being fully ambulant. However, because of neurological problems, he walked awkwardly and had particular difficulty when walking down steps. He was able to say a few words and to name familiar objects. He needed physical help to dress and although he could feed himself, he had difficulty in using a knife and fork. Staff who worked with him reported that he had a number of very difficult behaviours, particularly aggression and destruction of his clothing.

One of the others who moved into the house with David was Peter who was 17 years old and had spent approximately nine years in hospital. Peter had no verbal expression and, although being able to do some things for himself, for example eating, needed a great deal of physical help in most other ways. Staff reported that Peter also had quite severe behaviour difficulties. Another was Graham, aged 31, who had spent seven years in hospital. Although Graham was quite a capable person, he was deaf and had no speech. He was reported by staff to be aggressive at times. Ronald was 54 years old and had been living in a hostel for four years before moving to the house. He was largely able to look after himself and could hold a conversation. The fifth member of the household was Alan, who was 58 and had lived in a mental handicap hospital for 44 years. Alan needed physical help in most daily living activities but could speak in simple sentences. These four men are sharing the house with David today.

There are currently 13 people employed to work in the house. A senior care worker has overall responsibility for the running of the house and is also the key-worker for David and the other residents. Five care workers are employed on a full-time basis, with a further seven working part-time. Three of the part-time workers are night staff. Two of those who were employed when the house was first opened still work there. A range of backgrounds are represented among the staff, including nursing and social work, with others coming from employment unrelated to mental handicap. The role of the staff is to provide opportunities for individuals to live as full and 'normal' a life as possible and to assist in developing individuals' skills. They try to create a 'homely atmosphere' and to limit, as much as possible, the distance between themselves and the residents by sharing meals and household chores.

On four out of five weekdays, David attends a special needs unit of an adult training centre. He gets up at about 7.50 am, has his breakfast, and then leaves for the ATC. The ATC has 140 members, with 20 attending the special needs unit. David arrives home from the ATC at about 3.15 pm, when he has a cup of tea and a chat. He sometimes helps to prepare the tea, after which he goes out, either for a walk or to the pub. He usually stays out until about 8.30 but then generally wants to return home. On evenings when he stays in, and when there is nothing in particular going on, he will go to bed between 8.30 and 9.00 pm and generally sleeps throughout the night. On the one weekday that he does not attend the ATC, David stays at home for his 'training day'. During 'training days', one worker and David will plan a number of activities in the house or leisure activities in ordinary community settings.

At weekends, in addition to doing the usual domestic and leisure activities, David has a great deal of contact with his family. They visit the house at about 2.30 pm most Saturday afternoons and on Sunday afternoons David has a bath and then makes a return visit to his family at their home.

On a weekly basis, therefore, David's life appears to be fairly structured, although those working with him in the house will readily admit that there are many times when there is little or nothing for him to do. They are also particularly concerned about the amount of time he spends in his day setting and the low level of activity and stimulation he receives while there.

The following are descriptions by two members of staff of their experiences of working with David. The first is given by a worker who met David before he left the hospital and has worked in the house for the four years since he moved.

> 'I first met David on the ward. He was a very sad looking character. The only response we got out of him was that he kept wanting to go to the canteen for a cup of tea or to see his father. He was very puffy eyed – he looked tired and lethargic really. I put the lethargy down to the drugs he was on which he had apparently been on for four years. When he moved to the house, he'd be awake from nine in the morning for about an hour and a half and then he'd doze off.
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> 'Before moving to the house, David came to visit twice. He appeared to be totally bewildered by it all, although it was difficult to judge his response. Everyone came to the house a week before the move: all the residents, their families and friends – it was a pretty chaotic day. David appeared to take very little notice and only asked for cups of tea. He didn't know the others who were moving into the house, although four of them were living in the same hospital.
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> 'He moved in a week before Christmas. We were supposed to open in October but there was a two-month delay because of opposition from the neighbours. On the day he moved in, there was great difficulty in settling him down. He was very disruptive, lots of – I don't like using the word – but "tantrums" really. If you weren't constantly giving him tea he would start to scream, lift up the table, push chairs over and also hit us or the other people in the house.
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> 'That went on for about two months. We had to take him away from the others when he was disruptive. We couldn't

leave him on his own in his room because at that time there was a lot of glass in his room. So we had to sit with him on the bed and hold his hands and try to talk him down as best we could. During these stages he would become very aggressive and we would be literally holding on for grim life.

'In the early days, he showed very little interest in anything apart from eating and drinking. It was just a matter of containment. It was one-to-one attention all the time, and that meant our staffing levels were pretty thin on the ground, since the other five men had their problems as well.

'After a couple of months we started spotting parts of David's personality. One of the things we spotted was that he enjoyed other people being in trouble or doing untoward things. We realised that he definitely had a strong sense of humour so we started playing to this. So we tried to do things more jokingly trying to get him to laugh. At this time, David's communication was very bad; he would keep repeating two phrases over and over. So we started teaching him the names of the other people in the house and just tried to get him out and about as often as we could which was difficult because he wasn't used to going out walking.

'So in the early days we were really wondering what we had landed ourselves with. After about six months we had a medication review done for David and the dosage of his drugs was halved. I suppose it took a month before we noticed any real change, but then he started to appear to be more aware of his surroundings and also stayed awake a lot longer during the day. His behaviour improved as well and he became more responsive and listened to what we were saying. We tried to involve him in very basic games which he could concentrate on for about 30 seconds and then we'd give him a break and just talk to him. During that period, it became apparent that he always wanted lots of attention and really appreciated talking to just one person.

'David had to keep going back to the hospital for day care for a period of two years and that was causing him real problems. I don't want to sound critical of the hospital, but it seemed to us that he was being left for long periods on his own. Consequently, he was getting very bored during the day and by the time he came home he would be very wound up. He would come through the door and for a long time we had to take him to his room immediately. We would get this shouting and over-excitement, and really, it wasn't until he finished going to the hospital during the day that it stopped. After the first week he spent at the ATC his behaviour improved tremendously, although it slipped back a bit after a month.

'In the early days, "training days" were spent concentrating on getting David to do more things for himself, even though we recognised that he did need a lot of help. We also tried to get him out of the house a lot because, even after the first two years, he was still very excitable when he was out. So we gradually built up, particularly by taking him to the pub. First of all, we were lucky if he would stay there for 30 seconds to a minute before we would have to get out because of the noise he made. We tried to extend this and it just got better and better. He also went for short walks around various parks or around the block. He seemed to enjoy just looking at people, it was like a whole new world that he was experiencing.

'He also began to take a lot more notice of the other people in the house. He knew that he could annoy certain individuals just by making a lot of noise. There is still a personality clash between David and Ron. He became very fond of Alan and their relationship developed. It wasn't a verbal relationship as such, it would be an occasional touch, and David used to get a real buzz out of it. He had become aware of the other people in the house very early on. About three months after he had moved, I remember sitting in the living room one evening with the other residents and staff. I just happened to ask David if he could tell me Alan's name, and he went right around the room and named everybody, residents and staff. We were astounded by this, because despite the fact that we had been throwing names at him constantly, until then we had got no response at all. I suppose it was after about six months that his vocabulary increased from under 50 words to over 150, which we thought was an enormous leap. It was still difficult to understand him if you didn't know him, but we understood him. After about nine months, he undressed by himself. Again it was slow but he did it. We still have problems with his behaviour. For example, he tears his clothes at times when he is bored or wants attention. I'm certain that it is boredom and that's something we've got to try and ensure doesn't happen.

'Among the most memorable times since I have known David have been the holidays that he's been on. The first one was about 18 months after moving into the house when we all went as a group to stay in Swansea. For the first three days he was there he didn't settle down at all. I think the reason was that he was in a room on his own and he just wasn't used to it. He shouted constantly through the first few nights and, of course, he became very tired and irritable. After those few days though he settled down and had a whale of a time. He went to the beach and to his favourite pubs. We did anything we could imagine that he might be interested in. For his second holiday, we again went to Swansea, largely because there was a new staff group. Again, it was a similar pattern; it took him about three nights to settle down, but after that he really enjoyed himself and responded as if he was on holiday.

'Looking back over the time I've known David, he's changed a lot. He can now dress and undress himself and he's doing some domestic tasks in the house. I certainly never thought he'd be doing things like going to the fridge for milk when asked, or helping with the cooking by putting things in the pan and stirring the food. He's becoming more independent in areas right across the board.

'In the short-term future, we are trying to increase his independence in all areas, particularly leisure activities and personal care. He's made very rapid progress in the last year, so we're just trying to build on this. We are also trying to get David to make decisions for himself. Sometimes he will still ask us if he can sit down, even after all this time. He's heavily institutionalised, and we've spent the last two years just breaking that down more than anything else. We've always said that David has a very strong sense of humour and, to my mind, that is a highly developed intelligence. He's very aware of what's happening around him and I think he'll make massive strides – he's already shown he can. With David, he's a bit like me really, he likes to feel he's safe before he does anything, so it will be gradual change over time.'

This first account, by one of the people who works with David, gives a clear description of the early days and the first two years that David spent in the house. This account and the second also give an idea of the commitment of those working with David to ensure that his experience of living in the community is as good as possible. The second account also gives an indication of the difficulties posed by having five men living in a house and in trying to achieve some degree of participation in the local community.

> 'I first met David as a volunteer about two years ago. I used to spend time with him, taking him swimming or horse riding, generally getting him out of the house and giving him a break from the others. When I met him I didn't understand a word he was saying, but in a fairly short time, I came to understand him. I think I got to know him quite well in the two months that I was a volunteer. After two months, a job became vacant in the house, so I applied for it and got it.
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> 'From the first meeting, there has always been a good relationship between the two of us. It seemed that we liked each other very quickly. It became apparent, because when I met him, there would be a smile on his face and he could see the smile on my face so that worked well. I also encountered some of the problems he had when he became a bit excited. I was a new face so he was testing me out. I got to find out about his background from the other staff and that made his behaviour more understandable. Our relationship has developed and we both know where we stand, although there are times when we don't, particularly when I try to get him to accept new things. For example, he can walk, but he isn't too fond of walking but acknowledges that he has to do it. Occasionally when walking to the post office he would refuse and he would just sit down in the middle of the road. That was very difficult when it first happened, and I had no idea what to do. Eventually I would just say, "Right, David, if you're going to sit there, I'm not hanging around. I'm off". I'd walk away, and luckily he would follow. David lets you know very clearly what he thinks, even if it means sitting

down in the middle of the road. So you have to talk him through things and he'll understand. I feel he understands far more than he communicates. Therefore I don't let him get away with using me. I describe the situation to him plainly and simply so that he can develop as an individual. He is developing very well.

'A major trial for David has been the problems he has had with his feet. He had very bad bunions on both his feet and needed an operation. The operation was done in August 1985, but it's taken years to get the treatment done. Our impression was that if he hadn't been handicapped there wouldn't have been all the hesitation about whether the operation was necessary or not. It took us over two years to get the operation carried out, and that involved going to see many doctors and consultants. In January 1985, they eventually held a clinical conference, but of all the doctors there, only one would agree to carry out the operation. They wouldn't actually say to you that they weren't interested, but they'd put you at the end of a waiting list and keep you waiting and waiting. What was actually said at one meeting was that the operation would be totally unfair on the "boy" considering his degree of handicap. What they meant by that I don't know.

'When he eventually got admitted for the operation, it was quite an experience for him. He spent one night in the hospital and I spent the night with him. He talked all night and couldn't settle down. Though I don't think I would settle on my first night in hospital. So I didn't push him at all, and just had the occasional word with him. I pretended I was sleeping to try to get him to sleep, but all he did was sit up and talk for 11 hours. He had his own room, so he only really met the doctors and nurses, but he responded really well to them and let them do whatever they had to. He's got over the operation exceptionally well. He's been in pain and coped with it really well. Now he'll be able to get about a lot more.

'The car has been a big thing in David's life lately. One of the people working in the house first mentioned the possibility of getting a car for David and I followed it up. I put in an application for mobility allowance and then David had to have a medical to see if he was eligible. There was no problem, the doctor could see immediately that his condition made him eligible. Under the Motobility scheme, the mobility allowance can be used to pay for the lease on a car. The confirmation letter came through fairly quickly, so I then spoke to David in more detail about the possibility of having a car and he showed a lot of interest. We then went to Motobility and leased a new car over a three year period. He is very aware that it is his car, and it's opened up the possibility of a whole range of experiences for him.

'I've been on weekend breaks with David twice now, and on both occasions we've used the car. The first time, we went to West Wales and stayed in what can only be described as a shack. It was a time when it was clear that David needed a break from the house, and the others in the house needed a break from him. It worked very well. We visited the local pub and spent time at a lot of places of interest in the area.

'The second break was an attempt to see how David would take to camping. It worked in the sense that once again David made himself perfectly clear, without losing his head, that he wanted to go home. The evening went very well, full credit to David. However, he made it clear that he didn't want to spend the night there, so we didn't. It was a very good experience for him though. You have to take things very slowly with him, so we might well try him again with camping. That's true of everything we try with him, because I don't believe it's fair on David to accept his first reaction to something as his final word on the matter.

'He is fairly insecure and that's because he hasn't experienced many of the things that he's having to experience now. That insecurity will probably stay for some time because we plan to keep exposing him to new situations. There are many areas in which it's apparent that he has become more certain of himself. For example, in going to the post office, he now takes his own benefit book. He knows where to find it – the book doesn't suddenly materialise anymore. So he uses a key to get the book from his cash box and puts the book in his pocket. We then walk down to the post office and queue for the money and I try and stay in the background. When I first started, I used to take the book and get the money. But quite suddenly that changed, and its now David's responsibility to get his own money. I think it's still unclear to him though, the connection between that money and the money he spends when buying things for himself.

'A major change for David over the four years was when Alan moved out of his room and Peter moved in to share with him. At the moment, David appears unhappy when he is not sharing a room with somebody, but I think he would get used to it. I think it's vitally important that both David and Peter should have their own rooms eventually. It's difficult to think who David's friends are. I think he sees me as a friend and sees certain other members of staff as friends, though not all of them. You can see he makes choices because he isn't as close to everyone who works in the house. He's met a friend of mine and asks about her and responds very warmly when he meets her. However, outside of the people who work in the house, he really has no close relationships, except for his family.

'In terms of the future, it appears that he will be living in this house for some time. I can't believe that is a healthy thing though, because we all tend to move on after a time. In addition, although the people living in the house do respond to each other occasionally, they aren't really close. When something does happen and somebody behaves inappropriately, the effect on the others is unpleasant. I would like to see people moving on. I don't like, and can't accept, the idea of the five of them living together, in that house, for the rest of their lives.

'For occupation during the day, it's unclear what's happening. There is talk of NIMROD setting up their own scheme to which David perhaps could go. I don't want to see him staying at the ATC because I think it's important for people to be able to move now and again. Once David gets to know the people, and the new environment, he settles down fairly quickly.

'In the area of friendship and interests, I think it's important that David has opportunities to meet new people. I feel that is important for any person. How that's going to happen is a bit more difficult. At the moment, what I try to do is to make sure he gets the chance to meet my friends. If we're going out for a drink, I'll ask him if we should call and see so and so and they can join us. He's probably met about half a dozen of my friends in this way. That he enjoys company and meeting people is apparent, although its also clear that he doesn't take to everybody. In terms of interests, he enjoys swimming and horse riding and he's interested in dogs. The interest in horses and dogs comes from his childhood when there was a horse and a dog that he knew. I play the drums and occasionally he's said he wants to play the drums. It doesn't last long, but that's not important. At the moment, the important thing is that he's expressed the interest.

'David's behaviour does, at times, cause us concern. It has improved a lot, however, and the amount of tranquillisers that he takes has been reduced to a quarter of his original dose since he moved to the house. I think its apparent though that much of his behaviour is due to not being able to develop relationships, particularly with women. Living in a house with four other men doesn't exactly help that situation.

'I would say that there are times when David is unhappy, particularly when he hasn't got anything to do and is bored, and those occasions happen too often. Most times, all he wants is somebody to sit down and have a chat with him, and unfortunately that can't happen as often as it should, because there are four other people living in the house. On the other hand, there are times when he is obviously happy and expresses his happiness. He enjoys socialising and he likes his own voice and his own appearance. Seeing himself in the mirror is very important to him, and he will go out of his way to look at himself in the mirror. For example, if you ask him to go and get a fork, the first thing he'll do is look in the mirror and a big smile will appear on his face. That is incredibly important for us to see and for David.'

LIAM ROACHE

by Simone Humphreys

Liam Roache is a batchelor, aged 36 years, who is living in a NIMROD group house. Cardiff born and bred, he comes from a large family and is the fourth of five children. His father was a chief petty officer in the Navy until just before Liam was born in 1949. His father then worked for British Rail but retired due to ill health five years later. His mother stayed at home to care for the family.

The eldest of the family is Liam's brother, seven years his senior, who is married, has a teenaged son and lives in Cardiff. Liam has two elder sisters – Susan who also lives in Cardiff with her husband, and Betty who has recently moved from Cardiff to Birmingham and is married with two teenaged daughters. Liam also has a younger sister who is married with three young children and lives in Cardiff. He is a very proud uncle to all his nephews and nieces.

The family home has always been in Cardiff. At the age of five, Liam attended an integrated Catholic infants' school, as did his sisters and brother. When it became apparent that he was not progressing as the other children, he was transferred to an ESN(m) school on the other side of Cardiff to complete his junior education, although his mother did not feel that there was anything wrong. Between the ages of 11 and 16 he attended an ESN(m) school for adolescent boys for his secondary education.

The family lived together until the oldest son left home to get married when Liam was 14. About this time, Liam's mother became ill with psychiatric problems. He didn't understand his mother's behaviour and was becoming aggressive towards her. His father arranged for him to be sent to a special unit in North Wales for a full assessment of his capabilities. Up until this time, his mother had done a great deal for him, such as washing, dressing and bathing him. Her life revolved around caring for Liam and she was totally opposed to his being 'sent away'. Because it upset her so much, and added to her mounting problems, Liam was brought back from North Wales after five months and, soon after, began taking medication for the control of what had been diagnosed as 'paranoid schizophrenia'.

When he was 16, he began attending an adult training centre, but was unhappy there and did not like being associated with large numbers of handicapped people. At about this time, Susan left home to get married, and four years later, Betty also left home. Soon after this, when Liam was about 21, his younger sister left home to get married and his mother was admitted to a psychiatric hospital.

Liam and his father continued to live in the same house, but his father was becoming ill with chronic chest problems. Each time his father suffered severe bouts of illness and needed to go into hospital for treatment, Liam moved in with Susan and her husband for a few weeks at a time. When not in hospital, the father was bedridden and not able to provide adequate supervision for Liam, and so Susan provided a great deal of visiting support to Liam and their father. Despite this practical support, his sister recognised the problems of ensuring that Liam was receiving his medication regularly. He suffered what was described as a 'nervous breakdown' and spent several weeks in a psychiatric hospital during the year that his father died in 1979. Liam was 30 when his father died. At this time he was living temporarily with Susan and was badly shaken by the event. The period following his father's death was a difficult one for Liam. He idolised his father and could not accept his death. He began wandering the streets looking for his father and calling in at the former family home asking for his father and disturbing the new residents. His father had willed the family home to Jane, the youngest daughter, so that she could look after Liam.

Jane and her husband sold their own house and the father's house and bought a large, terraced house. Their new home fell within the catchment area of NIMROD's first community. Work began on converting a loft extension to a self-contained flat for Liam. During the 18 months in which the flat in Jane's house was being made ready, Liam continued to live with Susan and her husband.

Then, in mid-1980 Liam moved into his self-contained flat with his younger sister, her husband and their three children. He was now attending a different adult training centre because of the change in his residential area. In January 1981, a NIMROD social worker made initial contact with Jane to describe the NIMROD Service and the support that could be provided for Liam and the family. Indeed, all was not well with the family, as Jane and her husband had been experiencing marital difficulties for quite some time. Liam had been living in his new flat in Jane's house for about six months when he was offered a place in the first NIMROD group house. By Christmas 1981, he had decided that he would like to move in. Susan and her husband were opposed to the move and were concerned that group house living would not provide the supervision and support that Liam had learnt to rely on, and which they felt he still needed. Until he moved into the group house in March 1982, Liam spent one day away from the adult training centre each week so that, with help from a NIMROD community care worker, he could work in the house which was to become his new home, learning daily living skills and preparing for his move.

When he moved into the group house, two other men who were receiving NIMROD services had already been living there for about six months. After the move, he had another change in day centre because he was not coping well with the time-keeping rules, and eventually refused to attend altogether. In June 1982, therefore, he began attending a social education centre which is about 8 miles and two bus rides from the group house.

Liam's home

The house in which Liam now lives, in Community 1, is NIMROD's only established group house. NIMROD's Community 1 is one of Cardiff's oldest established areas. About two-third's of the housing is owner-occupied, mainly pre-war terraces and larger semi-detached houses. The major shopping area for the west of Cardiff is situated along the major road which runs through the centre of Community 1. This major road leads directly to the centre of Cardiff, two miles away to the east, and links up with the M4 motorway to the west. This is an area with a wealth of community facilities and includes a range of shops, cafes, pubs, clubs, two parks and a community centre. The main bus routes to the city travel the main road. The group house is situated within a few hundred yards of the main road.

The house is a mid-terrace, four bedroomed house, indistinguishable from others in the terrace. There are three bedrooms upstairs and one downstairs. Each of the three residents has his own bedroom and the fourth room is rented by a social work student who lives totally independently of the three men. There are two bathrooms, one upstairs and one downstairs which has a shower unit and toilet. The front downstairs room is a comfortably furnished communal lounge, and there is a kitchen where meals are cooked and eaten. Furnishings and decor are to a comfortable standard and the house is well equipped with washing machine, tumble dryer, freezer, cooker and domestic appliances. On moving in, Liam brought with him a TV, radio, and a stereo. Susan had bought these items for him in preparation for the move.

Liam presently lives with Tom and Andy. Liam, Andy and a third resident, Jim, previously lived together in the house for 18 months. After two years of living at the group house, Jim decided to return to his parents' home for a number of reasons and so Liam and Andy lived alone for 18 months until Tom moved in. Tom is about ten years younger than Liam and Andy. The three of them live fairly independently of each other. They all have different daytime activities and only occasionally go out together in the evenings. Liam's keyworker described the relationship between the three men thus: 'Tom and Andy are both quite strong characters and there appears to be an uneasy truce between them, with Liam in the middle, frequently opting out for a quiet life.'

When the house first opened, each resident remained at home one day a week, on different days, for individual training with a community care worker. However, there seemed to be much duplication of effort, as some tasks, for example shopping and house finances, needed to be carried out for the group. There were early arguments about some residents 'not pulling their weight', and individual training days seemed to reinforce this. For the last 18 months, all residents have stayed at home together each Tuesday so that each can be seen to be taking a share in major household chores.

On training days every Tuesday, each resident goes to the post office to cash his giro for supplementary benefit and money is pooled for housekeeping. The three men then go together to Tesco for the main shopping trip of the week. Liam takes the shopping list as he is most able to read. Everything that is needed for the following week is bought and the freezer is very well stocked. After shopping, each person does his own washing and strips his bed. No physical help is given, but the community care workers feel that if they were not there each week to provide verbal reminders, sheets and towels would not get changed as often as they need to be. Liam operates the washing machine and tumble dryer. Even on a fine day he is more likely to use the dryer because it involves less effort than pegging out clothes – although he is quite capable of doing so. However, he isn't very motivated to iron his own clothes and, indeed, he has stated categorically that he is not in the least interested in housekeeping.

The training day, or the 'day off' as Liam prefers to call it, is no longer an occasion for the teaching of skills, but to remind the residents to complete tasks that they can already carry out. NIMROD staff feel that the system of setting six-monthly skill goals no longer seems appropriate for Liam, because for him the emphasis is not so much on the need to learn new skills but to receive encouragement to practice and maintain the old ones, such as cooking, personal hygiene and housekeeping. House meetings are scheduled to take place every other Tuesday morning. The residents, community care manager, key-worker and community care workers meet together, whenever possible, to air any grievances or to make decisions about new acquisitions and maintenance for the house. Such meetings used to be held in the evenings, but this was seen as an intrusion by the residents and also meant that staff were often not able to attend.

There used to be a cleaning rota for the communal areas of the house, but when it became clear that this was not being adhered to, the residents decided to apply for domestic assistance. A cleaner now comes twice a week to clean the lounge, kitchen, hall and bathrooms, although each resident is still responsible for cleaning and tidying his own bedroom.

The training day is also an opportunity for sorting out finances and paying bills. Liam has responsibility for collecting the housekeeping, cleaner's and television licence money from the others. Money for food, cleaning, and saving for the TV licence is paid for from each person's supplementary benefit. The three men are joint householders and each receives a one-third share of the joint householders allowance. Each pays £12 for food and £4 for the cleaner every week. Each resident receives a monthly cheque of about £220 for housing benefit from the City Council. Housing benefit covers rent and fuel costs and also includes an amount for replacing and maintaining fixtures and fittings to the house. Each resident's cheque is paid into a shared deposit account. A cheque is then paid back to the City Council every six months to cover rent, fuel, fixtures and fittings. Cheques have to be signed by all residents, and the interest accrued in the deposit account over this period is divided equally between the residents.

Liam was described by all who knew him to be very astute with money – never running out of money during the week, saving for special occasions, and always asking for the money first before shopping for anyone else. He is responsible for paying the milkman and always knows the amount due. He does, however, need guidance with budgeting and managing his personal finances.

Day time occupation

Liam has attended his present social education centre for the last 3½ years and says he is happier there than at any of the other centres he attended. The centre is the most recently opened and furthest from the city of the three ATCs in Cardiff and takes just under an hour to reach via two buses from Liam's home. About half the students at the centre have jobs or voluntary or community placements for the majority of the week, but Liam is not one of these. He spends four weekdays at the centre, remaining at home for the 'training day'. Although he has a timetable to follow at the centre, which is reviewed and revised every six months, he appears to have a good deal of personal freedom as to his hours of attendance and the activities that he actually takes part in.

On Mondays he is timetabled to attend a life skills and literacy class in the morning and gardening in the afternoon.

On Wednesday mornings, groups of six or seven students spend time with their 'tutor', engaging in group discussions ranging from what they did at the weekend to where they would like to spend their holidays. In the afternoon there is photography or art and craft. On Thursdays, the group that Liam is in spends all day in a cookery class and sets tables in the dining room at the centre for lunch. Friday mornings are spent in a computer class and the afternoons are fairly unstructured. Liam often uses this time to visit his mother, attend a disco session or to chat over coffee with staff or students. A range of activities are thus scheduled, should Liam wish to avail himself of them. More often than not, though, he chooses to opt out of formal group teaching sessions, preferring to run errands for staff at the centre. The hours at the centre are 8.45 am to 4.00 pm, with a 30 minute coffee break at 10.30 am, lunch between 12 and 1, and another 30 minute break for soft drinks at 2 pm. Liam usually leaves at 2.45 to catch the 3 pm bus and is home by 4 pm.

It is Liam's decision to travel to the centre independently on public transport, using a bus pass for unlimited travel which is renewed and paid for by the centre every month. He is well versed in the destinations and routes of the public transport system, knows the fares at peak and off-peak periods and is able to interpret timetables. His bus pass is very well used and affords him a great deal of freedom of movement.

At the centre he exchanges pleasantries with staff and students alike, but chooses to take his meal and breaks in a 'quiet room' away from the main dining room. He helps a physically handicapped student in a wheelchair to get to the dining room for breaks, and seeks out the company of his friend, Kate, at break times.

Several members of staff at the centre are ex-NIMROD staff and Liam speaks very well of the manageress and one of the instructors, both of whom worked in Community 1 in the early days of NIMROD. He seems to enjoy the time spent at the centre, and now attends regularly after a period of irregular attendance before his drug regime was reviewed. His sister Susan is particularly pleased that he is now attending regularly and receiving 'at least one square meal every day'. However, she felt that he had got on quite well at his previous training centre, and that she was always kept informed by the manageress if he failed to show up. She contrasted this with a situation in the last year when she was unaware that he had not attended for nearly two months. Unlike his previous ATC, Liam's present centre does not impose strict time-keeping regulations, because such a large proportion of the students come and go at different times of the day according to their outside placements.

Liam's sister also felt that he did not like to be associated with 'the mentally handicapped', particularly people with additional physical handicaps, and this is one reason why he chose not to travel on the 'special bus' to the centre. There is no longer a segregated special needs unit at the centre – the more severely handicapped students now join in groups with the other students. Liam, however, mentioned that he quite frequently 'helped' some of the students, particularly in reading and writing.

When discussing the subject of paid employment, Liam described a job he'd had during the summer holidays as an 'apprentice slaughterman', helping on a farm with slaughtering pigs and chickens. 'It was hard work for £5 a week and some tips off the rabbis, so I quit.' His sister describes this as a prime example of the way that Liam 'dresses up' the truth. She reported that he had occasionally helped to collect pig swill from a local smallholding in his youth and that although he might have visited a slaughterhouse on occasions, he has never worked on a farm or in a slaughterhouse. 'There's a grain of reality in everything he says but he tends to exaggerate the truth to make it a more interesting conversation.'

The question of whether Liam wishes to try a job of work is raised at each of his individual plan meetings, when he describes how he helps out at his local pub, washing the barrels and collecting glasses. He also described how he helps out at another pub in town where he is friendly with the bar staff. However, it became obvious that he wasn't getting paid for whatever help he was giving. His key-worker investigated with him exactly what having a lunch-time job as a 'pot-man' in a pub would involve. Although Liam liked the idea of work, he really didn't want to be tied to working at set times because he likes to be free to leave the centre early and go in late if he chooses. Following the investigation of what work would mean in practice, both in terms of his financial benefits and personal responsibility, and despite support from centre staff who encouraged the principle of finding valued work for Liam, the idea has now been shelved for the time being. The centre staff are not very satisified with the service that they are providing for Liam. They would much prefer him to sample some work, voluntary or community activities, but his key-worker is satisfied that Liam has made it clear in words and actions that his present involvement with the centre is what he wants.

Contacts with services

Even after 3½ years the NIMROD Service seems to play a significant part in Liam's life. In addition to the weekly training days, there is a daily 'early morning call' to Liam. At 8 am each morning, a community care worker calls at the house to ensure that he is up, that he takes a shower, changes his clothes and eats breakfast. At weekends, the community care workers, community care manager and key-worker visit on a rota basis. This was felt to be necessary since soon after his move to the group house. His sister Susan did not feel that he was getting adequate support from NIMROD, in that without very regular reminders and prompts provided by visiting staff, she felt that his standards of personal hygiene frequently fell below acceptable levels. There is agreement from within the Service that Liam has not yet established routines that he is comfortable with, and that a lot of input from staff is necessary to impose and maintain different standards. In addition there has been a large turnover of community staff in Community 1; five community care workers have joined and left the Service, and Liam has thus worked with many people over the years. His sister feels strongly that this lack of knowledge and understanding about Liam has contributed to some problems in appreciating the level of supervision that he needs. She says: 'It's no good leaving instructions for Liam and hoping that he'll carry them out. You have to tell him what to do and stand there while he does it. It's no good checking by asking him whether he's done something – he'll just say he's done it. He's very clever at disguising situations – getting people to think he's done what they've asked. Or, in the case of things he doesn't want to do, he leads people to believe he can't do it. He's very plausible – new staff fall for it every time.'

Liam's key-worker is one of the NIMROD social workers. She takes him to the local psychiatric hospital each fortnight, on average, to visit his mother. She also attends fortnightly house meetings, undertakes an 'early morning check' one weekend in four, and prepares for and attends Liam's individual plan meetings every six months. This involves contacting everybody who is involved in order to review progress since the last meeting. The key-worker also liaises with the family if staff are unable to provide cover on occasions when it may be necessary, so that there are no gaps in the support being provided. His sister is thus able to phone the key-worker at any time of the day or night. The key-worker is also on hand for advice on medication, for escorting Liam on doctors' appointments or for help with his benefits. The community care workers are Liam's main link with NIMROD, but the key-worker is the one who makes any necessary referrals to other service-providing agencies. Liam does not use any of the NIMROD Centre facilities, such as the activities library or the book room, but makes a weekly visit to the NIMROD Centre on his training day to chat to his friend, the secretary/receptionist, sometimes taking post to the post box for her.

Liam visits his GP about twice every six months. He used to go to the dentist twice a year before moving to the group house but has only been once since the move. He had a social worker from the social services department who visited infrequently before the move, but social work support is now provided, as necessary, by the NIMROD key-worker.

A community mental handicap nurse visits the house every fortnight on the training day to administer an anti-psychotic drug by injection. This was previously administered at the social education centre, but Liam requested that he had the injection in the privacy of his own home. Despite the medication, Liam still suffered distressing mood swings: sometimes extremely agitated and highly strung; sometimes very withdrawn and depressed with little interest in anything – just lying fully clothed on his bed for long periods. His sleeping and eating habits were also extremely erratic: sleeping for the best part of the day and therefore failing to attend for day care; alternating this pattern with very early waking, getting up and moving about the house at 4 am; or going out and wandering around the city and finding a bench to sleep on during the afternoon. Liam himself provided this summary: 'I wake at first light during summer months and get up then. I can't sleep when its light. I hear voices in my sleep, talking about me and swearing, so I get up, wait for the milkman, have a cup of coffee then go out walking. Its better in winter because I can sleep on later – its darker.'

His sister was very concerned about his behaviour, and through the individual plan system asked for something to be done about Liam's drug regime. In the year following his move, Liam visited the consultant psychiatrist on three occasions, but it was not felt necessary to alter his drug regime. Then, about a year ago, a registrar at the local mental handicap hospital changed his medication. Follow-up appointments were made with the registrar, three and six months later, in order to monitor Liam's response to the new regime; after 12 months, the altered regime is agreed by all to suit him far better. He still endures 'ups and downs' but his mood and behaviour swings are nowhere near as difficult and uncomfortable for him (and for those around him) to endure as they used to be.

Life for Liam seems to have maintained a much more regular pattern in the last year. Although he still wakes early, he is also in bed fairly early – by about 9.30 pm most evenings. He attends his day centre regularly and has lunch there. Now that the community care workers have helped the residents to organise shopping and cooking routines, he has an evening meal too, and it is no longer necessary for them to call in the evenings to check that a meal is being prepared. Also, for the first time, he recently went alone to the GP to get his certificate for severe disablement allowance. His accurate memory for dates ensures that he always knows when this is due, but he has always gone with his key-worker in previous years. After a little help from his key-worker in completing the form, he went alone for the first time soon after having had his drugs changed.

Despite his psychiatric condition, Liam enjoys good health. He gets stomach upsets occasionally and recently had a painful ingrowing toenail, but tends to suffer in silence. His community care worker has tried to impress upon him the importance of telling people when things go wrong so that doctors' appointments can be made as necessary.

There was widespread agreement on the impact that the change in Liam's drug regime has brought about. His CCW summed it up: 'He's the best he's ever been – very stable, very amenable and always the same when you see him. He doesn't shake or rock and doesn't get agitated, depressed or moody to extremes. He still goes out early in the morning, but it's because he wakes early and gets bored – but he always gets back with a newspaper in time for our morning visit.'

Degree of support

It is widely agreed by staff and family that Liam is capable of most tasks, but chooses not to carry them out without reminders. This has been put down to lack of interest or motivation, or that things such as personal hygiene, cleanliness, tidiness and balanced eating, are a low priority to Liam. Indeed, his maintenance of daily living routines appears to be dependent upon the vigilance of staff and family. At times when supervision has lapsed, such as holiday-time, Liam's attention to personal care has fallen to unacceptable levels. The CCWs and key-worker feel that he needs and enjoys the support he gets and likes to know that 'somebody cares'. With this support, they believe that the group house placement is far more suitable than living with a larger group of people with mental handicap in a staffed house. NIMROD staff felt that the 24-hour staff cover provided in staffed accommodation was not necessary or desirable for Liam, because even with staff constantly on hand, he would simply 'disappear' if he felt pressured. He could not be coerced into cooperating even in a staffed house. Also, because of staff rotas in staffed houses, his key-worker felt that he receives more consistent support from the small core of people who presently work with him than he ever could in a staffed house. However, his sister Susan, her husband, and a family friend who had known Liam for many years, felt very strongly that a staffed house would be a much more suitable option in terms of ensuring that Liam was well fed, living in clean, tidy surroundings and nicely turned out at all times. Liam himself says he does not wish to move, and that he'd like some sort of company if he was ever to move out in the future. As he put it: 'Anyway, it's not a group home, its my home'.

Liam was not felt to resent the 'daily nagging', as NIMROD staff put it, or going over the same ground day after day. They felt that even after three years, they had not yet discovered the right sort of triggers to ensure that he carried out daily tasks independently, even though various combinations of goal work, checklists, diaries and reward systems had all been tried over the years. All such systems depended on some degree of motivation from Liam to carry them out and, even now, it is only the physical presence of a member of NIMROD staff that acts as a trigger. NIMROD had planned for a heavy staff input to the group house in the early months after residents had moved in, when routines were being established and goals were being worked on, but it has not been possible, as anticipated, to gradually withdraw this support over the years.

Since Liam has been a NIMROD client he has attended regular individual plan meetings at six monthly intervals. Other people who attend these reviews include his keyworker, the community care manager for Community 1 who chairs the meeting, his sister Susan and her husband and, on occasions, the community nurse and a representative from Liam's social education centre.

Over six individual plan meetings, goals have been set to attempt to meet Liam's identified needs in a range of areas. Examples of goals have included: making a rug at the day centre; joining the local library; keeping a diary of day centre attendance; learning to use his typewriter; using short vowel words in reading and writing; showering daily at home instead of at the day centre.

Just under two-thirds of the goals set for Liam were recorded in his file as having been achieved, but just over one-third were not achieved. Although the records do not indicate the reason for this in the majority of cases, task difficulty and staff shortages were mentioned in a few cases. A small percentage of Liam's goals had no outcome stated or were abandoned. Liam's relatives felt this analysis of recorded information to be over-optimistic. Their experience of the proceedings at individual plan meetings led them to conclude that most of Liam's goals were not achieved or were abandoned.

The NIMROD CCWs and the key-worker are the staff who are mainly responsible for working on goals and tasks with Liam, but a small number have been the responsibility of non-NIMROD staff. Since the early individual plan meetings, the number of goals set for Liam has been decreasing, but the number of 'other tasks' has been increasing. This may be due to a number of factors: NIMROD staff have commented on the unsuitability of the highly structured goal planning system to meet the needs of a person as able as Liam and are perhaps now setting fewer goals; alternatively, as needs are identified, formulated into goals and subsequently achieved, they are transferred onto a list of 'tasks' so that staff can ensure that a skill is practised and maintained; another possibility is that Liam's real needs are not coming to light despite the individual plan system.

The input from the NIMROD social worker acting as key-worker to Liam has remained fairly constant at one or two contacts a month over a four-year period. The input from CCWs has increased steadily over this period from an average of once a month in 1981, to once every one or two weeks in 1982, to twice weekly in 1983 and daily in 1984. Clearly, the anticipated withdrawal of the intensive support offered by CCWs to group house residents after an initial settling in period has not occurred. This does not appear to be solely due to the rather special circumstances whereby Liam's relatives have insisted on him receiving regular visits from staff, because the other group house residents are receiving a lot of support from CCWs as well. However, in Liam's case, the family's demands have probably contributed to the type of support that it has been felt necessary to provide – for example, early morning visits by staff and the monitoring of personal hygiene.

Liam's family highlighted the fact that fewer goals are set for Liam nowadays. 'There used to be five or six goals set at each meeting, if you look back through the paperwork, but even then, there didn't seem to be any urgency to get things done. The usual response was that staff had left, so it wasn't possible to follows things through. Or that a particular goal wasn't achieved because staff were on holiday. Some of the goals have been plain silly – for example, "Liam will extend his cooking skills by making pastry dishes for the freezer". I'm not afraid to speak up when I think the goals being suggested are either unnecessary or unrealistic, but they still get written down.'

Family and friends

Although Liam has a large family, his most regular contact is with Susan, his oldest sister, and her husband. Every weekend he visits their home on Saturday afternoon and stays until Monday morning. He quite often visits for an evening meal during the week too. He enjoys his visits and his meals while he's there. This weekend arrangement began because Andy, Liam's co-resident, spent most Sundays at a local short-term care house where he was a volunteer and it was important to ensure that Liam was having regular meals because of his drug regime. Accordingly he would spend alternate weekends with two of his sisters. When Betty moved from Cardiff, Liam continued to visit Susan and her husband every weekend. If they go out for the day, he has a meal with their neighbour, with whom he is very friendly.

Liam is included in many of his sister's social activities: parties, weddings, and visits to social clubs and pubs. He has a holiday in Birmingham with Betty and her family occasionally, but hardly ever visits his youngest sister with whom he lived for a short time before moving to the group house. The family feels that the youngest sister reneged on her agreement to care for Liam – indeed, he appears to be in the middle of a family rift. He misses his young nieces and nephews and would like to visit his youngest sister for their sakes.

Liam's friends were not known to staff or family by name. However, as a casual stroll with Liam through his own neighbourhood or the city centre confirms, he does know a lot of people and has many acquaintances. Due to his propensity for embellishing his contacts in a way that he'd like things to be, most people were unsure about whether he had real friends. He often tells staff and family that he's been to visit friends but keeps his private life very private, and they respect his wishes. However, he did mention a particular lady friend of his, Kate, who also attends the social education centre, but said that he rarely saw her outside the centre or in the evenings. He has also befriended the secretary/receptionist who works for NIMROD and often drops in at her home at weekends for a drink and a chat, as she lives fairly near his sister where he spends his weekends. Recently, he thoroughly enjoyed a weekend's camping trip spent with the secretary and her husband in their caravan, when he was said to be 'a different person' by somebody who knows him well and sees him frequently. He demonstrated his ability to perform household tasks on his own initiative and with obvious pride and enjoyment, showing his capability to do things if he wants to.

He enjoys visiting pubs, which he does two or three times a week, chatting with bar staff and regulars. He has many people in his life who care about him and who support him in many ways, but he wouldn't think to mention them as friends by name. Instead he would rather talk about casual acquaintances: shopkeepers, barrow-boys, bar staff, and the like. As Liam's CCW summed it up: 'He's not doing an awful lot with his time really, so he makes up things and fantasises ... everyone wants interesting things to talk about, don't they? He wants to think he's like everyone else, with lots of things to do. He knows the people who work on the fruit stall in town, and if we see them when we're out, he asks us to walk on ahead – he doesn't want to be seen walking out with us past his friends. He doesn't want them to think he's being "taken out" by us – his helpers. He says he helps out on the stall on a Saturday – he might have, once – or he might like to, but it then becomes part of reality for him.'

He visits a range of community facilities: pubs and clubs; leisure centres; library; shops; hairdresser; parks; cafes; and occasionally attends church. He has begun attending a Gateway club regularly over the last few months and goes to another mental handicap club for a disco once a month. He has now ceased attending his literacy class on Monday evenings. He uses public transport every day to attend day centre, and enjoys group outings to places of interest. He spends a week at New Year at home with Susan, but as she always goes away for Christmas, he spends this time with other relatives or Susan's neighbour. For the first time ever, Liam went away with Susan and her husband to stay in a hotel in Torquay at New Year.

Liam enjoys television and is very fond of music: Buddy Holly, the soundtrack from The Sound of Music and, particularly, opera and classical music. He had recently watched

Wagner's Ring Cycle in its entirety over a weekend. He reads a daily paper and absorbs and discusses the news and current affairs. He is particularly interested in football teams, their managers, and their positions in the league table, and discusses this at length with people who share his interest. He thinks of himself as a good Catholic, going to church regularly, and knows who all the local priests are. He also follows the Pope's tours with great interest. His sister doesn't feel that religion is important to him for its own sake, but more for the social contacts afforded by attending the church services.

The future

Staff and family alike felt that Liam was not planning for the future and, like many people, was just living from week to week. In conversation he appeared not to have particular ambitions or wishes for himself for the future and did not express any specific interest in acquiring material possessions. His key-worker feels that he sees himself as remaining at the group house – that he's put his roots down, and is settled, comfortable and happy, particularly now that the residents are paying to have their home cleaned. Indeed, Liam calls the cleaner a 'god-send' – and refers to the group house as 'home'. He talked about the possibility of marriage and children and he liked the idea of both, but hadn't made up his mind: 'My girlfriend said she should marry me – I'm good to her . . . She's a bit young yet though and I'm getting a bit too old for all that I think.'

Afternote

Since the completion of this study, Liam has experienced another of the unsettling phases which have plagued him over the years. For several months he was very agitated and seemed to lose all control over his affairs, including responsibility for his own finances and those of the house. He became increasingly over-indulgent in his use of alcohol, exhibited episodes of inappropriate behaviour towards his friend at the day centre, and became very unreliable in keeping any appointments.

Accordingly, a number of 'controls' have been exerted and, for the time being, he has been relieved of responsibility for house finances and his sister now controls his personal finances. He chose to give up alcohol for Lent, and now reports to the deputy manager at the day centre each morning. As it is impossible to predict whether he will turn up in the evenings, communal mealtimes at the house have ceased and each resident prepares his own evening meal.

In order to observe and monitor whether his behaviour related to the phasing of his fortnightly injections, a clinical psychologist from the mental handicap hospital prepared a checklist for the CCWs to complete each day over a six-week period. During this period he failed to keep his appointment with the community nurse for the injection, but no changes in his behaviour were apparent. He visited the psychiatrist again, and it was decided to cease his injections and reduce his dose of Stelazine for a trial period. It was reported that this seemed to have made no difference after four weeks.

At present, therefore, investigations continue as to whether anything further can be done to stabilise his condition. Obviously, however, careful monitoring is needed if the disruption to his lifestyle, heralded by these phases, is to be adequately controlled and treated. Such episodes also highlight the importance of community support services for people who are additionally handicapped by chronic psychiatric illness.

VICTORIA ADAMSON

by Stephen Beyer

Before NIMROD

Victoria has a very youthful appearance. She is always smartly dressed – usually in sporting clothes such as track suits, or trousers and casual tops worn with sports shoes. She likes to keep her hair short, wears fashionable spectacles and generally looks ten years younger than her 42 years.

She has a great deal of energy. When she has something she needs to do, she doesn't waste time. On a trip to the shops or when catching a bus, Victoria moves quickly with a great sense of purpose. She also shows confidence in herself in what she can do well, and it is clear to even the casual observer that she is a capable woman in many aspects of her life. This extends to her manner with people: she will share a joke with them or comment on serious matters that concern her or her quality of life.

Victoria was born in Cardiff in 1944, the youngest of a family which consisted of her mother, father and two brothers. She was diagnosed as having Down's syndrome. At the end of the Second World War, most of the family were living in a house in the north of Cardiff, the war having taken the 18-year-old eldest son to America. Victoria's other brother married in 1963 and moved out of the family home; Victoria continued to live with her parents until their death in 1972.

Outwardly, the relationship Victoria enjoyed with her mother was very different to that with her father. Her mother had a very loving relationship with Victoria, although her demonstrations of that affection were almost exclusively confined to the home. While they did much together around the home, and her mother gave her much physical love and attention, she would seldom take her daughter out with her. In contrast, her father would often take Victoria out with him, and he was to play a dominant role in Victoria's development, both in her skills and in her experience of the world.

By the time she was 16, she could count to a hundred, write her own name and copy written words. Her father had been responsible for much of this achievement. In addition, he had introduced her to swimming, which was to play an important role in her life. In 1972 when Victoria was aged 28, her father died, and while this appeared to have had little emotional impact on her, it was to herald a period of change for her.

After the death of her father, Victoria and her now elderly mother had difficulty in coping, in spite of the support of their family. A place was obtained for Victoria at an adult training centre, to provide additional support for the family. During this period, Victoria was also to have her only experience of special hospital care. On two occasions, she attended Ely Hospital for short periods, the first being a period of rest for her mother during this difficult time, and the second as the result of an infection requiring treatment.

Victoria's mother also died later in 1972. In many cases, a series of such events would have inevitably led to the handicapped son or daughter moving into full-time hostel or hospital care. In Victoria's case, she was able to move in with her brother and sister-in-law who were living close by in north Cardiff. They were to continue with the outgoing attitude towards Victoria and her development that her father had taken. With the move to her brother's house there also came a move to a different adult training centre in the west of the city.

It was at this time that swimming came to play an increasingly important part in Victoria's life. Some years before, her father had introduced Victoria to a swimming club for people with mental handicap held at Ely Hospital. Initially, however, she had not left the safety of the pool-side, but had suddenly taken off and had quickly reached a high standard. During the late 1960s there were few swimming clubs for people with disabilities, and Victoria was often promoted as a model of what people with disabilities could achieve. Interest grew, however, as many swimming clubs were formed during the early 1970s and Victoria began to take part in many competitions across the country.

Victoria was always supported in her swimming by her brother and sister-in-law, who would drive and accompany her to training events and galas. One of the highlights of her swimming career came in 1980 when she was 36. That year, the first Special Olympics for people with disabilities was held in the United States of America at New York University, outside Rochester. Victoria was chosen to represent Great Britain in her age group. She flew to America with her sister-in-law and the rest of the team and won two individual gold medals and a silver medal for a team relay event. Victoria took up a number of other hobbies over the years and developed a very full social life. Apart from swimming, Victoria greatly enjoys dancing, both old-time and disco, and at one time became a regular attender at a monthly disco for people with mental handicap and their carers held at a football club, and discos held at a Gateway club. In all of this, her family was keen to support her, driving her to and from venues. In addition, she had been encouraged to develop an interest in cooking by her sister-in-law.

Life for Victoria at the time before NIMROD came into existence was regarded by her family as a very good one. She had her own bedroom, took part in many leisure activities, travelled widely, and was generally regarded by her family as a happy woman. Her family were, however, looking to the future – for Victoria and for themselves.

At this time, the daughter of Victoria's brother and sister-in-law was 12 years of age. Some conflict had developed between Victoria and her niece, and this appeared to have acted as a stimulus for change within the family. Her niece was maturing, with the prospect of eventually moving on to an independent life. At this stage, parents would normally be looking forward to a change of lifestyle, with a diminution of their role in supporting sons and daughters. In their case, however, Victoria's family could see that this responsibility would not tail off. With little prospect of Victoria becoming less dependent on them, her healthy social life would continue to require a great deal of support from them in the future. Although fully committed to fulfilling this responsibility, their view of the future and their commitment to Victoria's development meant that the entry of NIMROD onto the scene was seen by them as a major opportunity.

One of the first tasks undertaken by NIMROD when it came into being in 1980 was to contact all those people known to have a mental handicap in their catchment area. The family had heard of NIMROD through information in the press, but it was not until Victoria and her family were contacted by social workers from the Service that the possibility of Victoria moving into a staffed house arose as a serious option. The option was pursued by the family and, in July 1981, Victoria was one of a group of six people to move into the first of NIMROD's staffed houses.

Life with NIMROD

Victoria's brother and sister-in-law saw the move initially as a trial situation. They were always willing to resume support for Victoria if the trial failed, but decided that the move had to be given six months to a year to prove itself. Victoria finds it difficult to remember her feelings on moving into her new home, although it is clear that the transition was not without its problems. Initially, Victoria was asked to share a room with another woman much older than herself who had moved from the local hospital for people with a mental handicap. Sharing a bedroom was something Victoria had never experienced before. The two women did not get on well: arguments occurred, and Victoria was given a room of her own. Two men in the house had to share instead. This period aside, the general consensus of Victoria, the staff and her family was that she enjoyed life at the house.

In the past, and largely with her father's guidance, Victoria had made significant progress in everyday skills. These had been further developed in the years she had been with her brother and sister-in-law. This process of encouraging her further development was continued by staff in the house. In December of her first year, six months after moving into the house, Victoria was known to be able to tidy her own room, prepare food for cooking, shop locally for food for the house, recognise all the decimal coins, add combinations of two coins, and read price tickets. She also knew the alphabet, and had made a start on reading from first level reading books. With the support of staff in the house, she had kept up the many social activities she had attended prior to her move, such as the Gateway Club, dancing, youth club and, of course, swimming.

Once again, a change of home had resulted in another change of day occupation, albeit coincidentally. Her adult training centre had come under pressure to admit more young people leaving school. This had led to a number of people who were regarded as relatively more independent being moved to a workshop for physically disabled people to make room for others at the ATC. This happened only three months after Victoria moved into the staffed house.

The move to the workshop was greeted with mixed emotions by those involved. But Victoria welcomed the move. She complained that her previous ATC was too noisy and said that she had had many arguments with other workers there. In addition, the new workshop had the attractions of a coffee machine she was able to use herself, and a shop in which snacks could be purchased. The work in which she was to be involved was, in itself, very much the same as she had experienced before, involving the contract packing of small packets of screws and DIY materials. Occasionally, there were seasonal contracts involving Christmas decorations.

In the opinion of Victoria's family, the ATC had offered more varied and structured activities. Much of the work of the ATC had involved packing 'Maxipacs' but was interspersed with cooking and other activities and they felt that this helped Victoria who, in their opinion, had found it difficult to apply herself consistently to her work. The workshop for people with physical disabilities did not, they felt, have the expertise required for working with those with a mental handicap and their approach relied less on directing people in what they should do.

By the summer of 1982, Victoria had been helped by staff at the house to widen her abilities in cooking, building on what she had learned with her sister-in-law and her obvious enjoyment of cooking. On the 'training day', she would remain at home where she would work with a member of staff on successfully following recipes for basic meals for the household. She was also helped to use public transport independently, and had begun to attend an ordinary adult literacy class on one evening a week, the first NIMROD client to have done so. Also around this time, one of the members of staff at the house helped to obtain a job for Victoria – dishwashing in the restaurant of a local arts centre. Victoria carried out this work without the support of any NIMROD staff. This job was very significant for Victoria because it was the first time that she had obtained paid employment of any sort, apart from her work at the ATC and the workshop for disabled people.

By January 1984, as a result of the help she had received to use public transport, Victoria began to go to the workshop every morning on the bus, unaccompanied and using a bus pass. Initially, staff continued to go with her to the bus stop but even this became unnecessary in time. By June 1984, Victoria had been put in contact with a NIMROD volunteer who went with her to her adult literacy classes which were held at a school some distance from her home. The possibility of attending pottery classes was also pursued by the volunteer. In addition, they arranged trips together into the main shopping precinct, evenings at the pub, and other informal activities.

Following on from her interest in learning to read, she began to use the local library without staff help. With her increasingly independent use of public transport, Victoria also widened her use of facilities and travelled into the city to use the main lending library for books. The progress Victoria has made in her reading has been slow, and her family noted that while the number of words she uses has grown, her ability to recognise these is variable. The volunteer she had known since early 1984 left the area at the end of 1985, and Victoria continued to attend adult literacy classes on her own. As yet, no replacement volunteer has emerged.

The possibility of Victoria moving into a more independent living situation, possibly a flat, was raised within NIMROD in 1983. As part of this, Victoria spent a weekend in the NIMROD group house with two other people for a trial weekend. However, her family were very concerned over the appropriateness of such an option. They felt that her level of ability would make unsupervised living an impossibility. They feared that she would be unable to manage in a crisis or, indeed, with more complicated tasks such as paying bills. Her family did feel that the staffed house in which she was living was more crowded than it should be but that it was, nevertheless, Victoria's home. The option was not pursued at that time. However, in January 1986, an opportunity arose for Victoria to move into a housing association flat with one other woman. When Victoria's family heard of the proposal they felt that the fears they had expressed in 1983 were still relevant. A series of discussions subsequently took place with the senior care worker from Victoria's staffed house, after which her family felt more reassured. They found that NIMROD did not take the problems they had identified lightly, and that those from her staffed house had planned for intensive support and training in the early stages of the move, tapering out as time progressed. Victoria's family was also comforted by the fact that the move was being approached in the way that the original move had been, namely that Victoria would always have a place to go back to if things did not work out.

For Victoria herself, the build-up to the move involved four weekends in which she was given a budget and expected to live on a fully self-catering basis within the staffed house. Victoria's prospective flat mate, Mary, lived in Ely Hospital, was 61 years of age, and the two women had not met before. They subsequently spent ten weekends together in NIMROD's training house, again on a self-catering basis. They shared shopping and household tasks and went for walks and social outings together, all the time supported by NIMROD staff. Both women were involved in the choice of furnishings for the new flat, and Victoria moved into her new home in May 1986, followed shortly by Mary.

Like the staffed house, Victoria's new flat is situated in an ordinary residential street, close to local shops, and within walking distance of a main shopping area. It is one of two converted flats in a house built around the turn of the century, which has been recently modernised. The flat has its own internal entrance, and consists of a kitchen/dining room, a spacious living room, a bathroom/toilet, and three bedrooms. NIMROD ensured that the flat is well furnished, carpeted, and contains all the items usually found in anyone's home, including a television, a record/cassette player, a washing machine and a fridge.

The two women are currently supported by one member of staff on a 24-hour basis, a member of staff sleeping in at night. The staff work at Victoria's previous staffed house. The aim is for support to be progressively phased out to a minimum level, tailored to the needs of the two women. This is currently being done by withdrawing staff for between an hour and three hours at different times during the week.

Victoria admitted to being a little bit sad at leaving her previous home, particularly the contact with the staff group. She was also a little upset that she had had to miss the annual holiday for the residents of the house as it coincided with her move. She was pleased to have left behind the 'noise' and the arguments that she sometimes had with others she lived with. She was very impressed with the relative peace and quiet of her new home, and the fact that it was very clean. The relationship between Victoria and Mary is still in its early days, but Victoria describes Mary as 'a very nice person' with whom she had enjoyed spending her time over previous weekends.

Victoria's family had their doubts about the move, but seeing Victoria and Mary together in the flat has given them some hopeful signs for the future. For the first few days, there had been little communication between the two women, and Victoria's brother saw this as a key issue: 'If they can talk to each other and relate to each other, then it will be much better for the two of them'. On a later visit, her sister-in-law saw a great improvement, as the two women were 'talking nineteen to the dozen'. While recognising there may be problems ahead, her family are now hopeful that the two women have a good chance of being very happy together.

The present

Victoria's life remains a busy one compared to many other people with whom NIMROD is in contact. On weekdays, apart from Wednesdays, Victoria sets off for the workshop before 8 am and returns at around 5 pm. Most early evenings are taken up with cooking tea, and with tidying and cleaning the flat. When relaxing at home, Victoria spends her time watching television or listening to tapes. She has developed an enjoyment for romantic fiction and books are obtained in tape form to overcome her limited reading ability. Victoria trained for the 1986 Special Olympics; she swims on Sunday and Monday nights, and takes part in a training session on Sunday morning.

On Tuesday evenings, Victoria goes to her adult literacy class, and afterwards sometimes meets staff to socialise over a drink; she enjoys white wine or shandy. On Friday evenings she still works at the arts centre. At the weekends in summer she enjoys playing tennis on the local public courts. The highlight of Sunday is the Sunday dinner which Victoria has always taken great delight in helping to prepare.

Wednesday is Victoria's 'training' day when she does specific household jobs, tidying and cleaning her room or washing and ironing clothes. After this, she works on the weekly budget with a member of staff, calculating what she needs to put into housekeeping and what she requires for her own shopping needs. After checking the shopping list, she goes to the post office to collect her money before going shopping. In the evening of her training day she cooks a special tea.

Although Victoria has many activities in her life, the time at the workshop still dominates her week. The workshop itself has a number of outputs, including garden furniture, picture frames, pottery, and commercial printing, as well as contract packing. Victoria works on the job of packing, and this is split into a number of individual tasks. While others pack a set number of screws, nails, or other products into small plastic bags, and either staple identifying cards to these or mount them on display cards, Victoria completes the process and is responsible for the finished product. Her job consists of checking the work already done, attaching a final backing to the display cards, stapling them together, and keeping a written running total of packs completed. She usually works with three other people with whom she usually has a friendly relationship. She is valued by staff as one of the most capable workers, able to supervise others and to recognise and correct errors in the final product.

While she is undoubtedly good at her work, her family point out that she was used to it, having done it for many years previously at the ATC. There is a feeling, therefore, that the work no longer challenges Victoria, who herself feels the need for another job. Approaches have therefore been made on her behalf to the Pathways scheme. This scheme sets out to identify individual placements for people with mental handicaps in ordinary work settings. Little in the way of placement opportunity has come from the scheme for Victoria as yet.

Earlier in 1986 she attended a skill centre in order to be assessed on her ability to be placed in open employment. Although Victoria's main interests are in catering, the skill centre was not, at that time, able to assess her for this sort of work but instead looked at her abilities in relation to packing and stacking shelves in a supermarket. They found that she was quick and thorough when given a job, but that she had difficulty in moving on independently to further tasks that had been given to her. Although able to read basic labels, she was found to have some difficulty in telling the difference between similar foods, such as tuna in oil and tuna in brine. Their opinion was that Victoria would require too much supervision, and be too inaccurate for this sort of work in open employment.

The outcome of the assessment was not without controversy however. People who know Victoria well, feel that her ability to operate independently on a number of tasks was underestimated. Nevertheless, this reveals a basic problem that may limit Victoria's search for open employment. While she has a number of basic skills that could be used, in order to make the best of these, an open work situation would have to be prepared to be flexible in the way Victoria is managed. This could mean moulding the work to suit her talents, and it seems that employers willing to do this are extremely hard to find.

There is no doubt that the introduction of the NIMROD Service has been of great benefit to Victoria in recent years. While the members of her family have aided her development a great deal, they are the first to admit that families often face very real difficulties in promoting such development. Victoria's sister-in-law commented on their tendency to over-protect Victoria, not allowing her to go on buses or to go far on her own. 'We wouldn't let the wind blow on her' summed up their protective attitude. They also suggested, in retrospect, that the presence of their own daughter made a difference to their treatment of Victoria. Her brother was able to say: 'Nimrod let her grow up. It is easier to have two children in the house than to have a child and an adult.' They felt that NIMROD had been detached enough from the situation to allow Victoria to 'make mistakes'. It had occurred to Victoria's brother and sister-in-law that often they had foreseen mistakes Victoria would make and had stopped them before they happened. However, they had found that NIMROD was 'careful and not irresponsible' in the way they allowed risks to be taken.

As she has mastered some of the essential tasks of daily living and began to work on others, more subtle problems involving personality, expectations and relationships with others have come to the fore.

Problems of this kind commonly arise in situations where staff and those they support are thrown closely together for long periods, and where staff have to adopt conflicting roles. We all naturally tend to select friends from the people we know well and see often. For many people, the potential numbers from whom friends may come is very large. For people with mental handicaps, their social network may be limited to other people with handicaps and those who are paid to support them. Staff may often be cast in the role of friend by those they support, and may themselves wish to promote friendships with those with whom they work closely. Friendship implies an open relationship, equally entered into on a mutually-agreed basis. However, staff have other obligations, especially in trying to help people become independent, and to promote age and culturally appropriate behaviour among those they support. Often, they need to do and say things that emphasise their role as supporter or teacher rather than as sympathetic friend.

Those of us without handicaps may often find it difficult to cope with very different 'sides' of the people we know. Victoria is no different in this respect and, while being very independent in a number of aspects of her life, still requires help to cope with the different 'sides' presented to her by those she is close to. This is especially important as Victoria has, in the past, invested a lot of her affection in those who support her, and regards staff members as her principal friends.

It has also been suggested by staff and her family that Victoria needs help to appreciate the needs and difficulties of others. This has led, on occasions, to her making demands that others have thought unreasonable, and even refusal to accept that things cannot be done for her even when they may be physically impossible. A second consequence of this difficulty has been the interpretation of her actions as representing an uncaring attitude towards friends, family and acquaintances. Victoria focuses on the people in her life at the present time. The outcome of this is that she will transfer affection from one friend to another as they become more important to her current activities, and has been known to walk past relatives and close acquaintances without acknowledging their existence. This obviously can have serious consequences for the building and maintenance of social networks that are important parts of a normal life.

Victoria has often been found to need 'pushing' to do things that are difficult but beneficial to her. While this is a feature we all may have in certain aspects of our lives, in Victoria's case it threatens the route she sees open for herself – that of open employment. It has been said by staff that she needs help to make a distinction between work and any other activity she might take part in, such as swimming or dancing. It is certain that she recognises the benefits of a wage and the relationships between money and possessions. However, her attitude to the workshop and to her part-time job fluctuate: when she doesn't feel like going she may not go.

Full-time work is a major goal for the majority of people, handicapped or not; employment is sensed by all to be a key activity defining our status in society. However, that status, as a fully-fledged member of society, is not related purely to the receipt of a wage. It is related to the fact that if we have a job we are seen to be taking certain responsibilities in return for that wage. If a person with a handicap is to move into the open job market, he or she has also to satisfy some of these responsibilities if status and respect are to be gained. It may be easier for people with handicaps to recognise and respond to these responsibilities if work offered to them is similar to that valued by others. It would appear at present, however, that Victoria may require help to come to terms with these aspects of work before she can reap the full benefits that employment can offer for her status in society and her independence.

The future

The future for Victoria is an exciting and challenging one, but one which remains uncertain. As her sister-in-law says: 'The flat will stretch her, but how it will effect her nobody knows'. Victoria herself says that she is very happy in her new home, and looks forward to continuing independence with her new flat mate. There are two major elements in her life for which she would wish in the future – a job in open employment, and a boyfriend. While efforts continue to find her a full-time job, there remain formidable problems. In the area of relationships, Victoria's life is dominated by her contacts with NIMROD staff, and it would seem that she may have to face a lot of disappointment before her hopes become reality.

Although members of Victoria's family supported her moves towards independence over the last few years, and are happy with the progress she has made, they find it difficult to see a situation where she will be fully independent without requiring a significant level of support from NIMROD staff. They see a potential problem here as staff working with Victoria leave the Service and are replaced. They feel that it takes time to get to know Victoria and how she needs to be approached if her progress is to be maintained. In their eyes, therefore, there is a danger that her progress could slip back when experienced staff are replaced with those who don't know her so well.

Current NIMROD staff have made no assumptions about Victoria's ultimate level of independence and are willing to support her in continuing moves towards a more independent life. As her independence increases, Victoria's contact with staff will, by definition, decrease. Given her dependence on staff, the task is to build an alternative network of friends for Victoria to take over from the strong affections she has towards staff. Without this, it is unclear how happy Victoria will ultimately be with an independent life.

Victoria has come a long way down the road towards independent living, with the help of her family and NIMROD. Her life demonstrates some of the problems that face any person with a handicap setting out to build a life in the community. The further one gets towards a valued life in the community, the more complex are the problems to be faced. The problems shift from the more practical ones of learning basic skills to those which involve the forming and maintenance of relationships, the taking of decisions and the carrying of responsibilities. And the staff helping to support people on the road towards independence face greater challenges the further down that road they are able to travel.

PAULINE DAVIES

by Kathryn Lowe

Pauline was born in Dover in 1934, the eldest of three children. Her family settled in Cardiff when she was two years old. At five years of age, she attended a local primary school, and later moved on to a normal secondary school. While there, she also began attending a cookery school for one day each week.

In 1949, when Pauline was 15, she left full-time education and began work in a local rope factory as a machine operator. She liked this job and it was conveniently within walking distance from home. She stayed in this job for ten years, but then things started to go wrong. 'The work started to get a bit dangerous ... I kept falling over and things would fly off the machines and hit me on the head.' Pauline said that she nearly caused a serious accident to someone else: 'He was in the machine and I didn't know. I nearly turned it on. I had to tell, he could have been badly hurt.' Seemingly, after a series of such accidents, Pauline was sacked from her job.

After leaving the rope factory, Pauline tried various other jobs, usually on a basis of a week's trial period. She worked in a cafe in the city centre, and in a nail factory close to the rope factory, and she also tried working in British Home Stores canteen. 'We used to wear green aprons in the Home Stores. I liked it there, but they said the work was too hard for me.' None of her attempts at securing another job was successful. For the next 14 years, Pauline continued to live at home with her family, but without a job or any alternative day-time occupation. Her records suggest that during this time she was offered a place in a psychiatric hospital day centre and a place in a local adult training centre, but she has no recollection of this.

Pauline's memory of these years is focused on her relationship with her mother. It is clear that she was very close to her mother, and has happy memories of her childhood: her weekly shopping trips into town with her mother and their regular outings to the beach at Barry Island during the summer months. Pauline and her mother continued to spend a lot of time together after Pauline stopped working. Her mother used to teach her how to carry out various household tasks, like cooking. 'I used to make tea and that, and pastry, but my mother used to tell me not to use the oven in case I hurt myself.' However, Pauline's mother was not well. She had suffered from diabetes for many years and this had affected her eyesight. Also, during this time, she suffered a stroke which caused partial paralysis to her right side and she became unable to walk without the use of a walking frame. Pauline continued to stay at home to look after her mother. However, her mother's condition gradually deteriorated. She had several spells in hospital and died in 1969 when Pauline was 35 years old. She remembers this time vividly. 'I was with my mother when she died. I had just gone into the kitchen and I heard a funny growling sound. When I went back into the room, my mother was already dead.'

After her mother's death, Pauline continued to live with her father and her brother. Her sister, by this time, had married and moved away from Cardiff. Unfortunately, Pauline's father too was unwell. He had had a coronary thrombosis and was suffering from bronchial carcinoma. The first reference to the family's difficulty in coping with Pauline appeared in 1971, two years after the death of her mother. Her hospital records noted that her father had reported she was causing trouble at home, that she was wasting money and that she hoarded things and refused to sit with the family during meal times. He also reported that she kept the fires on all the time and sat so close to them it was unsafe. The result of this was that Pauline was assessed at the mental subnormality clinic in October 1971. In this report, she was described as not making friends, as sometimes being sullen and offensive to people, and also as being 'a terrible liar'. A social worker's report at this time suggested that Pauline had not accepted her mother's death, and that her father could no longer cope with her. It also suggested that while her mother was alive, her father had been sheltered from the effects of Pauline's behaviour. It was reported that Pauline's mental condition had gradually deteriorated after her mother's death. She used to fight with her brother and this would lead to him and their father quarrelling. The report also suggested that there had been 'a history of domestic and marital disharmony'.

The main outcome of this assessment was that diazepam, a minor tranquilliser, was prescribed for Pauline. However, there was no improvement in her behaviour and her father was reported to be 'in despair'. The possibility of admitting her to the local mental handicap hospital to stabilise her medication was suggested at this time, but she refused to go to hospital or to the hospital day centre. She also refused to take any further medication unless her father forced her.

Pauline continued to live at home, but her father's health was deteriorating. The social services department referred her to the consultant psychiatrist at the local mental handicap hospital (Ely Hospital) in the latter half of 1973. Pauline's father, by this time, was terminally ill and his doctor wrote to the consultant psychiatrist to explain the father's situation. Pauline was visited by the psychiatrist and offered short-term care in Ely Hospital. At first she refused, and it seemed possible that she would be admitted under section 29 of the Mental Health Act 1959. However, she finally agreed to be admitted as an informal patient in October 1973. Her admission record states that she was admitted 'for social reasons', and that she was diagnosed as 'subnormal and rather dull. Mildly hypomanic.' One year later, in 1974, Pauline's father died.

On admission to Ely Hospital, Pauline was placed on an all-female ward with approximately 50 residents of widely differing ability. Later, the structure of the wards throughout the hospital was altered. The number of residents to each ward was reduced, and residents were housed together according to their level of ability. Pauline was transferred to a mixed sex ward, with residents of fairly high ability where she has remained to the present day.

The lack of recorded information about Pauline's life before she entered hospital is striking. All the information about her early life has come from her own memories. Her medical records give no clear indication of how, in her late 30s, she came to be diagnosed as 'subnormal' for the first time, after having had a 'normal' education and even holding down a job for ten years.

Pauline is now 52 years old. She is a small, trim person with a pale complexion. She wears glasses with one opaque lens to compensate for double vision. The nails of her right hand are deformed and discoloured which, she says, is due to diabetes. Like her mother, Pauline has a long-standing condition of diabetes mellitus. Although her condition is controlled by diet, she has experienced some severe reactions including comas and blackouts. She still constantly feels cold, and regardless of weather conditions, is always to be seen dressed very warmly, with many layers of clothing and scarves, socks and boots.

Where Pauline lives

The ward on which she lives houses 28 permanent residents (14 men and 14 women). Some additional places are reserved for short-term residents. All the permanent residents are adults, ranging in age from 20 to approximately 66 years. The general ability level of the residents is fairly high in terms of self-help and domestic skills, although the ward also houses people with difficult and violent behaviour problems.

The ward is a large, two-storey building situated towards the back of the hospital grounds. On the ground floor are two sitting rooms and a games room with a bar. Also on the ground floor is the staff office, the door of which is usually left open, so that the office is seen as part of the ward rather than a separate room solely for the use of staff. There is a large canteen-style kitchen adjoining a dining area, and these two rooms are linked by a large hatch where the residents queue up for their meals. All bedrooms are situated on the upper floor. Pauline sleeps in a room which contains five beds. Three beds are taken up by permanent residents, while two are reserved for short-term residents. Each resident has a wardrobe and dressing table for her personal use.

The ward is staffed for 24 hours each day, with 11 members of staff: four female and three male nursing assistants; one female and two male SENs; and one male charge nurse. Pauline seems to get on well with the staff of the ward. They say that she has a good sense of humour and can be an interesting conversationalist. Staff also mentioned that she regularly buys Christmas presents for them, properly wrapped, although the timing of these gifts is sometimes inappropriate. However, she does not interact much with the residents of the ward, and is described as a rather insignificant figure – quiet and enjoying her own company. She dislikes social events, regarding them as too noisy for her liking. Also, staff suspect that she is a little afraid of some of the other, potentially violent, residents and, therefore, tends to keep her distance, avoiding any disturbances which occur. The other residents tend to leave her alone in return.

Pauline willingly participates in the domestic routines of the ward, which she seems to enjoy and is good at. For example, she dusts, makes beds and washes up. Although she takes a long time to complete these tasks, she does them thoroughly and without prompting and will often redo tasks, like washing up, that other residents have done less thoroughly. She is very neat with her own possessions, keeping her wardrobe and dressing table tidy and her clothes folded. Unlike some of the other residents, she doesn't display her possessions on her dressing table, but staff think this may be because personal items are often stolen.

Pauline's leisure activities

Pauline spends much of her spare time in the dormitory. Staff feel that one reason for this is that she likes to hide her possessions and discovers inventive places for doing so, such as behind radiators, underneath her mattress, in the lining of her coat and inside her umbrella. She often complains that her personal possessions are taken by other people and are either not returned or broken, which is why she feels it necessary to hide them. However, staff report that Pauline's main, perhaps only, behaviour problem is that she has a tendency to hoard certain types of objects such as soap, tights and umbrellas. It is also strongly suspected that she 'steals' some of these items from the ward and from other residents, as they regularly discover hoards of about 30 bars of soap or 12 umbrellas among her possessions. Pauline complains about not having enough money to buy personal things like soap and tights. She doesn't like using the hospital soap as it chaps her hands, and so she prefers to buy her own. However, it does seem that Pauline actively enjoys being on her own. She will spend her spare time washing out her own underwear, tidying up for herself or after other people, watering plants around the ward and just generally pottering around. She does not appear to have any regular hobbies, but will read the paper and magazines or watch the television for a little while.

In recent times staff have tried to encourage her to go into Cardiff city centre with them. They succeeded once, but Pauline was so horrified at the price of everything, including the £1 bus fare, that she refused to go again. She talks of when she used to shop in town with her mother, many years ago, and how she used to enjoy this. She still enjoys buying things for herself at local shops, the hospital shop and at jumble sales, but will not contemplate shopping in town again because she feels that it is too expensive. It seems that, throughout her 12 years in hospital, Pauline has completely lost touch with the outside world, in terms of the cost of living, and now finds the adjustment hard to make. Pauline is, in fact, very conscious about money. Staff say that she saves her money for her own shopping, but that she's very secretive about how much money she has. The money she has at her disposal is meagre, as all items of major expenditure are provided by the hospital. She attends a rehabilitation unit at the hospital for which she receives 'pay' comparable to that from an adult training centre. In addition, she receives 'pocket money' of £1 each week and £1 reward for completing her weekly ward project.

Pauline does not show much interest in clothes, or in her own appearance. She dislikes wearing dresses and can usually be seen wearing trousers. Her main consideration is keeping warm; she constantly complains about cold draughts. Consequently, she wears many layers of clothing, several pairs of tights, woollen scarves, and boots and socks, even in the summer. This appears to have been a long-standing problem since before she was admitted to hospital, as her habit of keeping fires on and sitting too close to them was mentioned by her father in 1971. Staff have tried to persuade her to wear fewer layers of clothing, but have not succeeded. However, some staff have noted that, however warm the weather and however many layers of clothing Pauline is wearing, she rarely appears to be overheated. They have wondered whether her constant feeling of cold is related to her diabetic condition, but are unaware if any tests have been done to discover if there is any physical cause. In fact, one of the recommendations of the occupational therapy department in their 1984 annual report on Pauline, was that tests should be done to ascertain if there is any medical reason for her constantly feeling cold.

Day-time occupation

Pauline has been attending the hospital rehabilitation unit since 1973, and now usually attends on four days each week from 9 am to 4 pm. Each Wednesday is her training day, which she usually spends on the ward. The rehabilitation unit is a large, purpose-built building situated near the front of the hospital grounds. Although day-time occupation is provided for about 100 of the hospital residents, 80 or 90 usually attend at any one time and are divided into working groups, the size of which varies according to the ability of the members. For example, the most able residents are in groups of 11 or 12, the least able work in threes or fours, but the average sized group is of eight or nine residents. Qualified staff are available to work on a one-to-one basis where necessary. However, staff have reported that, with the recent development of a new adult training centre and of community placements in the area, the more able people are being 'creamed off', and this means there aren't enough staff to meet the needs of those remaining.

The rehabilitation unit has 19 regular members of staff: the head of the department; one full-time and one part-time senior occupational therapist; an art therapist and helper; three basic grade occupational therapists; a domestic science teacher; an industrial therapy manager; handicraft teacher; and six general assistants. In addition, there is an occupational therapy student on placement every six weeks, plus some student nurses. The mornings are spent working on industrial therapy programmes, mainly packing items for local contractors (Maxipacs). The afternoons are taken up with occupational therapy activities, such as personal care, creativity, cookery, visits into the community, art sessions, music and drama, swimming and adult literacy.

Staff at the rehabilitation unit say that Pauline is encouraged to participate in all the activities provided, but that she is not pressurised to do so. She has been placed in a high capability group and gets on reasonably well with the other residents and staff. She is prompt and regular in her attendance and is said to follow her timetable without complaint. She is reported to be a neat worker and to be able to recognise errors, and to learn fairly quickly from verbal instructions and demonstrations. However, staff report that although Pauline is capable of many skills and activities, she needs supervision to initiate and carry through activities, otherwise she will not ask for work, or for help if she is unable to complete a task. Indeed, because she is so undemanding, staff say that it is easy for them to forget that she's there.

Pauline does not have a very favourable opinion of the rehabilitation unit. When asked what she thought about it, she replied: 'I don't like rehab much. I want to find a warmer place. They put my money down. It's cold there, they leave the door open, and I can't work when its cold. So they only gave me ten shillings, not a pound. It gives me cold in my legs and pains in my legs and arms ... I like knitting, but I can't do this all day long as it makes my eyes hurt.'

Staff say that Pauline likes to go on the bus trips arranged during the summer months for groups of residents by the occupational therapy department; she is quite sociable from that point of view. However, although she mixes with other residents in the rehabilitation unit and will talk with them, she has not made any friends. But she does like to chat with staff. Apart from bus trips, she doesn't join in with any of the other social activities within the occupational therapy department or in the rest of the hospital.

One of the regular sessions Pauline attends with three other residents is domestic science, which is held every alternate Wednesday afternoon. The domestic science staff explain how a structured programme is followed, concentrating on 'survival' cookery skills, with the aim of preparing a simple snack by the end of each session. It is reported that Pauline's concentration is poor during these sessions, and that she may benefit more from a one-to-one method of instruction. Staff feel that she does not use her initiative, although it is evident to them that she possesses the necessary skills. They say that she can be very stubborn, but will generally 'come round' given time, and that her ability and concentration are variable, seemingly dependent on her mood. She appears to be fully aware of danger in the kitchen, but tends to be rather too nervous. She hasn't made much progress in her cooking skills during the last year, but staff feel that she could improve if more sessions could be made available to her. The domestic science teacher has not been able to assess whether or not Pauline actually enjoys cooking, especially as she dislikes having to take her coat off for these sessions. Although it seems that Pauline does not have much patience with the other people in her cookery group, it was reported that she interacts well with the domestic science staff and displays quite a sense of humour.

Every Wednesday is Pauline's training day, which is spent on the ward completing tasks. She is called at about 7.30 am by staff, but is usually already awake. After breakfast she starts her chores for the day. She cleans her locker and wardrobe and changes her bedclothes. She gets paid for all these chores and receives extra pay for any additional ones she does. This takes her until about 10 am when she goes to the hospital canteen for a cup of tea. At 11 am her next task is to lay the tables for lunch on the ward. She stays 'on duty' until about 2 pm when she helps to clear up and wash the dishes. After a break, she plans a snack for her own tea. She goes shopping for the ingredients and cooks her meal under supervision. After she has eaten her tea and washed up after herself, she is free from about 6 pm to 8 pm. Her last task of the day is to wash up the cups and saucers for the ward.

Pauline's life is focused almost entirely within the hospital environment. Apart from her annual holiday, she leaves the hospital grounds only to visit the local shops or for the occasional organised bus trip with other residents. Her visits to the doctors, chiropodist, dentist and hairdresser all take place within the hospital, as do her occasional evenings of entertainment at the hospital disco and cinema. Pauline's own description of her free time illustrates effectively her lack of contact with the outside community. 'In the evenings I sit and have a rest. I like watching TV, but it's sometimes too cold to sit and watch it. I read the Echo – I've got special reading glasses. I spend a lot of time upstairs in the dormitory. On Saturdays I stay on the ward and watch TV. I go shopping sometimes up Grand Avenue (opposite the hospital) to buy things they don't sell at the hospital shop, like cotton and scissors. Sometimes I go to the hospital pictures – they have cartoons, Donald Duck and all that on. On Sundays I watch TV. You can't do much on Sundays. You can't do much around here anyway.'

Contact with family and friends

Over her years in hospital, Pauline's contact with people outside the hospital has diminished. Since her admission she has had no contact with either her brother or her sister. During the first few years after her admission, she was visited quite regularly by a close neighbour who used to help Pauline when her mother was still alive. However, as the neighbour had an ailing sister to look after, these visits decreased and then stopped completely over ten years ago. During her early years in hospital, Pauline used to exchange visits with a family friend, Mrs Gooden. Although Mrs Gooden is still in contact with Pauline, her visits now take place only within the hospital once or twice a year, usually at Christmas and sometimes on Pauline's birthday. Some years ago Mrs Gooden replaced Pauline's sister as official 'next of kin' as stated in hospital records and is now Pauline's sole personal contact outside the hospital.

Contact with NIMROD

In 1981, the NIMROD Service was introduced into the first of its four 'communities' in the west of Cardiff. According to NIMROD's eligibility criteria, a person living in a mental handicap hospital can receive the Service if their next of kin lives in the NIMROD catchment area or, where the person has no effective next of kin, if he or she was admitted from the catchment area. Pauline was admitted to Ely Hospital from NIMROD's third community and, as she has no contact with her family, is therefore eligible to receive the NIMROD Service.

In the latter half of 1982, NIMROD staff were in the process of making contact with all the people from their third community who were eligible to receive NIMROD services. In November 1982, as part of this process, a NIMROD key-worker conducted an assessment of Pauline's abilities and needs. It was decided that Pauline was eligible to move into a NIMROD staffed house and that, if and when this occurred, she would need to attend an adult training centre. It was also noted that Pauline would probably benefit from regular contact with a volunteer, as she had no contact with relatives. The assessment carried out by NIMROD also concluded that Pauline needed more opportunities to go out of the hospital accompanied, to use buses and shops, as well as to attend a leisure class in the afternoons or evenings.

Following this assessment, NIMROD arranged an initial individual plan meeting for Pauline at the hospital on 9 December 1982. This was attended by four hospital staff: a doctor; a remedial gymnast; an occupational therapist; and the charge nurse from Pauline's ward. Pauline also attended, and the meeting was chaired by the community care manager of NIMROD's third community. The discussion centred around Pauline's eligibility to move into a NIMROD staffed house, when one was obtained in Community 3. The opinion of the doctor was that, due to her then unstable condition of diabetes mellitus, Pauline needed to be in an environment where trained nursing staff would be available to observe her night and day, in order to give prompt medical treatment (intravenous glucose) whenever necessary, as she could become hypo or hyper glycaemic rapidly. The nursing opinion, however, was that Pauline should not be prevented from leaving Ely Hospital because of her clinical condition, and that a satisfactory situation would be for her to live in a house fairly near to the hospital where there was an adequate ambulance service. It was also noted that, if she lived in the community, she could regularly attend the diabetic clinic at the main teaching hospital for the area. Pauline's own opinion was that she would like to live in a staffed house, but realised that she needed medical attention as she could become ill very quickly.

The decision made at her individual plan meeting was that Pauline should remain in hospital, pending further discussion as to whether her needs could be met in NIMROD staffed accommodation. Shortly after this meeting, Pauline's condition was considered by the hospital to be stable. Accordingly, in December 1982, NIMROD's community care manager wrote to the consultant psychiatrist at Ely Hospital requesting an indication of the period of time that he considered necessary before Pauline could leave the hospital. The community care manager also stated that NIMROD would review Pauline's situation in one year's time.

There was no further recorded contact until November 1983, when NIMROD's senior clinical psychologist sent a letter to a social worker at the hospital with regard to a review of Pauline's situation. However, since then, there is no record of any further contact between NIMROD and the hospital concerning Pauline or, indeed, between NIMROD and Pauline herself. At the time of writing, NIMROD has been operational in Community 3 for three years. The residential component in this community was delayed, but a staffed house for five people opened in May 1984. All places in this house have been filled, and plans for a second staffed house in this community were not included in NIMROD's original proposals. However, it seems that, because no alternative accommodation is currently available, NIMROD has failed to maintain any contact with Pauline and has not offered her any other services during the intervening period.

The future

Pauline clearly remembers the contact she had with NIMROD and is still waiting for them to get in touch with her again. 'They've talked to me about moving to a new home, and they said they'd teach me to cook. They said they'd let me know about the house, but I haven't heard a thing.' Pauline also has her own ideas of where she would like to move to. 'I'd like to move out if the place is warm, and if there's more money ... I don't want a room on my own. If I get ill, no one will know if I'm on my own. I got bad here once and a girl in the dormitory told someone. I was knocked out all night and in the morning I was lucky to be alive. So I feel safe here, I go to sleep with other girls around ... I used to have another friend, a neighbour in Gabalfa. She used to come on Sunday and cook the dinner when my father was at work. Maybe if I moved back there, I'd see her again. She lived in the same street where we used to live.'

Pauline has now been living in Ely Hospital for over 12 years. Throughout these years, she appears to have changed very little. Some of the 'behaviour problems' which contributed to her eventual admission to hospital, such as feeling cold all the time and hoarding various items, have remained, although her reported aggressiveness and non-cooperation are no longer part of her current life. The ward staff feel that hospital is inappropriate for her and that, especially now her diabetes is fully controlled by diet, she would be well suited to living out in the community. In that situation they feel that she may start to blossom, change her life and form friendships.

They realise that the hospital environment does not actively prevent her from doing more things, but they feel that it stifles her and that she really needs to be 'at home'.

DISCUSSION

PAST AND PRESENT PERSPECTIVES

The foregoing has been concerned mainly with introducing the reader to the seven individuals and presenting an account of their life experiences. As was stated in the Introduction, no particular effort was made to select these individuals because their stories are special or because they are seen as being representative. They were chosen primarily to reflect a range of ages and to illustrate the differing relationships that individuals have with the NIMROD Service. The seven accounts do, however, illustrate some common experiences which reflect the situation of people with a mental handicap in the recent past and in present-day society. They also highlight occasions where expectations of people with handicaps have been shown to be false, or where low expectations have resulted in particularly severe consequences for the individual concerned. The aim of this chapter, therefore, is first to analyse some of these common experiences and to identify some of the not so common situations the seven people have faced during their lives and, second, to assess the present-day situation of the individuals in terms of a number of key areas.

LOOKING BACK

The individuals featured in the seven accounts span a wide age range. It is therefore possible to examine crudely the changes which have occurred for handicapped people and their families over the last 50 years or so. Every story has a beginning and, for a number of the people described, the day which probably dramatically influenced their lives was that on which the news of the presence of a handicap was broken to their families. David Stevens was born in 1955 and

Mrs Stevens was told that 'he was an imbecile and would never be any different'. In 1967, Mrs Wilson was told: 'Your child is a mongol. He's mentally handicapped and will never amount to much.' Michael Collins was born in 1975. Mrs Collins was told that, because of his epilepsy, he was likely to 'be left retarded' and the consultant and students then left saying, 'I expect you want a little cry'. The change in the approach of professionals over the 20 years appears only to involve the use of different words. In all cases, the words used revealed little positive hope for the future of David, Carl or Michael, and the manner in which the families were told was not helpful to them in understanding the implications of mental handicap for the individual and the family. Informing parents in such a negative way does nothing to encourage those involved to plan for a positive future for the individual. From the beginning, the person is thought of as someone who will never amount to much and will always be dependent and a burden on their family – which is hardly a hopeful way to begin one's life.

Once parents have been told about the presence of a handicap, it appears that what they require above all is advice, information, support and a chance to talk things over. For Mrs Stevens it appeared that over a period of years, no help or advice was given. Mrs Griffiths stated: 'Nobody told you anything'. Mrs Collins felt 'a desperate need for some form of information and advice about Michael's handicap'. On the whole, it appears that a common experience of the mothers of the people described was a failure to obtain any information which would help them to understand their situation and would help them to ensure that life for their children would not be as bad as everybody led them to believe.

In common with other research studies, the accounts reveal that it is the women in the family who do most to provide the practical support to their handicapped relative and in fighting for services to help them. The results of such continuous struggles for support were also apparent. Louise Wilson 'lost her ability to socialise and mix with other people' and Mrs Stevens described feelings 'like claustrophobia' on always being in the house with David and his sisters. When such findings have been reported in the past, they have been rationalised in terms of the inevitable result of the burden of supporting a person with a mental handicap, thereby attributing 'blame' to the handicapped person rather than questioning the effectiveness of service supports. The comments made by the mothers demonstrate their determination, in the face of opposition from services, to support their sons at home: 'I didn't want him stuck in an institution' said Mrs Collins; Mrs Wilson was determined that Carl should not 'be shut away indoors'. Mrs Wilson did not find out about short-term care until things were at crisis point and, similarly, Mrs Griffiths was unaware of the availability of short-term care until Robert was 14. Parents had a strong sense of not wishing to see their relative admitted for long-term care, but wanted flexible support from services which would allow them to provide the necessary support at home.

Although this may be the wish of parents and people with a mental handicap, the history of service provision is very different. Services appear to have been delivered in an 'all or nothing' fashion. Once contact with services is made, the effect is that people with handicaps become increasingly drawn in and taken over, leading a life primarily in a service world rather than in the world shared by others in the community.

At an early age, both Michael Collins and Carl Wilson led a life away from all the other children in their locality during day-time hours. In Michael's case, the home advisory service provided early home-teaching, but then he started to attend a 'playgroup within a general hospital for children with all types of handicap'. At the age of two, Carl Wilson was reported to have started attending a school for 'severely educationally subnormal' children. From the age of three, Robert Griffiths went from one specialist school to another, until he was finally judged to be mentally handicapped and sent to an appropriate 'special' school. David Stevens was six years old when he began attending a 'special' school. Liam Roache attended an ordinary school until he was transferred to a school for 'moderately educationally subnormal' children. Victoria Adamson attended a 'special', pre-school nursery and then moved on to a 'specialist school'. Of the seven individuals, Pauline was the only one to complete her education in ordinary primary and secondary schools. For six of the seven individuals, therefore, from a very early age, a major part of their day was spent away from their own locality and from the other children in the area. The move to full-time special education marks a clear beginning to the process of segregation that occurs to people with handicaps. Mrs Collins comments on the irony of Michael having to travel to the other side of the city to a 'special' school when his home is situated between a nursery school and primary school.

Of the seven people described, Michael Collins and Carl Wilson are the only people remaining in the special education system. The views of Mrs Collins perhaps reflect a more general change in attitude in recent years concerning the issue of special education. Over the ten years since Michael was born, Mrs Collins's attitude has changed from that of purely fighting for services for Michael to a recognition that she wants to change the situation of people with mental handicaps in society. She now says: 'They're not separate people – they're us' and to that end she wants Michael to have the opportunity to share the same educational system as other, non-handicapped, children.

Once embarked upon what has come to be known as a 'career of handicap', and relying on a specialist service system for any necessary support, the options available to people with handicaps rapidly decrease. Carl Wilson's life story clearly illustrates this fact. While those who work with Carl want him to have as ordinary a life as possible, with the support that he requires, the post-schooling options available to him are apparently limited to the adult training centre. This is an option which Mrs Wilson is unhappy with and states: 'There's no way he's going to put candles in a box all day. I'll keep him at home first.' The accounts of Victoria Adamson and David Stevens reveal that their experience of attendance at day centres is one largely of boredom. It may be argued that, given the current high levels of unemployment, opportunities for real work for realistic pay are limited. Others argue that the work experience of many non-handicapped people is also one of boredom and exploitation, although there is a clear discrepancy in the amount earned by those in open employment and the token amounts paid to people attending centres for people with handicaps.

The ultimate form of segregation arises when people with handicaps are 'admitted' to specialist accommodation. This has usually resulted in them becoming completely encapsulated in a service world, with their living setting, day setting, and often their leisure activities, all provided in specialist buildings shared only with other people with handicaps and with paid or voluntary staff. Historically, this has commonly occurred to individuals at times of crisis, because there has been no clear planning for the future of the person with the handicap. The seven accounts also reveal that this has occurred at varying times in people's lives. For Michael and Carl, this situation has not yet arisen and it appears that their parents, together with NIMROD staff, are beginning to plan for such an eventuality by attempting to ensure that Michael and Carl's interests will be a primary consideration in planning for their future accommodation needs. For Robert Griffiths, such attempts at future planning have temporarily failed, and for some time now he has been living in an institution. David Stevens was 'admitted' to a mental handicap hospital at the age of ten and his story describes the deprived life he led while there. Now attempts are being made to overcome the effects of those years of segregation and the comments made by those who work with David reveal the difficulty of reintroducing people to their own communities. Liam Roache and Victoria Adamson have largely avoided this total segregation, mainly through the assistance of the NIMROD Service. The major form of segregation which they currently experience is in their day settings. Pauline Davies's story gives an indication of how easily people can become segregated in large institutions. For over 30 years she lived with her family, admittedly with problems, but there had been no mention of Pauline having a mental handicap. Because of the lack of options available to people in Pauline's situation, her life was transformed, and she now lives in a world completely controlled by services and service personnel.

This brief analysis illustrates how the experience of people with handicaps is commonly one of increasing segregation as they grow older and become divorced from their own communities. What have been the implications of such a process for the seven individuals in terms of the lives they lead today? The next section examines their current experiences in what can be considered the five key areas determining the quality of peoples life experiences.* These five areas cover the extent to which the individuals are present in the community and share the places that we all use in our everyday lives; the extent to which people have close and rewarding relationships; the extent to which they control their own lives through the choices that are available to them; the extent to which they experience a growing ability to undertake activities which will enrich their lives and their position in society in terms of their status and the respect that is given to them.

CURRENT EXPERIENCES

Community presence

> 'Community presence is the experience of sharing the ordinary places that define community life. Without focused effort, people with mental handicap will be separated from everyday settings by segregated facilities and activities. Valued activities increase the number and variety of ordinary places which a person knows and can use.'

Five of the seven people described here are currently living in ordinary houses in ordinary streets in localities that are familiar to them and where they have some family roots. As appropriate to their youth, Michael and Carl live with their families, and their stories demonstrate how, due mainly to the efforts and sacrifices made by their parents, they have been accepted by and integrated into a local network of family friends, neighbours and relatives. For such young people today, there is the expectation that they will continue to live 'in the community'. Michael's mother recognises that she needed and received support from services to enable her to continue caring for him at home, and that for the future, a small, ordinary, staffed house for Michael is the sort of alternative to institutional care that she desires. Victoria and Liam lived in the community with their parents until their death, when their care was transferred to their sisters and

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* John O'Brien. A guide to personal futures planning. In: G Thomas Bellamy and Barbara Wilcox, Editors. The activities catalog: a community programming guide for youths and adults with severe disabilities.

brothers. NIMROD has enabled them to continue living in the community by providing them with homes in which any necessary support is provided by paid staff. For both these people, the transition to more independent living did not occur until well into adulthood when they were in their 30s.

Both Robert and Pauline are physically segregated from the mainstream of life in the community and live in a mental handicap hospital. Although Pauline managed to avoid the damaging effects of being labelled mentally handicapped for many years, she is now part of the mental handicap service system and plans for her return to a more ordinary life in the community appear a very distant prospect, despite the fact that she has been identified as a NIMROD client. David has been more fortunate: after 16 years in a mental handicap hospital, NIMROD has provided the physical resources of a house and support staff to enable him to return to his community of origin. For the majority of Robert's young life, he lived at home with his family, but his future appears more uncertain that anybody else's, being solely dependent upon the creative response of the service system to provide for his very challenging needs within a community setting.

Each of the adults with mental handicap lives with other people who have been so labelled, whether in a large mental handicap hospital or in a small house in the community. Even in respect of the latter, it would seem that five or six mentally handicapped people living together with staff support is still too large a number because, like many other services providing residential care in ordinary houses in the community, NIMROD experienced opposition from neighbours before staffed houses were opened and people moved in. Clearly, for people with mental handicaps, living together in such numbers detracts from the benefits of physical integration within the local community, particularly for people who have historically suffered the stigma of a devaluing label.

Nevertheless, for the three adults living in NIMROD accommodation, the impact and feasibility of providing a service for adults to enable them to move out of their family homes or institutions into a home of their own in the community, albeit with other handicapped people, has been demonstrated in their life stories. The domiciliary services provided by NIMROD have supported the two families of the school-aged children in continuing to care for them at home and, in Michael's case, have prevented the need for his parents to seek residential care for him.

Having a home in the community is one thing, but gaining access to and having opportunities to use the ordinary facilities and amenities provided in the local community is quite another. Each of the five people presently living in the community makes extensive use of local facilities and surrounding environments. This contrasts strongly with the restricted opportunities for doing so shown up in the stories of the two people who live in a mental handicap hospital. Michael's family believe that despite the practical difficulties in achieving community presence, it is very important for him to visit shops and cafes to experience the normal routines and activities of daily living which provide natural opportunities for interacting with others. Carl uses a wide range of facilities in his immediate environment very regularly, both alone and accompanied by his community care worker. The three people who live in NIMROD accommodation also make extensive use of local amenities: Liam organises such activities independently; David is always accompanied by a member of staff; and there are many examples to demonstrate the way in which Victoria has extended her independence since moving away from her family home.

The physical presence of people with a mental handicap in the community clearly sets the preconditions for a range of social experiences, both positive and negative. Although five of the seven people live in ordinary accommodation in the community, all are removed from their natural communities during day-time hours in order to receive segregated day services where they are unlikely to meet non-handicapped people, except for paid staff. Not only are these day settings distant from people's living environments, as indeed are many places of work, but their physical locations are away from the mainstream of the community.

The ATCs attended by David and Liam are tucked away at the back of large council housing estates, and the workshop attended by Victoria is situated between a residential area and a large cemetery. These are clearly very different places to where most people spend their day-time hours, and do little to enhance a positive and valued image of the people who attend in such large numbers. A large proportion of the working week for these people is therefore in a very different environment, where the majority of contact with non-handicapped people tends to be in groups, or where non-handicapped people are in a position of control. For the two school-aged children, the special school they attend is located on the other side of the city to where they live, and is set in the grounds of a social services residential hostel for adults. There are no community facilities within easy walking distance, but some 'community trips' for groups of handicapped children are organised. Special transport is arranged for these trips and between school and home. These practices take place despite the determination of the parents of the two school-aged children not to segregate them unnecessarily. However, in practical terms, this amounts to leisure time and weekends only, as opportunities for integrated educational services are very limited in this county, as in others.

The provision of integrated, challenging and valued day services for people with mental handicaps is now seriously lagging behind developments in residential services throughout the country, and many valuable opportunities for community presence and community participation are being denied to people with mental handicap. There is a large gap still to be filled in the day-time hours spent by many people who are segregated for the whole of the normal working week.

Although most of the accounts have demonstrated how people are living in the community and participating in a wide range of the ordinary activities available, there also appeared to be much use being made of special, segregated social and leisure facilities. For most of Michael's leisure pursuits, including the Gateway club, youth club for handicapped children, swimming in a pool located in a mental handicap hospital and gymnastics in a further education college with other handicapped people, there is very little opportunity for meeting non-handicapped children. Many stories described attendance at the Bluebirds Club, the social club of Cardiff City Football Club. However, people only ever attended on the one Tuesday each month reserved for people with mental handicap, their families and care staff.

Carl, Victoria and Liam all attend regularly and enjoy the club atmosphere, drinking, dancing and seeing people they know. It is disappointing that handicapped people, though clearly enjoying this club, do not become members so that the facility can be extended to them on nights other than the one Tuesday a month when it is patronised by large numbers of other handicapped people. There is clearly room here for investigating a wider range of options for sports and social clubs for people with mental handicaps. For most people, spare-time leisure and social activities provide many opportunities for developing friendships and broadening social contacts. As a means to increased community participation, non-handicapped members of the community need to meet people with mental handicaps as individuals. All too often, segregated facilities mean that non-handicapped people are effectively cut off from naturally occurring opportunities to get to know any people with mental handicap.

Valued relationships

> 'Community presence is a precondition of community participation – the experience of being part of a growing network of personal relationships, including close friends. Without focused effort, people with mental handicap will have unusually small social networks whose membership is restricted to clients and staff of the services they use, or perhaps immediate family members; many of these contacts will be impersonal and temporary. Valued activities will provide opportunities for a person to meet and develop a variety of relationships with an increasing number of people.'

There are several examples in the accounts presented here which demonstrate that services have been reasonably successful in the last five years in overcoming the barriers which, in the past, have prevented people with mental handicaps from being physically located 'in the community'. This is no longer the major ideological or practical challenge to service providers. The quality of the life experiences of people with mental handicaps living in the community is a much greater and largely unresolved challenge. Only through interaction with people who have different life experiences can any of us hope to achieve a degree of personal enrichment.

The accounts presented here demonstrate strikingly the very narrow social networks experienced by people with mental handicap. The two school-aged children have clearly benefited from their families' network of neighbours and friends, although these are mainly adult networks. Close personal friends were entirely lacking for each of the seven individuals: 'Michael has no friends outside the family other than NIMROD staff who are paid to do so'; 'Besides a close relationship with his parents and a school teacher he once knew, Robert is something of a loner'; 'Although Carl gets on well with people, he hasn't developed any real friendships and prefers socialising with staff'; 'It's difficult to think who David's friends are – he likes some members of staff more than others and has a good relationship with his volunteer'; 'Liam's friends weren't known to staff or family and most people were unsure about whether he had any real friends'. Such comments as these can be traced through each of the accounts. The lack of close relationships outside the family and paid staff is very apparent.

Many of the key individuals in the lives of handicapped people are paid staff or volunteers, who generally tend to be transient figures resulting in a lack of continuity in such relationships. Many staff were at pains to point out that they considered their relationship with the handicapped person much more than that of paid staff and 'client' but, nevertheless, such relationships create expectations, dependence and conflicts that are not normally present when people enter into a relationship on an equal basis.

Although most contacts with the age peers of the handicapped people were with other people so labelled, in many of the accounts examples were given where people were clearly rejecting relationships with other handicapped people. It does not follow that people with mental handicaps congregated together to receive services will necessarily choose to befriend each other. In the short-term care house where Carl stays he 'prefers socialising with staff and doesn't appear to like to be associated with other mentally handicapped people'. While living in a staffed house, Robert 'didn't have much to do with the other residents, but developed a strong rapport with staff'. Liam was 'unhappy at one of his day centres and didn't like mixing with large numbers of handicapped people; that is one reason why he chose not to travel to the centre on the special bus'. For Pauline too – living in a mental handicap hospital – it was reported that 'although she gets on well with ward staff she does not interact with other residents'.

Indeed, many of the individual accounts illustrate the extent to which people with mental handicaps are solely dependent on staff for creating opportunities to develop social networks outside the world of handicap. David's care worker recognised the importance of David meeting new people, but that the practicalities of doing so were more of a challenge. His solution was to introduce David into his own circle of friends, while recognising that much of David's behaviour may be due to difficulties in forming close relationships with other people, particularly the opposite sex. Carl's community care worker had also introduced him to two of his own friends – a young couple who have subsequently become his volunteers. The staff of the NIMROD Service seem to play a significant part in Liam's life also; they feel that he enjoys and needs the support he gets and likes to know that somebody cares. Victoria's close relationship with certain members of staff has created some conflicts of role, as staff are paid to provide certain types of support, (skill teaching, for example) that would not be expected from friends. There is a clear commitment from staff to attempt to ensure that experiences of community living for the mentally handicapped people with whom they work are as good as possible. It is also clear that the development of outside relationships for people with mental handicaps should be encouraged in ways that support existing and growing relationships rather than replacing them with staff friendships.

Competence

> 'Competence is the experience of growing ability to skilfully perform functonal and meaningful activities with whatever assistance is required. Without focused effort, people with severe handicaps will be deprived of the expectations, opportunities, instructions and assistance necessary for development. Valued activities will increase a person's power to define and pursue objectives which are personally and socially important.'

If there is one defining characteristic of mental handicap, it is that people who have been so labelled have some degree of learning difficulty. A considerable number of specialist day services, for example, special schools, ATCs, and sheltered workshops, have evolved to enable people with a mental handicap to overcome some of those difficulties. Such services aim to provide an environment where people with a mental handicap can learn and receive training and experience to increase their independence. The individuals described here can be seen to spend a significant proportion of their time in such day settings.

Six of the seven individuals receive day services. Only Robert, who is perhaps the most disabled of the seven people, receives no formal or structured learning in a day setting or, apparently, anywhere else. There is no structure to Robert's day and NIMROD staff who had worked with him while he lived in the staffed house are concerned that in his present environment he is in danger of losing the skills he already possesses and those he had developed while living in the NIMROD staffed house. As was mentioned earlier, the day settings attended by the other six individuals are completely segregated. This has major implications for determining how adequate and appropriate they are in providing an environment which promotes individual growth and development.

In special schools, another set of concerns relates to the range and type of skills that are taught and how appropriate they are to individuals' needs. Michael's parents struggled for a highly structured and intensive educational environment for him, and are dissatisfied with his curriculum. Carl, as part of a scheme for preparing him for leaving school, is receiving a 'first-aid' survival educational kit, which consists of visits to community facilities and to public services. However, he already uses a number of community facilities fairly independently and uses others with his CCW and family. For Michael and Carl, therefore, it is questionable whether the day services provided for them are helping to overcome aspects of their learning difficulties.

The skills taught to children with a mental handicap are obviously related to the role they are expected to perform in their post-school years. For most of these children, their post-school options are restricted largely to attendance at an

ATC. The orientation of day services for adults has shifted over the years towards providing training for community living and leisure and has moved away from providing work-related training. During the period in which information for this book was being collected, Carl's future educational needs were being discussed by staff and his parents. Although there was some recognition that he requires on-going education, it seemed likely that he would attend an ATC and it was hoped that the changing nature of ATCs would provide more valuable experiences than previously. However, the curricula of such settings do not appear to be directed at meeting individual needs. Despite the hopes of those involved in planning the future training and learning needs of young school-leavers such as Carl – that ATCs are changing – the problems of the segregated setting and learning content are as relevant here as they are for school-aged children.

David attends a special care unit attached to the ATC and the staff who work with him in the house are unsure of the benefits he gains from going there. David requires individualised training and support but, as the name suggests, the activities that go on there are more 'care' than 'training' oriented. Again, such an environment is likely to be based on low expectations of the students' abilities, a situation which does little to facilitate learning. For Liam, Victoria and Pauline, staff are unsure what they gain from attending day services. Pauline demonstrates a lack of interest and motivation in her work. She already has a number of skills. Some of the skills taught in the rehabilitation unit (cooking, for example) she has little opportunity to use in practice. She is also taught personal care skills which could more appropriately be taught in her living environment. Liam is best described as being on the periphery of the social education centre and it is difficult to see what he gains from attending. Many if not all the activities he pursues at the centre could be carried out in more appropriate and integrated settings. The discussion groups, photography classes, art, cookery and discos on Friday afternoons, could all be pursued and enjoyed in alternative community settings. Victoria, like Pauline and Liam, is disinterested in many of the activities undertaken in her day setting and finds little to challenge her. She does, however, attend an adult literary class at an ordinary school on one evening a week and is employed at a local arts centre on another; she seems to enjoy and derive benefit from both these activities.

For all seven individuals, there is little evidence that the day services they receive provide a coherent system for acquiring skills, despite the fact that they are aimed towards preparation for a more independent life. Any learning which does occur takes place in largely segregated settings, and there is little opportunity to put skills into practice in the setting in which they are supposed to be used. Some of the skills taught are, on occasion, inappropriate to individuals' needs and not generally taught by individualised teaching methods.

As described in the individual accounts, considerable time is also spent on skill teaching outside the day settings. The NIMROD Service has a home-teaching component provided by CCWs working primarily with individuals living at home. For Michael, these sessions largely involve visiting shops and cafes to attempt to improve his social responsiveness by structured interactions. Carl seems to enjoy his sessions with his CCW – they visit pubs and cafes and he is encouraged to take more responsibility. People living in NIMROD houses who attend ATCs have one day each week set aside as a 'training day'. For David this consists of learning to carry out a greater range of domestic tasks to increase his confidence and independence. Liam also has contact with CCWs who come to the house to make sure he gets up early enough to go to the centre and to check that the day-to-day running of the house is still in order. Their level of assistance is kept to a minimum so that they do not intrude too deeply into his life. It thus appears that NIMROD has recognised that people with a mental handicap will learn more easily in those settings where the skill is supposed to be practised.

Given the nature of mental handicap, very few of the individuals described here appear to receive valued and effective learning strategies to help promote their independence and to provide a sense of self-fulfilment. Some efforts have been made by the NIMROD Service to redress this balance. Those individuals receiving the home-teaching component have benefited in terms of their use of ordinary and valued community facilities and activities. Nevertheless, most of the individuals described have dull and unchallenging experiences in their day settings. To some extent this reflects the limited range of options for day occupation discussed earlier, but there are areas which could be worked on within these limitations. However, until bold initiatives are taken to provide more valued and optimistic educational and learning experiences, people with a mental handicap will continue to live, learn and be seen on the margins of society.

Choice

> 'Choice is the experience of growing autonomy in both everyday matters (like what to eat or what to wear) and large, life-defining matters (like who to live with or what sort of work to do). Personal choice defines and expresses individual identity. Without focused effort to increase available options, people with severe handicaps will be passive, and without a voice or the ability to exit undesirable situations. Severely handicapped people can challenge others' ability to direct personal preferences. Some people may be judged incompetent to make some important decisions and rely on a guardian to choose in their interest. Valuable activities increase the variety and significance of the choices that a person makes.'

People with a mental handicap have, traditionally, not been expected to exercise much control over their own lives, and seldom have they had the opportunity to do so. In retrospect, their lives appear to have the stamp of inevitability and are marked by a stark absence of individuality from birth to the special school to the ATC; from a home to an institutional life. However, this is due much more to societal attitudes and the effects of mental handicap services than it is to abilities and preferences of people with a mental handicap. While there may be a developing view that people with a mental handicap should have more choice, it must not be restricted only to day-to-day choices but should extend to more life-defining matters. It is the range of options and the way that they are presented to individuals which partly reflects their status in society.

As can be seen from the current lives of the people described here, those individuals in regular contact with NIMROD do have some say in determining everyday activities. For the two individuals living in hospital, this choice seems to be missing. Within the hospital environment, opportunities for Robert and Pauline to exercise some control over their lives is minimal. The account of Robert's day in the ward portrays him aimlessly responding to events and, in his boredom, reacting aggressively. He waits for the food trolley for meals prepared in the hospital kitchens, where the level of choice is minimal. Pauline also has little control over the events of her day-to-day life. Even in areas where it is clear she has some personal preferences – for example, her own soap and tights – she is unsure whether they can be afforded from her allocated income. Pauline's poverty also restricts her from being able to go into town to choose new clothes.

The three individuals living in NIMROD accommodation can be seen to exercise rather more control over their day-to-day experiences. David, who spent considerable time in hospital before moving to the staffed house, still requires the support and encouragement of staff to take more responsibility and initiative at home. For example: 'He will still ask us if he can sit down, even after all this time'. Although he still requires prompting to carry out domestic tasks around the house, he is involved in preparing meals and looks after his own benefit book, going to the post office with a member of staff to withdraw his money. Victoria's experiences while living in the staffed house suggest that she had considerable control over a number of aspects of her life. She was involved in planning and going on shopping trips, and on some days was responsible for preparing meals. Liam prepares his own meals, looks after his own clothing and finances and, like Victoria, chooses when to go out and return, and where to go. The two individuals living at home with their parents appear to make choices appropriate to their ages. Carl is given the opportunity to take part in activities independently – for example, going to football matches and shopping on his bicycle. Michael, who is much younger, does not have a great deal of control over his own life. As his account shows, he is capable of demonstrating preferences to certain foods and activities, and he was also offered opportunities to make decisions for himself.

The five individuals living in the community are, therefore, to some extent becoming more involved in making decisions about everyday matters. It is less clear, however, that they have similar control over more life-defining matters.

In terms of where people choose to live, only Victoria can be seen to have been consulted about her two moves. Pauline's case reveals the dangers of consulting an individual about moving and then failing to follow it up. She relates the exerience adequately in her own words: 'They've [NIMROD] talked to me about moving to a new home, and they said they'd teach me to cook. They said they'd let me know about the house, but I haven't heard a thing.' Two-and-a-half years later she was still waiting. For Liam, David, Pauline and Robert, there was little choice concerning the other people they live with. For individuals living in the smaller, more personalised accommodation provided by NIMROD, there is a clear lack of real friendship with the people with whom they live. For Michael and Carl living with their families, NIMROD is beginning to consider future accommodation needs. In Michael's case, this may seem premature, and any decision about his future will need to be reconsidered at a later stage. Both sets of parents, however, appear relieved that there is now an alternative to institutional accommodation and support their children's right to move away from home.

As was mentioned earlier, the development of a wide range of integrated and valued day services for people with a mental handicap is lagging behind the achievements of residential services. We live in a society which attaches importance to people's work: earning a wage rather than living on state benefits is a more valued alternative. Liam has indicated that he would like to work. Victoria would also like to work, but there are fears that she would be given low-paid work. However, she already performs routine and unchallenging work and receives little reward for it. People's wishes apart, there are real problems in trying to enter the job market where the high level of unemployment leaves mainly low-paid jobs with poor working environments.

From the foregoing, it is clear that NIMROD has provided individuals with more responsibility and increased opportunities for control over everyday matters. It has also provided the support necessary for people to choose a wider range of activities in the community, and to extend their range of residential alternatives. There is, however, concern that services are still not sufficiently flexible to offer indiiduals the experience of more challenging situations. If individuals are to have the experience of making decisions about their lives – for example, where they would like to live and with whom, or what they would like to do during the day – then services must have sufficient flexibility to be able to adapt to the needs of individuals. Some of the accounts also demonstrate the powerlessness of individuals, even within a 'progressive' service. A number of individuals may be judged unable to express preferences regarding life-defining choices. It is important that if people are to break out of their dependence on services that their interests and welfare be protected to the fullest extent. To this end the idea of advocacy has been developed. Citizens who act as advocates for people with mental handicap are independent of the service system and may therefore exert some pressure and influence on services to address the needs of individual clients, with the result that a more appropriate level of accountability is introduced into service design. Such a move would be beneficial for all the individuals described here in becoming more independent from services which, for many reasons, often have the effect of making individuals more dependent.

Status and respect

> '[Status and] respect is the experience of having a valued place among a network of people and valued roles in community life. Without focused effort, people with severe handicaps will be confined to a narrow range of stereotyped, low-status community roles which will restrict their opportunities to be seen and valued as individuals. Valuable activities will challenge limiting, negative stereotypes about a person and provide access to valued roles.'

'Mental handicap', as a term used to describe individuals with learning difficulties resulting from intellectual impairment, is an unsatisfactory term. Undoubtedly, mental handicap can be understood in terms of impairment and resulting disability, but such factors cannot be used to explain the quality of life which individuals experience, why they have been excluded from valued activities and experiences in work, home and leisure, and why they have been denied the right to have some say in determining the direction of their lives.

A full understanding of this requires an examination of society's response to 'handicap' and a lot has been written about this subject. It is only necessary here to consider the value or status of people with a mental handicap in society.

There are numerous aspects to consider. At one level, there is the image that an individual presents in daily interactions with other people – for example, through their choice of clothes, the expression of their tastes, likes and dislikes, and possessions. While such expressions of individuality underline the importance of individual choice, they also provide a powerful basis for an individual to develop a more valued image of himself. NIMROD has been active in attempting to support and foster more postitive images of people. David, for example, has his own car which he uses frequently for travelling to and from home and the ATC. Victoria, through being given support and increased choice, has developed a high level of individuality and comes across as an energetic and sporting woman. At another level, NIMROD has encouraged parents to have higher expectations of their children. Both Michael's and Carl's parents recognise and support their right to leave home. Michael's mother talks of the way NIMROD has helped to transform her attitudes towards mental handicap: 'They're not separate people – they're us'. For the individual, enriched and valued experiences of this sort enhance the feeling of well-being and confidence. NIMROD has, to a great extent, been instrumental in fostering such positive images.

However, while these gains are significant, the status and image of individuals with a mental handicap in society has seldom been prompted by any detailed knowledge of any one individual. The accounts in this book describe experiences too common to be attributed to individual problems and character. Society's response to mental handicap is still largely one of negative perceptions of people segregated from their communities, treated as a group with special and different needs and denied access to a wide range of 'positive' experiences. All seven individuals are, to a large extent, still dependent on services for meeting many of their needs. This level of dependency still precipitates views that people with a mental handicap are a 'burden' on their carers and society. They 'receive from' rather than contribute to society and are forced into situations where they are the passive partners in the determination of their lifestyle. NIMROD has attempted to break down the traditional dependence of clients on their service by attempting to create more use of community facilities with the hope of eventually increasing and developing an individual's friendship and contact network. The Service has also tried to intervene as little as possible in an individual's life so as not to 'take over', as described in Liam's case.

Confronting and tackling society's reaction to mental handicap is a difficult and arduous task that may be beyond the greatest efforts of any individual service worker. In such a situation, there is a tendency to retreat in the face of overwhelming negative attitudes and to believe that nothing can be changed until the basic structures of society are changed. However, the NIMROD Service has to some extent attempted to overcome some of these barriers. To wait until society changes is to deny change by default. Change has been shown to be possible: NIMROD is but one demonstration of this. Ending segregation in all aspects of an indiidual's life is a major aim in helping people to struggle to develop individual identities which can break out of the stereotype and answer the prejudice that people with a mental handicap have suffered from for too long.

FUTURE DIRECTIONS

In drawing to a conclusion, it is to be hoped that these seven accounts of the past histories and current life experiences of people with a mental handicap have helped to illustrate some of the ways in which service provision is slowly beginning to change. The NIMROD Service is one example of the way in which many services today are beginning to focus on the needs of individuals, and to take these needs as the cornerstone of the service planning and delivery process. However, as numerous specific examples have illustrated in the stories of the seven individuals, many large, unfilled gaps in people's lives still remain and these should serve as pointers to the direction of service development in the future.

The description and examination of people's lifestyles as adopted in this book are a particularly helpful way of looking at the needs of individuals in a more holistic way than is usual or possible by more traditional forms of assessment. Life for all of us, whether mentally handicapped or not, could be said to be composed of the need to find somewhere to live, to earn a living and to have leisure time and a social life, and there is no doubt that major advances have been made in the provision of real homes in community settings for people with mental handicap. However, in the future the factor which will have the greatest impact on change of lifestyle for most people with mental handicap is the development of non-segregated work and leisure opportunities. Only then will real community participation be established with subsequent opportunities for the development of mutually rewarding friendships and relationships with other people of the same and opposite sex. It is not difficult to imagine how such opportunities could be one of the best means of achieving integration, participation and ultimately, following on from a real shift in attitudes and perceptions, the acceptance by society as a whole of people with mental handicaps.

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Lifelines

LIFELINES: an account of the life experiences of seven people with a mental handicap who used the NIMROD Service.

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