Building Community

WITH PEOPLE WITH MENTAL HANDICAPS, THEIR FAMILIES AND FRIENDS

ANN SHEARER

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WITH PHOTOGRAPHS BY
RAISSA PAGE

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And thanks especially to friends and colleagues in Campaign for People with Mental Handicaps and l'Arche, from and with whom I've learned so much over the years.

Ann Shearer

THE PHOTOGRAPHS

Special acknowledgements are due to the people in the photographs and the schemes with which they are involved: Contact a Family, Bournemouth; Gillygate Bakery; Greenwich Social Services Department supported housing; Hasland Community Living Unit; Islington Adult Education Institute; Northumberland Area Health Authority housing for young people; Pathway, Bradford; Springfield Road School; The Wedge.

A word of explanation is due, too: the photographs have not usually been set alongside their specific text. They illuminate something wider than a single scheme: the theme of participation and the enjoyment of community life which is the central theme of the book.

1 INTRODUCTION

SETTING THE SCENE

No plans can be made, no services can be developed, until we know what these services should achieve. Campaign for People with Mental Handicaps believes that the aim of any service for handicapped people must be to enable them to live as normal a life as possible...

It sees no place for the large and isolated special hospitals in future planning, but instead aims to see these replaced by a network of locally based small homes, which draw as far as possible on the services a community provides for its 'normal' population, and which are backed by a large expansion of services to families with a mentally handicapped member living at home.

Future Services for the Mentally Handicapped, CMH, 1972

If the ideal of community care means anything, it must mean services which provide for all levels of disability...

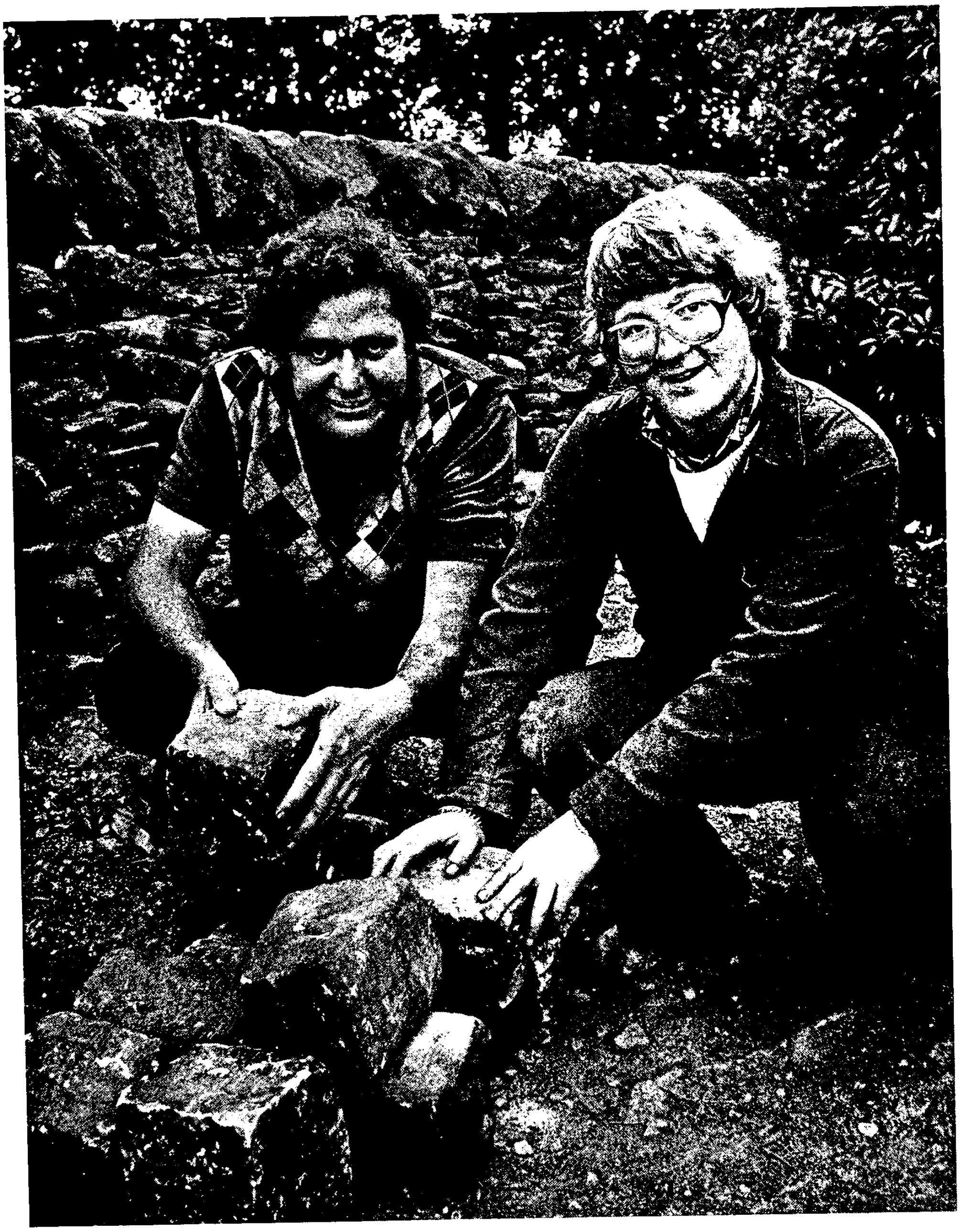
We recommend that new residential services for all but a small minority of mentally handicapped adults be in the form of ordinary housing within the wider community...

There remains the pressing question of the future pattern of residential services for that small minority of profoundly mentally handicapped adults, who may also be behaviourally disturbed and/or physically handicapped ... Many of these people are currently living in hospitals; in the short term there may be no readily available alternative. In the long term, however, there is no reason why such care should be given in hospital wards and many reasons why it should not...

The essential point is that new provision of residential care for the small minority of severely handicapped adults must be planned and carried out in accordance with the principles of genuine community care. It is a challenge, but one that we are confident can and will be met.

Community Care, House of Commons Social Services Committee, 1985

When CMH first set up shop in 1971, 'naïve' and 'idealistic' were two of the kinder epithets to come its way. To insist that people with mental handicaps



could never be accorded their rights as members of our society while those mental handicap hospitals existed to tell their fellow-citizens that there was an unbridgeable gulf between their 'abnormality' and the outside world's 'normality' was seen as a philosophical luxury at best. Fifteen years on, the issues look rather different from that. After more debate and discussion about the opportunities and services offered to people with mental handicaps than at almost any time since those services first began, we all know far better the principles from which to work. And we are beginning to see these principles made reality in individual opportunity.

This hasn't been easily or glibly come by. There has been shame and revulsion at the revelations of conditions in so many of the hospitals, each of them part of a National Health Service whose own ideals have been, so we're often told, the envy of the world. There has been excitement as the news of what could be happening for people with mental handicaps, their families and their staff has filtered through (especially from the United States) and defensive dismissal of such schemes as 'experimental' and foreign at that. There has been a lot of lip-service paid to the notion of 'community care' – and a lot of scepticism behind the easy phrases. There is danger here. As the Social Services Committee pointed out: community care 'has become a slogan, with all the weakness that that implies'.[1]

But slogan or not, it is increasingly being taken up. The plans to close mental handicap hospitals which would have drawn huge comment in the past are now becoming, if not commonplace, at least an accepted part of current thinking. There is danger here too: 'Any fool', as the Social Services Committee also said, 'can close a long-stay hospital. It takes more time and trouble to do it properly and compassionately.'

But along with the dangers, there is a solid basis of hope. The principle of normalisation is offering to many not just a foundation for planning and running services but a vantage point for judging service quality. It is teaching us how intimate a connection there is between the value we place on people and the services we offer them – and how to use means that our society values to help people with mental handicaps to live in ways that are themselves valued.[2] We are learning that without a set of principles from which to start which have been studied and deepened, both we and the people who use services can run into some terrible messes, and we are learning what the principles are that will keep us straight.

Mentally handicapped people, said the Jay Committee on Mental Handicap Nursing and Care in 1979, have a *right* to enjoy normal patterns of life within their community, a *right* to be treated as individuals, and a *right* to the additional help they will need to develop to their maximum potential. It was clear, in its 'model of care', about the implications of these assertions. They meant that people with mental handicaps should have access to the full range of ordinary community services, with 'special' back-up only when these could not meet their needs. They meant that professional interventions must strengthen, not supplant, existing networks of community support. And rights were not somehow to be 'earned' by ability: Jay's principles applied as much to those whose handicaps were severe and multiple as any others.[3]

These basic principles have been further deepened since and their implications further explored. The King's Fund working party on *An Ordinary Life* elaborated the concept of a local 'residential service' which would be truly 'comprehensive' in that it excluded no one from its area because they were 'too handicapped'. It reasserted the fundamentals: people with mental handicaps have the same human value, and therefore human rights, as anyone else; living 'in the community' is both a right and a need; services must recognise each person's individuality. It knew too what that should mean in practice: residential services should, wherever possible, be delivered to people in their own homes (the *staff* should move about as needed, and *not* service users unless they choose to); individuals should always be served by the 'least restrictive alternative' possible; people's need for a residential place should be offered where everyone else finds theirs – in an ordinary house.[4]

But if a place to live is anyone's starting point, an 'ordinary life' means more than that. The fundamental principles of access to ordinary community patterns for people with mental handicaps have been extended to work. *An Ordinary Working Life*, for instance, asserts that 'whatever support is needed to enable a person to work should be provided'.[5] The principles are creeping into our assessments of the education offered to children with mental handicaps, through the growing realisation that learning in ordinary schools is also both a right *and* a need. We are learning that the same is true of leisure activities.

And in our learning we are slowly beginning to take advantage of an expertise that has been around all along, if only we had stopped to think. People with mental handicaps are themselves finding their voice and telling us some things we need to know about the opportunities they are offered – and denied. They are reminding us both of the very 'ordinariness' of their aspirations and that within those there are as many quirks and preferences as there are individuals. If one of the challenges of the 1980s is to lay the foundations of a truly comprehensive pattern of community care – stretching across the country and open to all who need its support – then the other is to ensure that this pattern belongs not to the providers and planners, but to the people who use it.

By 1985, CMH was able to draw up its own criteria for the development of all care and services in the community:

* Services should provide the maximum opportunities for integration – not just physical but social.
* Services should be based on the needs of individuals – and so rely far less on planning and provision for 'groups'.
* Services should allow a range of choice.
* Services should be comprehensive.
* Planning and management should involve consumers as widely as possible – including people with mental handicaps as well as their families.
* The highest standards must be maintained – by internal and external monitoring, by advocates or 'friends' who promote the interests of individuals, and by 'self-advocacy' through which people with mental handicaps themselves are heard and respected.[6]

By 1985, too, we knew – at last and after all those debates and discussions –

what the real issue in comprehensive community care was about. The Social Services Committee put it trenchantly:

> It is now idle to take refuge, against all the evidence, in the misguided belief that new patterns of care for severely mentally handicapped people are impossible. Their practical possibility has been demonstrated, where the staff and the money are there. Where sufficient money is not forthcoming, where the political will is weak, or where staff cannot be found, the hospitals remain.

Now, at last, we have found the question. It is not: 'Are these aspirations impossible?' It is simply: 'Do we want to do it badly enough?' And to that, there have been some dusty answers.

During the 1970s, the number of people living in mental handicap hospitals fell steadily by about 1000 a year from its 1970 total of 55,000. But it is a sombre fact that most of this fall was not because people with mental handicaps left hospitals for new opportunities in their communities, but because they left them when they died, and new admissions were restricted. The pattern continues. No less than 40 per cent of the decline in numbers at one large hospital at the start of the 1980s, for instance, could be attributed to deaths. In another, between 1979 and 1983, there was a net reduction of 199 people; 194 of them had died.[7]

Overall, by the end of the 1970s, it was reckoned that only a tiny trickle of 150 or 200 people a year were leaving the hospitals. The reason is not far to seek. Local authorities simply didn't have the ability to create new community opportunities for people coming from hospital when they could barely stretch to preventing new admissions. The situation has maybe got worse, not better. Local authority day services nearly doubled over the 1970s – from 23,500 places in adult training centres to 42,000. But today they are in desperately short supply in many areas. And the continuing rise in 'short-stay' admissions to mental handicap hospitals – as many as 25,000 in 1982 – is testimony enough to the local authorities' inability to provide the patterns of support that families need.[7]

At the end of the 1970s, by CMH's calculations, it would have taken 17 years, rather than the ten anticipated in the government's White Paper targets, to bring hospital numbers down to the level thought proper. Today, the situation is very much more serious than that, because today we want more for people with mental handicaps. The White Paper, after all, anticipated that at the end of the period of reform there would still be 27,000 people living in hospitals.[8] By 1982, it was the hospitals that were still providing 71 per cent of all the residential places in the land. And there is some indication, too, that a 'new' long-stay population is slowly building up, as those 'short-term' stays stretch out.

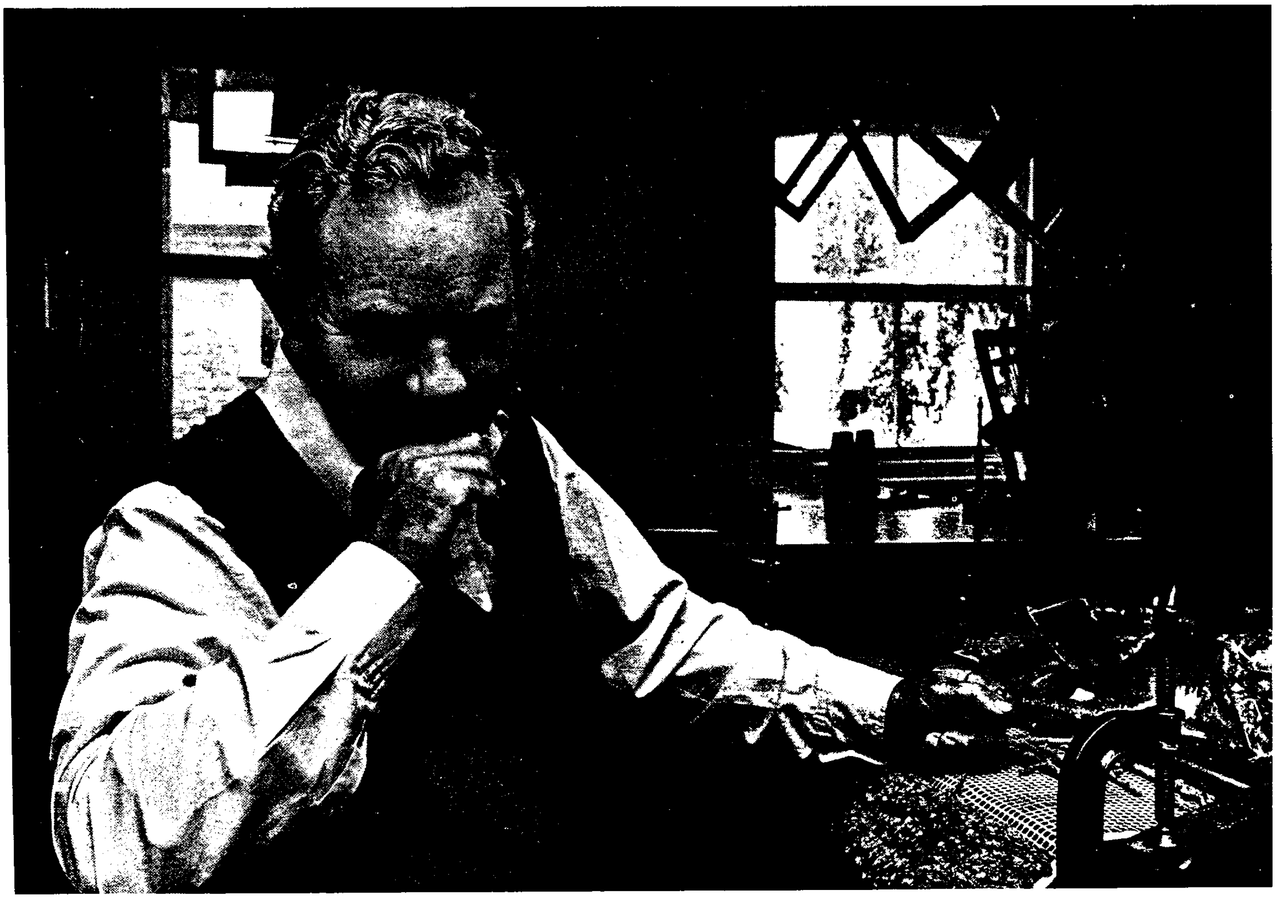
The hospitals, then, have proved immensely tenacious in their hold over services to people with mental handicaps. And their very tenacity makes them more tenacious yet. The 'backstop' they provide is at the least a psychological barrier to creative thinking about community alternatives for people whose handicaps are most severe. Their existence is at the least a psychological barrier to 'public acceptance' and willingness to find the money for alternatives, when public images of what it means to have a mental handicap are still so often associated with that strange and 'different' hospital world. And the existence of the hospitals brings a terrible financial dilemma. Throughout the 1970s and beyond, they have gobbled up the vast bulk of NHS funds. While people are still living in conditions that lack the most basic decencies, who is to say that expenditure must stop? But as CMH has pointed out: 'There are two problems in this sort of spending. First, it fails to achieve even the minimal standards required; second, even when buildings have been upgraded to these standards, they remain totally inappropriate to the kinds of service people nowadays are trying to develop.'[9] That dilemma does not go away.

Nor have governments done much to push it. The financial mechanisms dreamed up over the years to shift funds from the NHS – which, relatively speaking, has them – to local authorities – which, relatively speaking, don't – have certainly fuelled some valuable local initiatives. But as the Social Services Committee found, they have proved completely inadequate for the task.

Joint finance, it said, 'is still an essential part of the infrastructure of community care, but as a means of transferring further responsibilities from the NHS to local authorities, it is now virtually played out'. The 1983 Care in the Community initiative extended the period during which the NHS would continue to support jointly-funded schemes and, in certain cases, extended these to include housing and education as well as social services. It also allowed for some lump sum payments by health authorities to local authorities, as well as introducing some 'pilot projects' paid for out of the joint-funding coffer. But as the Social Services Committee said, these initiatives went no further than joint-funding itself to offer 'a persuasive and lasting solution' to the problems of transferring resources together with people.

'The facts remain. Health authorities at present spend scarcely enough per capita on mentally ill or mentally handicapped patients to enable a decent community service to be provided at the same price even if immediate and full transfer of patients or cash or both were available.' It saw no alternative to a central DHSS bridging fund, in addition to other capital and revenue expenditure, and available over a period of years. Who's betting on that?

So the first and enormous issue is to find ways to shift resources from the



hospitals together with their populations. The second, however, has to do with the shape of what comes next and it is beginning to look as important.

Services have not stood still over the past 15 years. And what has happened too often is that the institutional stock has grown. The land is becoming littered with these monuments to lack of thought and attention to individuals. The major residential investment of local authorities in the 1970s was the 'hostel' – that travesty of an ordinary house in an ordinary street, catering as it did for an official maximum of 25 adults and, in 40 per cent of its clones, more than that.[10] Those who run our local authority services would have read by now, you'd have thought, the huge amount of literature on exactly why a place that stands out from its neighbours as 'different', that clusters together people who have not chosen to live together in a 'group' regime, that may create real personal anguish among its inhabitants, is not exactly what we mean by 'an ordinary house'. Yet in 1985, such places were still being newly planned.

Nor have health authorities been slow to add to institutional stock. They have built onto existing hospital sites; they have pressed into service redundant old hospitals for the purpose of 'decanting' (*sic*) people with mental handicaps from other old hospitals; they have planned entirely new hospitals. And they have, in their own efforts to help make a contribution to 'community care', followed the lead suggested by the National Development Team and put plans for new 'community units' of up to 24 places onto their list of good things.

The private market is also seizing on its opportunities to add to this dismal catalogue. Between 1980 and 1982, the number of places for people with mental handicaps in private homes rose from 1617 to 1858, by one fairly comprehensive count. The numbers were maybe relatively small – but that rise represented an increase of 13.7 per cent and the current government makes no secret of its hopes of the private sector. The 'average' size of these homes was something like 17 places – and others are larger still.[11]

Convenient these developments may be; true community care they are not, reproducing as they must the 'differentness', the social isolation, the strains of large group living and the threat to individuality that have come to be associated with the word 'institution'. People with mental handicaps, it seems, are having to grapple with a new hazard: the 'just like' provision. There are aspirations to build residential institutions which are 'just like' home in their 'domestic detailing' and 'homeliness'; even to build special campus developments which are 'just like' communities. The only real problem with them is a quite decisive one: they are not the real thing. There is only one way to provide 'domestic scale accommodation' and that is to find a house. There is only one way to offer 'community' and that begins with siting that house within a neighbourhood with an ordinary mixture of people.

So what we still need more of is not just cash but thought about what we are providing and a constant recourse to those principles of service which should be our guide. That recourse needs to be a real one, too. In its major study of regional health authority plans in 1983/4, CMH found that not a few started with a general statement of principles with which no reformer could disagree, but went on to propose services which often had very little to do with them at all. It found that RHAs were still fixated on capital planning, on the extremely dubious premise that once you have a building, you have a service. It found that RHAs were still isolated from their local authorities, which minimised the chances of developing a coherent overall service. It found that RHAs were still woefully ignorant about the new approaches and the new services from which they could learn so much.[12]

Yet the Select Committee did not draw its conclusions and recommendations out of thin philosophical air. Those new approaches and services exist. The component parts of the comprehensive community services of the future are slowly growing, in more and more places. They are there in family support services and new opportunities for integrated education. They are there in the increasing use of ordinary housing by people with mental handicaps – and that includes people whose handicaps are very severe. They are there in the attempts to break down the bulk-provision called 'day care' and offer people instead their chance to share in ordinary places of learning and working. They are there in the building of social networks and opportunities to enjoy ordinary leisure, without which 'community care' would be a bleak enough prospect for any of us.

These sorts of developments are no longer 'experimental'. Some of them have been going for years. There are enough of them now to fill a hearteningly weighty bibliography.[13] In one or two places, these components are even being welded together into the start of the truly comprehensive local service to which the philosophy aspires. And in Wales, if not in England, they have been accepted as the basis of a national strategy for developments over the next decade.[14]

So 'community care' can be more than a slogan. There is another way. That is what this book is about.

ABOUT THIS BOOK

This book does not set out to do five things.

First, it does not set out to offer a blueprint for comprehensive local services to people with mental handicaps and their families.

Such a thing doesn't yet exist and it probably never will, for local services means services that respond to local needs, and these are always going to vary from place to place and time to time. The advantage of this could be that planners and providers of services, professional workers and pressure groups, service users and their neighbours, can all be involved together in creating a comprehensive pattern of provision that is truly their own.

Secondly, this book does not set out to discover instances of total enlightenment.

The services described here are about real people in real places, and so they are necessarily imperfect, for there is no such thing, thank goodness, as a people-proof system. The advantage of this could be that all those local people need feel no inhibitions about using what they find here as a starting point for dreaming,

discussion, debate, and coming up with something even better of their own.

Thirdly, this book does not at all set out to offer a comprehensive review of everything good that is happening for people with mental handicaps across the land.

One day a large team with huge resources and a computer may do it. But the ambitions of this project are very modest. One advantage of this could be that the book isn't too heavy to read, to carry about and to lend to friends. Another could be that by offering simply a sketch of the wood rather than the detail on every last tree, people have space to do some planting of their own.

Fourthly, this book does not set out to make any sort of scientific evaluation of the projects, schemes and services it describes.

Some of them have done their own, and these are reported. But what's on offer here is a series of snapshots of services as they were in mid-1985 based on a visit to each (in 1984), supplemented by information provided through a questionnaire, updated where necessary. One advantage of the approach could be that people find their own imagination triggered and want to find out more.

Lastly, this book does not set out to describe only those services which are 'new'.

Some of them have been going for quite some years. One advantage of that could be that they have a wealth of experience to offer others. Another could be that more people start to ask why, if a service is so well established, and sometimes so well known, so little has yet been done to build on its lessons and example elsewhere.

So what is this book about?

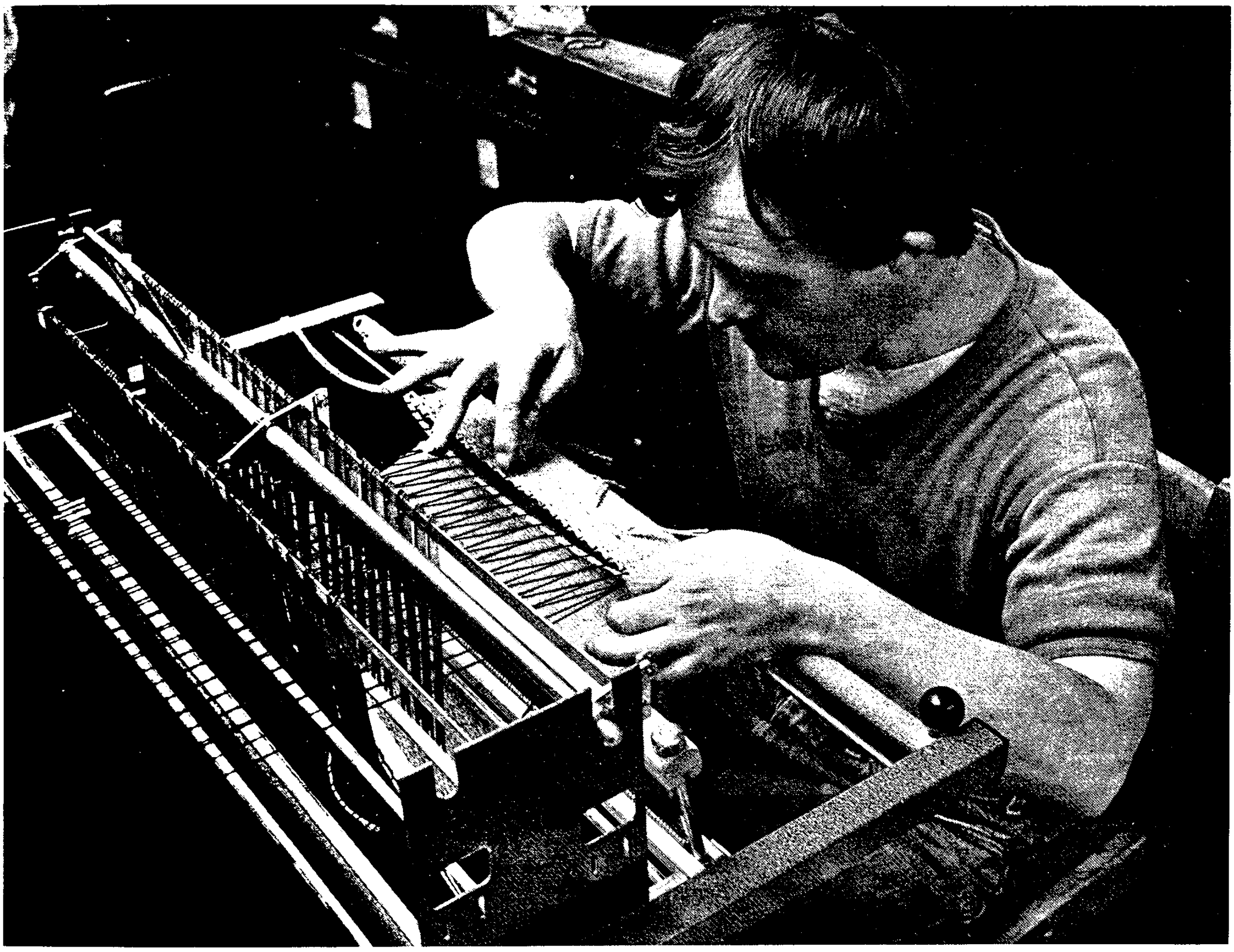
It is about projects, schemes, services and gatherings together of people which seem to offer a taste of what future opportunities for people with mental handicaps and their families could be like. Although taken together they don't amount to a blueprint, they do between them show that community initiatives are growing at every stage of the life of a person who has mental handicaps. Although taken together they don't amount to a prescription for planning, they do between them show that initiatives can come from statutory authorities as well as from voluntary ones, from community groups as well as professional teams. Although they don't offer even a proper random geographical sample, they do show how change is happening in inner cities as well as rural areas and in small towns.

All of the schemes and projects are inevitably very different. But all of them, too are united by certain common principles that seem to ensure that they keep trying to offer something of sustained quality.

* They are committed to enabling people with mental handicaps and their families to share in the ordinary life of their communities.

Sometimes this commitment comes from an explicit basing of the service on the principle of normalisation; sometimes it has simply seemed the right and proper and enjoyable thing to do. Each of the slices of 'ordinary life' with which the sections of the book are concerned will demand different expressions of the commitment, according to the ordinary patterns to which they relate. But the principle doesn't change.

* They try to involve the users of the service in their work and to remain responsive to their views.



Sometimes, they have done this very deliberately – by asking people with mental handicaps and their families what sort of service they want and planning accordingly. Sometimes, the service is there only to respond to what current service users say they want. Sometimes the response is more implicit. But it is always there.

* They try to respect individual needs even in the context of provision for a group.

Sometimes the attention to individuals is built in through the mechanism of regularly reviewed individual programme plans, for which a single 'key worker' is responsible. Sometimes, the attention is more informal. But it too is always there.

* They try to build in opportunities for individual choice.

At some times this is easier than at others. A residential service, for instance, may find it harder than a leisure one to encourage individuals to choose the *overall* pattern of service – even though it may just as easily offer choice in the *detail* of what it provides. Encouraging choice and acting to make it possible is part of respecting individual needs – and these schemes and services try to do it.

* They try not to exclude people whose handicaps are more severe.

Some of these services are specifically for people who have been put in this category and so may exclude people they consider 'too able' for what they offer. Others may be more geared to people who have a certain degree of social skill. But overall, they do show how people with even very severe handicaps can be offered non-discriminatory community services, when support is varied according to their needs.

It is not too easy to make this point in the context of descriptions that endeavour to respect the dignity and privacy of each individual who features; if anything, the descriptions come down on the side of leaving out the details of certain behaviours. Readers will have to make do with an assurance that there are people in these pages whose degrees of handicap are sometimes very considerable indeed, and could certainly be described as having 'profound mental handicap' or 'severe behaviour disturbance', if that's the sort of labelling that helps them to make the essential point.

* The schemes believe in people who have mental handicaps as people who are growing and developing and each have their own contribution to make – whether that's by making their way in the world or simply by being who they are.

Some of the schemes have very clear mechanisms for helping people to grow. In others, again, the belief is more implicit. But this too is part of respecting individuals, and it is always there.

* They enjoy it!

No one would pretend that the services they're involved with aren't hard work. It isn't always easy to keep quality high and enthusiasm going. But maybe it's too easy to forget that the best services and schemes are the ones where people actually like being together and sharing across the divide of 'staff' and 'customer', 'them' and 'us'. They are the ones, after all, that are showing, in miniature, what 'community' is all about. Each of the ones described here is, in that sense, a true 'community' scheme.

So this book offers some examples of schemes, services and gatherings together of people which are trying to put the essential philosophy of community opportunities for people with mental handicaps into action.

All these examples could be used by planners and providers, professionals and parents, pressure groups and service users, as building blocks in the creation of their own comprehensive local patterns of provision. They could juggle with them and try out different ways of putting them together. They could whittle them into rather different shapes. They could find, as they go along, that they need some different blocks altogether to build what they have in mind, or some others to add to the ones they have found here.

If people who read this book do any or all of these things on the way to coming up with their own particular local translation of the philosophies, then the book will have succeeded.

In the end, it has just three very simple aims.

The first is that it will trigger thought and imagination and energy for action among the whole range of people who can be involved in creating new community opportunities for people with mental handicaps and their families.

The second is that it might offer something of a common starting point for their joint discussions along the road to action in place of the misunderstandings, hidden agendas and unexpressed philosophical differences that so often make joint planning and consumer involvement more honoured in the paper preambles than in the reality.

The third is that it might help all sorts of people in all sorts of places to say not 'But that could never happen here' but 'Why don't we get in touch with them and find out more about it?'

2 FAMILY SUPPORT

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

Report of the Committee of Enquiry into Mental Handicap Nursing and Care, HMSO, 1979[1]

About 80 per cent of children with mental handicaps live with their own families and that, it is generally agreed, is the best place for them. But if life is to be as happy and satisfying as possible for the children, their brothers and sisters and their parents, then families are going to need different sorts of help to make it so.

There has been a great deal of discussion in recent years about what that help might be – against a growing realisation that too often it simply isn't there. Professional workers have started to think of parents in a new way: 'the 1970s', as one experienced observer has put it, 'saw the emergence of the concept of "parents as partners", with a shedding of the often negative image of families as guilt-ridden and depressed by the experience of living with handicapped children'.[2] By the end of that decade, the National Children's Bureau was able to draw together some heartening examples of how the concept could be turned into services in which parents and professionals worked together to share their skills and knowledge and build on these so that children could be better helped to develop.[3]

At the same time, there had been a more realistic recognition that although living with a handicapped child brought its own rewards, it could also entail a great deal of sheer hard work and financial constraint. Government made its own contribution to easing the costs when it introduced the attendance and mobility allowances and set up the Family Fund to make specific grants. Others made their own contributions to sharing in the work – and the rewards: play schemes, toy libraries and a variety of volunteer projects grew and social workers sometimes (though not very often) offered well-planned and sensitive support.[4] The availability of short-term care for children with mental handicaps increased dramatically during the decade, though mostly still in mental handicap hospitals. The Crossroads care attendant schemes* began to spread and offered a new

*See Appendix B for address.

model of respite care by providing carers who would go into family homes as the permanent carers chose to have them. Although these schemes were originally for people with physical disabilities and their families, the model has been extended to families with a mentally handicapped member as well.

Yet by the mid-70s, it was clear that there was a long way to go. Official services could still be far from helpful. As the Court report on child health put it: 'Parents ... are faced with a conglomeration of professionals, the majority working in separate, uncoordinated services with limited roles and limited communication with each other, and few of whom are specially trained to work with children. Not all are equally accessible and parents often do not know to whom to turn for help. So parents fail to obtain the ready help and support for which they constantly and sometimes desperately feel the need.' Even where parents did work out where to go for help, that help could be far from adequate: 'The standard of diagnosis, assessment, treatment and care for children suffering from physical, mental or multiple handicaps whether in the hospital or in the community does not reach that largely achieved by the Health Service for the treatment of acute illness ... There is a prevailing but unacceptable lack of urgency in providing adequate assessment in the community ... Assessment and advice all too readily become depersonalised and perfunctory ... Nor is it always clear as to where or with whom the responsibility lies for the continuing surveillance of handicapped children.'[5]

Poor services could contribute to a poor quality of family life. A Family Fund survey found that the large majority of parents felt their leisure was curtailed, that ill health was very common among mothers, and concluded: 'It is almost incredible that families survive the difficulties they encounter when so few of them get help.'[6] An in-depth study of 17 families re-emphasised the point: they were often isolated and overwhelmed by the work entailed in looking after their child; services were variable in quality and lacking in coherence; above all, parents were aware of how they too were handicapped – by their ignorance of what help was available, by the unresponsiveness of bureaucracies, by still-stigmatising professional attitudes.[7]

Some messages take a long time to get through. At the beginning of the 1980s, a study from the prosperous south-east of the country was stressing yet again the things that parents had been saying for years and years: they wanted more information, more relief for the family, more short-term care.[8] And the Independent Development Council for People with Mental Handicap was still calling for closer cooperation between the professionals involved in the lives of families.[9]

By then, this was supposed to be happening, through the district handicap teams recommended in the Court report and/or the community mental handicap teams which the National Development Group had wanted to see.[10] But too often it wasn't. A survey of the operation of these teams, three years after the government had urged that they should be set up, showed that although a quarter of the 158 health authorities surveyed had both, another quarter had neither. It showed that there was a huge variety of interpretations of what a district handicap team should actually be doing and that few had truly incorporated parents as full partners. And in a situation where more than half the teams did not assign a 'key worker' to each family, there was clearly still room for parents to be dropped straight into the old exhaustions of trying to cope with a plethora of ill-coordinated professional services. Community mental handicap teams seemed no better organised. The very name seemed the wrong one, when most of them were so firmly allied to the health and mental handicap hospital services and so few worked closely – or indeed at all – with social services and educational departments. Where these teams worked with children as well as adults – as over half of them did – there was often little clarity about how they and the DHTs designed especially for children coordinated what they offered.[11]

By the start of the 1980s, too, it was becoming apparent that the continuing identification of children with mental handicaps with mental handicap services rather than with the range of *children's* services open to all non-handicapped children, was having one particular and damaging effect. Institutional short-term care in specialist hospitals and homes, concluded the first major study of this increasingly used resource, was likely to cause as many problems as it was supposed to alleviate. 'In its present form, it is too crude and simplistic, too much based on the idea of separation being good in itself, with a denial of the warm, normal affection parents feel for their handicapped child' – and far too insensitive to the bewilderment, homesickness and need for loving care and well-planned activities of the children as well.[12]

So services to families with a child who has a mental handicap still seem to find it hard to recognise some simple essentials. They too often fail to honour the fact that most families love and value their child and want sensitive help and relief not as a prelude to unloving abandonment but just because they want the best for their child in the family. In their continuing reluctance to work to build true partnerships, many professionals still fail to honour the fact that, as the National Development Group once put it, 'The families themselves are the first and best resource a child can have.' And there is still a reluctance too, to recognise that in some situations and at some times, it is parents themselves who may have the most to offer to others.

The five families support schemes described here don't provide any standard blueprints: they have grown up, as any successful service must, in response to local needs and conditions. But between them, these services show how parents can offer each other valuable mutual support and how families can overcome the isolation that too many still often feel. They show that parents and professionals can work together in partnerships of mutual respect to the benefit of family and child. And they show how parents, professionals and the people who make up the wider community to which each child and family belongs can together create some of the supports that parents say they need – and enjoy it.

PARENT TO PARENT: GROUP SUPPORT

Each meeting is a tremendous support – to know people with the same problems, to see the hurdles ahead and prepare for them . . .

I just switched off until Michael was four months old. I thought I'd never cope. But now he plays in the garden, and goes to nursery school two afternoons a week – and we're learning sign language!

I didn't bother, because Shirley was so poorly when she was born. In the end, it was my sister who got in touch for me. I used to be envious of the others in the group, because Shirley did so little compared with theirs. But now we're talking about school for her – and full-time, too!

My husband notices a big difference in me since I started meeting other people. I tell him he could do with coming too!

Oh, it's a very big help to us, both of us. Before, there was hardly any support at all. Now you know you're not alone, you can measure progress by talking to the others, seeing other children.

These comments come from parents whose young children have Down's syndrome and who belong to the 0–2 Group which the Southend and District Society for Mentally Handicapped Children and Adults has been running ever since 1971.

Barbara Crowe, who is herself the mother of a young man with Down's syndrome and has been the key 'parent leader' ever since the group work service started, knows well what this 'parent to parent' service can mean to 'new' parents. For a start, and from the very first visit from an 'experienced' parent, they can find the assurance that they are not alone – and that here is someone to help them who has the unique authority of having lived through an experience similar to their own. They will learn that their feelings of guilt and rejection of their baby are not abnormal. They will have the chance to explore and explode some of the myths which still surround children with mental handicaps. Mothers – who tend to worry most about immediate problems that they've heard are common in babies with Down's syndrome, like chest and heart complaints – can start to sort out myth from reality. Fathers – who tend to look straight away to the long-term future and wonder whether the family should keep a child for whom one day they may not be able to care – can start to learn about the pattern of services available. And this whole process of exploration will start, most usually, within 48 hours of the baby's birth.

By the time parents come to their first meeting of the 0–2 group, their baby is still usually under a month old. There, they will be able to begin to share their feelings and concerns with other parents who, again, have experienced much the same themselves. As time goes on, they will be able to share in the practical concerns of the group – about how to help their child with feeding and toileting, for instance, or about the best sort of toys to bring enjoyment. There can be discussion about the attitudes and reactions of brothers and sisters and others in the family, or of neighbours and friends. The questions may be very specific, like whether it's possible to get a grant for a climbing frame for a child whose superabundant energy is driving his mother to distraction. They may be very general, like how far you really can treat a child with Down's syndrome as 'normal', up to and including disciplining them in the same way as you do their brothers and sisters. They may arouse some very deep and often painful emotions, like those which are so often around when the time comes for the child to start school and spend more time outside the protection and 'specialness' of the family. Sometimes, specialist workers like physiotherapists or speech therapists will visit the group to advise. But it is parents who remain the strongest help and support to each other.

Southend's group network offers this help and support in other ways as well. There is a group of parents whose children have brain damage and are usually diagnosed much later than those with Down's syndrome. When parents feel ready to move on, there is a 2+ group, geared to the changes when their children start school. A group for parents whose children are reaching adolescence is convened as the need arises.

None of these groups has been set up randomly. They correspond very precisely to common crisis points in the lives of parents and their handicapped children: the times when the diagnosis is first made, when it becomes clear that the child isn't developing as the neighbours' children, when the child first starts school and when he or she is entering puberty. But though the preoccupations differ with each group, what they all fundamentally offer is the same: mutual support, information and practical help and, through their leaders, an early warning system to alert professional workers to particular family needs.

The mixture is one that local parents find helpful. Some 170 families have been touched by the groups since they began and very few parents who could have joined them have not. They include couples – although not all fathers are as consistent in their attendance as mothers – and single mothers and adoptive and foster parents too. And although Barbara Crowe is insistent that no parent must ever be pressured to accept their child, it's perhaps one measure of the groups' success that only once has a child been rejected by its parents once they have decided to take it home after its birth.

How did the network start?

The Southend group-work started in 1970, when Dr Mike Mellor, then deputy medical officer of health, realised just how much time was involved in individual crisis interviews with parents, how little professional workers knew about the complexities of their situations, and how isolated and frustrated parents often felt, faced with their lack of technical skills to help their children and the shortage of preventive and crisis help.

With the cooperation of the local parents' society and the then junior training centre (soon to become a school under the 1970 Education Act), Dr Mellor brought together six couples, who met as a group for 16 weeks. Their experience was so positive that two further short-term groups were set up. By then, it was evident that group-work had a lot to offer on a continuing basis. It was evident too that professionals lacked the time to ensure that it did. So was developed the notion which has been central to the Southend group-work ever since: that parents themselves should become 'leaders and therapists' for other parents.

Yes, but . . .

Parents find the groups helpful. They have the added advantage of costing pretty well nothing, run as they are as a purely voluntary service and meeting as they do in their leaders' homes. Training for leadership is not a problem either: although Barbara Crowe has studied group-work, leadership is primarily built through group experience. So why, after some 15 years, does the Southend scheme remain one of the few consistent projects of its kind in the country?

By now, Barbara Crowe has heard most of the arguments against making this sort of opportunity for parents available elsewhere. And in answering them, she identifies the key factors that make for success.

People say: 'But we can't get the professionals interested'

Professional cooperation is clearly essential if the scheme is to reach *all* new parents as soon as possible after diagnosis rather than collecting them randomly through an unreliable grapevine and word of mouth. In Southend, the relationship with professionals is clear. No one from the Society can approach a 'new' parent except through a key professional – the consultant paediatrician, hospital social worker or midwife in the case of babies with Down's syndrome –

who has already obtained the parents' permission for the contact. Such is the degree of cooperation that most parents of babies with Down's syndrome are visited within 48 hours of the child's birth.

Certainly relationships between the society and professional workers started with an advantage, in that the initiative for the groups came originally from a well-placed doctor. There are other local advantages, in the children's centre at Southend Hospital, which through its different services to handicapped children and their families provides a focal point for parents and professionals alike.

But the Southend scheme has worked on these beginnings, too. When a newly appointed local paediatrician was doubtful, he was invited to a group meeting to hear from parents themselves precisely why they found the groups so important. Barbara Crowe reinforces the message in her lectures to nurses and social work students. She remains convinced that it is parents' enthusiasm to make the scheme work that is central – and that there isn't an area in the land where at least one potentially interested professional doesn't exist.

Professionals say: 'But there are parents who would do damage . . .'

Where attempts to set up similar schemes have failed, Barbara Crowe has found, it is often because professional workers have not been helped to trust what parents are doing. Often, for instance, too many parents have been involved in making the crucial initial contact with 'new' ones; responsibility has not been clearly defined and accepted. In Southend, they are very careful to limit 'leadership' to a few key parents who have been well-trained through their own experience and participation in groups. The initial interviews with 'new' parents are nearly always done by Barbara Crowe herself.

Professionals say: 'But parents don't want to join groups . . .'

If parents in Southend are like parents elsewhere, then this evidently isn't true. But the way in which professional workers present the service to parents may be critical, and this depends on how far the professionals themselves find it trustworthy and valuable. There is a world of difference between saying 'There's this parent you might like to have a word with . . .' and 'There is a mother you could meet who knows from her own experience what it is to be in your situation and who will be able to help you.' Barbara Crowe emphasises two further factors. The first is the importance of giving parents enough unpressured time in the early interviews. The second is how valuable it can be for them to meet someone whose own experience of family life with a child with a similar handicap is clearly positive, and whose child is growing up well and happily, at a time when the 'new' parents may find it hard to think they have much of a future at all.

Professionals say: 'But what about confidentiality . . .'

They say it, in Barbara Crowe's experience, quite a lot. But in her experience, too, they stop saying it when they are convinced of the trustworthiness and respect for individual privacy and group confidentiality of the scheme. After all, as she points out, who are the people who suffer if parents aren't helped to make contact with each other? It is not the professionals, but those parents and their families.

'As a result of the group-work in Southend', one mother of a child with Down's syndrome has said, 'we as a family feel relatively stable, accepting and very self-reliant. The group is rarely used as a crutch, for if it were, I don't think it would be so successful. The groups are happy and forward-looking. We have learned to deal with problems one at a time and not to get things out of proportion. In view of the steady progress of our children and enlightenment of families we have achieved, we feel that the facilities we have should be extended to all such children and families.'

FURTHER INFORMATION: Mrs Barbara Crowe, 19 Avenue Terrace, Westcliff on Sea, Essex SS0 7PL

PARENTS AND THEIR HELPERS: MAKING A BREAK

We never went out before, we never even went shopping together. You lose the art of going out, you know. The first night we had a sitter, we didn't know what the hell to do. The wife worried all the time, we couldn't get home fast enough. But now . . . wooarh! It's the best thing that ever happened!

Before the Birmingham Multi-Handicap Group started its Parent Relief Service, life was often hard for parents whose children's mental handicap was compounded by other disabilities – and for those children as well. Sometimes they might be excluded from school, because, say, of hyperactivity. Quite often, they might be denied any day service at all once they left school, because of the lack of suitable transport and facilities. Parents who loved and valued them could get to wonder whether any service could exist that was sensitive enough to meet their very particular individual needs – particularly if those children were now coming to adulthood and they and their parents had experienced much rejection over the years. As one mother put it: 'It's hard to find anyone in this community you can trust.' Even friends could fail to understand the complexities of caring for someone with very profound and multiple handicaps: 'You lose friends, you know – they say "Come over for a drink" but you can't just go like that.' And it wasn't easy to find the people who might make that sort of small break from caring possible. As one father says: 'You can't have just anyone for our "special care" people, you know.'

But for these parents, who are now among the 100 families who use the Parent Relief Service, the service is not 'just anyone'. Set up in 1980 with the specific aim of giving permanent carers a break by providing care attendants to look after people with profound and multiple handicaps in their own home, it has since expanded in more than the numbers on its books. The Multi-handicap Group has moved into some community premises attached to those huge tower blocks right in the centre of town, three minutes' walk from the main railway station and on major bus routes. And those premises are open every weekday for people who want to drop in for a chat or advice, as well as for the monthly coffee morning that provides a meeting place for parents and care attendants, and sometimes children as well. On Saturdays the centre is run by the care attendants, and parents can bring their children there during the day. This 'out of home' service was extended in 1984 to cover the summer holidays, with the centre open six days a week and transport provided to collect the users and take them home again.

But it is the Parent Relief Service which remains the centre of the Group's work. When this started, in 1980/1, it offered 80 hours a week of 'sitting time' to 20 families. Now the 75 families on the books can draw on 220 hours a week – which makes between 40 and 50 'sits'. The original aim was to offer these to families with a multiply-handicapped member over the age of 10, to a maximum of 20 hours a month, with priority for those who were at home 24 hours a day. Those aims have held, but there is flexibility too. Some of the families have children under seven; some will use the service twice or three times a week; others only need it once every six months. The service can cope with one-off extremes of need as well: once it found three care attendants a day for 16 days for a very severely handicapped woman of 42, to enable her widowed 70-year-old father to take a much-welcomed holiday. And the service continues to expand: now there are plans to arrange for care attendants to live in for weekends, to enable parents to go away.

Never once since it started has the PRS had to turn anyone on its books down when they needed help. 'Over-demand' just isn't a problem, for it knows what it isn't there for as well as what it is. 'If people want too much, they want something else', says the coordinator, Susannah McCorry. And as the service has grown, so has its role as advocate for parents in the search for other services they may need.

How did the service grow?

'We didn't know what we were doing – it wasn't ability, it was desperation!' That is how Mary McCormack, herself the mother of a very severely handicapped young man and now honorary secretary to the Group, remembers its beginnings. She had read an advertisement in the local paper inviting schemes to apply for Inner City Partnership funds, and the offer seemed too good to refuse. Together with two other parents who also had teenage sons with multiple handicaps, she started to sketch out ideas for a service to this neglected group. They formed a committee of parents and interested others. The Birmingham Voluntary Service Council inner city unit gave much-needed advice on how to apply for funds; the Crossroads Care Attendant Scheme (which offers care attendants to people with mostly physical handicaps in their own homes) offered organisational expertise. The Social Services Department, well aware of the gaps in its own provision, was helpful. The Parent Relief Service got its ICP/SSD core funding for five years from 1980.

There was some initial suspicion of it, from professional workers who feared that a burst of enthusiasm from well-meaning volunteers would evaporate to leave parents disappointed. There was misunderstanding, too, among some of the parents the new service found through leaflets in schools, adult training centres, local voluntary organisations and social service offices, and through announcements in the local press and radio. Would parents be expected to 'sit' themselves if they used the service? What exactly was their relationship with their care attendant?

Today, the shape of the service is clear. The relationship between parents and care attendants is established as a 'professional' one, based on the building of mutual trust but not dependence. It is satisfying to the 25 care attendants. As one says: 'You learn so much about people with multiple handicaps. I enjoy working with them, guiding them, talking to them – it's absorbing.' And it is satisfying to the parents as well: 'What I like', one says, 'is the attitude. They say "It's no bother", and you can tell it really isn't.'

How is the PRS organised?

The key elements in getting the service started, Mary McCormack reckons, were the coincidence of a very evident local need with the availability of funds and a social services department that saw the value of bringing the two together. Those are elements in the service's continuation as well, but she would now add others: efficient and professional coordination, a recognition that volunteer time is limited and can't be too much relied on, and a recognition too of the importance of securing adequate funding through grants rather than relying on the hit and miss of jumble sales and coffee mornings.

Today, the Multi-Handicap Group is run by a committee which includes the original parents, and has a full-time coordinator and an assistant coordinator who works 20 hours a week.

It is their job to look after the Group's premises and activities, and to ensure the smooth running of the PRS. Susanna McCorry, the coordinator, herself a trained nurse and community worker, assesses each family and introduces them to at least two care attendants, and more if the work will be particularly demanding. It is through her that parents book their 'sits'; she is responsible for matching not just the personalities of family and care attendants but the demands with the hours available.

The care attendants, many of whom have nursing or residential work experience, or have worked in the home help service, get a week's induction training before they are introduced to a family and occasional talks from professional workers with relevant skills. But their main training is on the job – finding out the needs and routines of particular families so that they can care for the handicapped person exactly as the permanent carers do themselves. The aim is to ensure that each care attendant has one or two regular weekly commitments, with others as needed and possible. They are paid £1.80 an hour, which puts them rather under home help rates, though the aim is parity.

In 1984/5, each sit was reckoned to cost, including all overheads, some £15, and the income of the Multi-Handicap Group was about £40,000. Of this, £2000 came from parental payments; PRS found that they were glad to pay the £1.50 asked for each sit and that they rarely asked for the charge to be waived, as it may be in case of hardship.

The ICP/SSD core funding made up about half of that £40,000. The balance was made up by grants from the Mental Health Foundation, the Spastics Society, Marks and Spencer and local Trusts. The social services department made one major capital grant, of about £7000, to set up and equip the new premises. Smaller capital sums, for items like camp beds for care attendants who stay overnight, a typewriter and a photocopier, have been found through different grants.

The future

The main concern of the Group is now a measure of its success so far: how to keep up the quality, which has been ensured in the past by the service being small enough for everyone to know each other well?

There are plans to split the PRS into two bits, one to serve the north and the other the south of the city. In this way, the Group hopes, the inevitable challenges of a 'dispersed workforce' will be more easily met, and the essential ingredient of friendliness will be preserved.

FURTHER INFORMATION: Birmingham Multi-handicap Group, Cleveland Tower (Ground Floor), Holloway Road, Birmingham B1 1UB

PARENTS, PROFESSIONALS AND OTHERS: WORKING TOGETHER

I'm sure there are a lot of saner mums around because of Honeylands. I think an awful lot of people would have cracked by now if it hadn't been for them. Even if you don't use a place like Honeylands very often, it's lovely to know that it's there. It's like learning to swim. You know that somebody's there in case you sink. You'd just feel panicky, it would just feel all dark, wouldn't it? And Honeylands is there so that you can hope, and you know that when you cry for help, the help will be there.

Honeylands is a resource centre for children with different handicaps and their families in Exeter, part of the service offered by the local health district. Its aim is to respond to what parents say they need, and to make a bridge between families and their community by complementing rather than supplanting other services.

In practice, this means that Honeylands is still perhaps the most comprehensive service of its kind in the country. It currently has some 150 children and their families (including some foster families) on its books, drawn from the Exeter and East Devon Health District's total population of 285,000. It is also in touch with about 75 other children and their families who have used its services and now moved on. Altogether, it has worked with some 300 families since it started in 1968.

To those families, Honeylands is open every day and night of the year, and that includes holidays. It is proud to say that it has never turned down a request for help – whether that is for immediate respite care at a time of family crisis, for advice or counselling, or for something more practical.

The regular package of services is wide-ranging. The multidisciplinary team of professional workers and 'experienced' parents offer information and counselling, whether on an individual basis or through the regular parents' groups, some of which meet during the evening so that fathers as well as mothers can come to them. Assessment and six-monthly reviews of pre-school children are translated into action through the different play and therapy groups in Honeylands itself and the 'home therapy' programme, in which a specific 'developmental therapist' visits weekly to help parents acquire the skills which will help their children develop. The parent-relief service offers residential care for up to 30 children at a time; this is available on demand to any parent at the end of a phone as well as on a regular and planned basis – for a day, a weekend, two weeks or, occasionally, longer. And finally Honeylands offers all sorts of less formal support – from the nine summer holiday play-schemes offered free of charge, to the use of its beach hut during the summer, to parties.

How did Honeylands grow?

The idea for a resource centre came to Dr Freddie Brimblecombe, the local consultant paediatrician and later Professor of Child Health at Exeter University, when he began to realise during the 1960s just how poorly parents with handicapped children were served. When a local TB sanatorium for children, in what had been a large private house, became obsolete, he seized the opportunity, and the resource centre was launched in 1968 to cater for 30 children and their families.

Freddie Brimblecombe was determined that the service should provide not just what he and his colleagues thought was needed, but what parents themselves had identified as useful and lacking in their lives. A research project identified all the 310 children born with sensory, motor, and intellectual handicap in the city of Exeter between 1967 and 1971 and managed to interview all their parents, as well as the parents of 310 non-handicapped children for comparison. Each group had many unmet needs. But the additional ones of the parents whose children had handicaps became plain. They needed far more information about the nature of their child's handicap, services available and future prospects and sympathetic counselling too, in place of the abrupt, unhelpful and hurtful 'diagnosis' which was too often all they got at present. They needed skills to help their own children, rather than having to rely on professionals who too often refused to share their own skills, and they thought that they could learn a lot not just from professionals but from other parents whose children also had handicaps. And they needed support from professionals who too often did not understand the strains that a severely handicapped child could bring to the family.

It is to meet these needs that Honeylands is organised. Parents continue to be involved not just in its everyday life – they are encouraged to come to playgroups with their children, for instance, as well as to specific therapy sessions – but in its management and planning for its future. They have been represented on the long-term planning committee since 1976, and the best ideas for developing the service, Freddie Brimblecombe says, often come from them. It was parents, for instance, who had the idea that each day there should be a 'coordinating' mother who would welcome new parents and children and help them feel at home.

How is the service organised?

The staff of Honeylands, as they themselves put it, includes cleaners, gardeners, cooks, two psychologists, laundry staff, one social worker, one nursery teacher, two physiotherapists, one occupational and one speech therapist, a dentist, three doctors, 'highly professional' parents, six SRNs, five SENs, 15 auxiliary nurses, an orthoptist, a video technician, two secretaries and the local clergy. There are also the volunteers, whose numbers have risen from 10 when Honeylands started to some 60. The hospital car service is essential in its backing of Honeylands' own minibus to provide free transport to parents and children; and although this is particularly true of a service to a largely rural catchment area, it should be seen as no less so, Dr Brimblecombe says, of any such service anywhere. The whole show is under the direction of Dr John Tripp, a consultant paediatrician, but day-to-day responsibility is delegated to the nursing sister in charge.

To weld all these people into a coherent team involves, according to Freddie Brimblecombe, 'a massive debriefing and reorientation from previous professional training' and a continuing process of losing a specific professional identity to become one of Honeylands' 'developmental therapists'. 'Brainwashed' doctors – who, he says, find this far harder than anyone else – must learn to work as equals. Nurses must learn to work without the hierarchy offered by traditional uniforms. Inservice training comes from monthly meetings and the far more frequent discussions with parents from whom the professionals have so much to learn. Like the parents, professional workers of all grades are represented on the long-term planning committee.

Organisationally, Honeylands is part of the paediatric department of the

Royal Devon and Exeter Hospital. This means that there is always a doctor on call, and a ready source of extra night staff if necessary. It also means that the NHS pays the bulk of the bills, with contributions (in terms of staff) from the local education and social services departments.

In 1978, the last time that Honeylands was separately costed, its running costs were £167,535 – or something over £1,000 per user. At 1984 prices, at a guess, those costs have roughly doubled. But that is still around half of what it costs to keep a child in local long-term residential care.

The major capital cost came at the start of the service, when the NHS shelled out £30,000 to reconvert its TB sanatorium into something more like the house it once had been. But funds have consistently been raised from voluntary sources too – including £10,000 for the minibus, £50,000 for the heated indoor swimming pool which Honeylands shares with its neighbouring Spastics Society school and offers as a resource to local people with disabilities and, most recently, £25,000 within three months for a new toy library. Money, says Freddie Brimblecombe, has always been the least of Honeylands' worries: if you can identify and describe a real need and show endurance and persistence in pursuing it, money will be found.

Endurance and persistence are also two of the qualities he sees as essential to keeping Honeylands alive and developing – together with leadership, motivation and participation in planning by parents themselves. 'If you believe only in words and talk', he says, 'you will not get very far. If you believe in action, there is absolutely nothing that can stop you.'

How effective is the service?

There are estimated to be something like 300 children with handicaps in the Exeter Health District to whom Honeylands might be helpful – excluding those with severe psychiatric disturbances like autism, who are served by the local department of child psychiatry. Honeylands is currently serving about half that number. Some of their families will already have used Honeylands' services and moved on; others may know about these but decide they do not need them. But how effective is Honeylands in bringing help where it is needed? And how far does it offer what parents want?

In 1979, an independent evaluation of Honeylands concluded that there was still work to be done in these areas. It saw a need for closer cooperation between the centre and local professionals like GPs and health visitors, so that it became a resource for them too. It saw a need for more social work time to go to parents when their child was first identified as having a handicap, so that they could be helped to see how Honeylands might be of use to them. It thought more work should be done on finding ways to keep channels of communication open between parents and the centre, so that they might find it easier to approach it once they had assimilated the implications of their child's handicap.

Once parents do come to Honeylands, the researchers found, they may sometimes experience difficulties. There are the constraints of human resources: some parents felt they could have done with more specific and helpful advice on the management of very disturbed behaviour in their children. There are the constraints, too, of a very old and much-adapted building: parents could be distressed if their less handicapped child was in a group with those whose handicaps were very severe, or if their non-mobile child was in the same group as those who were very active. There were some individual comments that the standard of care was not always as high as they would have wished, and some feeling that the turnover of staff was too fast (although the researchers found that, objectively measured, this was not in fact unduly so).

Against this, however, must be put the tribute of one mother: 'I know it's silly, but when something like this happens to you, you feel hostile towards the outside world. You just want to cocoon yourself at home. And they did a very good winkling job of getting me out, you know. At the same time, I didn't like being pressured into things, but they didn't, they left me alone ... They just let me know (through the social workers' visits) the facilities were there if I needed them, and please use them, because they'd love to have Natalie any time. And I'm glad they did.'

There is this comment, too, one of the several the research quotes on parents' satisfaction with the way Honeylands helped them, both through sessions at the centre and through the home therapy programme, to help their own child: 'I used to be sort of anxious, I used to sort of think to myself "Oh well, he'll always be the same, he'll be no different". When he went to Honeylands, I sat back a bit more. I thought well they won't be able to do much, but they have, they've been marvellous. If it weren't for him (the therapist) he wouldn't be what he is now. "We work together", he said. "You worked with me", he said, "and we all worked together", because I was doing so much at home and they were doing so much there...'

Honeylands knows that it isn't perfect. It tries to strengthen its links with the community, especially through the eight community mental handicap nurses who are in touch with it, and through the arrangements for some of the children who come to its playgroups to go to local playgroups and nurseries on one or more days a week. The amount of social work time available to it has gone up to that of one full-time worker since the research was carried out. Reorganisation within Honeylands has made for a greater attention to the grouping of children whose needs may be very different. There are plans to do something to break up the dormitories in which the children who come in for short-term residential care still sleep.

Overall, though, the researchers found that Honeylands offered a most valuable service. Parents spoke frequently and warmly about its friendliness, its informality and – critical to its success – the way it managed to combine a very great amount of flexibility in its approach to individual needs with complete reliability and trustworthiness. By comparison with another part of the country which had no such service, the researchers found that Honeylands' mothers showed much less evidence of depression; the rate of marriage breakdown was much smaller, as were the number of children in permanent residential care; the intellectual progress of the children with mental handicaps was far greater.

'No service ever achieves perfection', the researchers concluded, 'either in the eyes of the recipients or of the providers – and Honeylands is no exception to this general rule. But . . . this resource centre for handicapped children and their families appears to have been meeting – perhaps uniquely – a need all too frequently not met by more traditional or conventional means. Given the special local circumstances, it should not be regarded as a "model" that could be reproduced elsewhere in its present form: it is rather to be viewed as a challenging example of what *can* be done if the necessary will, leadership and team-work can be brought to bear on this particular pattern of problems as it presents in each particular area.' (*Honeylands: progress report*, Rosemary Evans and Josephine Green, Paediatric Research Unit, Royal Devon and Exeter Hospital (Heavitree) Exeter.)

FURTHER INFORMATION: Honeylands, Pinhoe Road, Whipton, Exeter EX4 8AD

FAMILY TO FAMILY: EXTENDING THE BOUNDARIES OF CARE

I wasn't sure at first – I didn't think there were many who would do it. One of my daughters was only a baby, and the other was very funny with other people. But I went to meet these two families, and they seemed very nice – and they'd been on courses, which was important to me. So now the girls go for one week in six; the families have children of their own, they get fussed over. And then it's just me and my husband. You start looking forward to it! The main difference is us getting a break, because on your off days you do get very tired. I'd miss the service if it went away.

It's not something that grows on you, you can either do it or you can't. I've been doing it that long now, it comes natural. They just come and fit in, like having a friend come to stay with you. There's a child here about three out of every four weeks in the year. But now they just fall in. We do our own thing, and if it's 'No' to my three, then it's 'No' to them.

Everyone has to be in favour, or it doesn't work. My husband wasn't sure at first, but I was so sure that he was willing. If my three didn't like a child I'd say 'No' – but there's none they've objected to, they'd miss them if they didn't come. If they come during the holidays, there's all sorts of kids in and out; I tell them they won't bite because they can be a bit wary, perhaps through the ignorance of their parents. The neighbours just accept it – they know each one, they shout 'hello'.

I feel I can do just as important a job at home as I could if I worked in a school: to help the children live as normal a life as possible, not to make any excuses for them, not to treat them any different – and they're quite happy with that. They're here. And if they're happy, we're happy.

The Leeds Family Placement Service aims to offer a break to any local family with a child with a mental handicap which feels the need, by linking them with another local family who will have their child to stay for anything from a night to three weeks at a time, and for up to 46 days in a year. It reckons that about half the eligible families in its area have either used it or been in touch with it since it started in 1976; it now serves 144 of the 420 or so children identified.

The scheme is free to the families which use it and they can organise their own breaks with the carers, as long as the organisers are kept informed. Families are encouraged to book ahead – and some plan for up to a year at a time. But the scheme is flexible enough, too, to cope with individual family emergencies.

Any family with a child with a mental handicap in the catchment area – which includes three market towns and villages as well as Leeds itself in its total population of nearly 705,000 – can join the scheme. Right from its start in 1976, it has found caring families for children whose handicaps are very severe – like the two daughters of the mother quoted above, both of whom are very immobile and although beginning to show some small responses, need careful handling and looking after. Right from its start, too, the scheme has been able to include children whose behaviour is said to be 'very difficult' – like some of those who have been cheerfully accepted into the caring family whose mother is also quoted at the start of this description.

The essence of the scheme, according to Mary Blackburn, its organiser since 1980, is friendliness and informality backed by careful organisation and financial and other support. Parents and carers are encouraged to get to know each other and the relationships they build may continue for some years. There is no clear cut-off point to the scheme, either: children who have 'grown up' in it may remain with the same family, but will move to a similar scheme for adults which is gradually being built up.

Apart from offering relief to natural families, the scheme has the advantages that come with involving local people in a service. It introduces families who have a child with a mental handicap to a wider social network. It does the same for their children – and it introduces other children who don't have handicaps to contemporaries they might otherwise find it hard to meet. And it costs just over a third of what it would to provide short-term care in a residential setting for its user families.

How did the scheme grow?

By 1976, it had become evident that Leeds parents who had children with mental handicaps needed a break from caring – either regularly or from time to time. Official finances were such that to provide this through residential homes seemed impossible. So the Social Services Department introduced an experimental family placement scheme through which 16 children were found a place with six families for a short period during the summer holidays.

The scheme went well – and the fact that 31 families had applied for relief care confirmed the need for this sort of service. During the next year, 59 placements with families were found for 48 children. In 1978, the scheme became more structured, with the introduction of joint-funding between social services and the area health authority and the appointment of a full-time specialist social worker. The scheme began to operate throughout the year, and it became apparent that what many families needed was regular 'phased care' rather than a one-off placement.

As the scheme grew – and extended its upper age limit from 16 to 19 years and beyond – it became clear too that the informality and friendliness on which it had been based from its start needed containing if the bills run up by parents arranging their own breaks were not to outstrip the budget available. So the 46-day limit was introduced and the involvement of the organisers in the arrangement of care was strengthened. This seems to work, as families on average use less than that top allocation of caring time. An element of choice for them that wasn't there when the scheme started has also been introduced, since the opening in 1979 of two specialist children's homes which provide short-term as well as long-term care. (When the scheme started, there was only one available short-term bed!)

How is the scheme organised?

The scheme is part of Leeds social services advisory and voluntary service section, part of a wider network of family support which had grown to include, by 1984/5, family placement schemes for adults with mental or physical handicaps and for elderly people, as well as long-term fostering for children with mental handicaps.

Until 1984, the short-term fostering scheme was run by Mary Blackburn, a specialist social worker, with part-time clerical assistance. Now that assistance has increased and there is a second, half-time social worker. She and Mary Blackburn are responsible for recruiting, training and supporting the carers and matching them to the natural families. These families are introduced to the scheme through their own social worker, with whom they continue to liaise. When they want to arrange a stay for their child, they discuss it with the carers and inform their social worker, who then checks with the organisers at headquarters, where all the planned stays are entered on a board that shows at a glance what is going on. When carers are approached to provide a stay, they too can check with headquarters. This way, the organisers can keep in touch with the pattern of service that develops and ensure that what's provided remains within budget.

This system seems to work well and to allow for emergency placements, either with the regular carers or with others. On average, in 1983/4, use of the scheme worked out at 39 days per family, in blocks of a week or so. Within the 46-day limit, families have the opportunity to renegotiate the stays they want once a year, just before budget time.

The first experimental scheme in 1976 cost £1500, put up by the social services department. By 1983/4, when the department was once again entirely responsible for the costs, these amounted to £67,610, exclusive of the salaries of social worker and clerk. This represented an allocation (not necessarily taken up) of £371.32 for each family for the year; in 1984/5, the equivalent sum was £368.40, and an extra £640 was set aside to buy equipment to be lent to the carers.

In that year, fees to the carers, which took up most of the budget, amounted to £66 per week per child. This was calculated – as payments have been since the scheme started – by taking the ordinary local rates for boarding out payments and adding on roughly 50 per cent plus 'incentive'. (The ordinary rates ranged, in 1984, from £22.50 to £39.75, according to the age of the child fostered.)

Careful budgeting and financing which is as watertight as possible is second only, Mary Blackburn reckons, to the informality and friendliness of the scheme in importance. It can do a lot towards persuading parents who might otherwise be too nervous, protective of their child or concerned about their well-being to use the service that it is worth while and of value.

The carers: recruitment, training and support

There was some concern, a year or so ago, that the supply of new caring families might be drying up. But then a new group of 10 was recruited and 'new' parents were assured that the waiting time to join the scheme was only two months.

Most recruitment is now done by word of mouth. At the very start of the scheme, carers were found through advertising and features in the local mass media, and through local parents' organisations as well as the schools to which children with mental handicaps went. But only once since then has there been a comparable campaign, and the organisers say that they would rarely run another, because although 50 people came to an initial meeting, in the end – and after a great deal of hard work – only two families were recruited.

The initial criteria for recruiting families boil down to three. They must be prepared to accept and befriend the natural family; all members of their household must be involved in the decision to take on the work; and they must have enough time to put into a job which, for instance, is hardly suitable for a family where there are two shift workers.

A great deal of thought has gone into the preparation of families that follows this initial selection. By 1984, this consisted of weekly sessions over a month, which concentrated mostly on the nature of relationships, designed, as Mary Blackburn puts it, to 'set people thinking', and to present the work in as realistic and unsentimental a manner as possible. On average, between 10 and 12 potential carers will come to these, and on average eight of them will move on to the next stage of preparation, which consists of visits to families in their homes, with visits to schools and hospitals also encouraged, before references are taken up.

Those who do not want to become carers after the initial sessions will, Mary Blackburn finds, tend to realise this job isn't for them and withdraw; occasionally, she finds, she must help them see this. When people are accepted as carers, they are introduced to two or three families; both sides are free – as they are at any stage in their relationship – to decide that they could not work together.

Once the match has been made, most carers choose to work with between two and four families. They tend to remain in the scheme for two or three years, and the most common reasons for their leaving indicate that the initial selection procedure is effective: they leave not because they are tired of the work, but because the mother is having another baby (some come back later), because she is moving into full-time work, because the family is moving from the area, or because, in recent times, they have decided to become long-term foster parents. These patterns are not, however, inevitable. There are still eight families who have chosen to make this work pretty well full-time, by caring for 48 children between them – a feature of the scheme since its start. And there are still carers at work in the scheme who have been there since it began.

Once the carers are at work, support remains important. The fact that they have to check with headquarters each time a stay is being arranged means that they are in fairly constant touch with the organiser; Mary Blackburn stresses the value of 'someone to listen' and the importance of all the workers on the section's desk at headquarters being ready to do this. To back this informal support, there are group meetings for the carers, sometimes with a specific theme, like feeding or lifting or the management of behaviour; attendance depends very much on the topic under discussion. Finally, there is practical support to some of the carers, as there is to the natural parents, from professionals such as psychologists and physiotherapists, who will visit and advise about play, behaviour management, physical handling and so on.

These are all ways – and so is the contact that natural parents have with their own social workers – to monitor the running of the scheme. Cooperation with health visitors, paediatric units and the schools – which provide advice as well as the invaluable services of educational transport – also helps to ensure that potential difficulties and disagreements between natural and caring families are brought up and discussed before they get too heated. In this way, the scheme becomes one of wider community involvement.

FURTHER INFORMATION: Family Placement Scheme for Mentally Handicapped Children, Department of Social Services (Advisory Section), Merrion House, 110 Merrion Centre, Leeds 1

FAMILY TO FAMILY: BUILDING THE NETWORKS

It's good, because sometimes you feel totally isolated and however good old friends are, they can't understand. It's nice to share.

There's a lot of love in the group – and you really need that acceptance. People grow through what others do for their kids.

Life isn't dull and uninteresting any more. Having a handicapped child, you actually have fun!

Contact a Family starts from the belief that a problem shared is a problem halved. Its aim is to encourage families who have a child with physical or intellectual handicaps to form their own neighbourhood groups, to give mutual support, to organise activities with the help of volunteers, and to press for the services they need. It has 10 projects of its own in different parts of the south and west of England, and offers a linking and advisory service to over 200 independent self-help groups throughout the British Isles.

There's no set pattern to the local CaF projects, as each group grows at its own pace and takes its tone from what its parents want. But as the projects develop, there are certain common threads: building-in the support and opportunities for shared enjoyment; organising 'breaks' for parents and their children; and developing opportunities to learn more about handicap and the help available.

All 10 CaF groups run holiday play-schemes. They also find volunteers to sit-in with their children, or develop their own 'share a family' schemes to build relationships with local families who will have children to stay for a day or a weekend. They work at building-in the mutual support that parents find so valuable; this may include, for instance, a one-to-one scheme to link 'experienced' and 'new' mothers. They produce booklets about what's available locally and discuss what they would like to see developed.

These local activities are reinforced and strengthened by the sharing of information with others through CaF's LinkUp Information and Advice Service – which in turn can draw on the projects' own expertise. In 1983, CaF answered over 500 initial inquiries from parents, groups and professional workers; by 1984, the total had risen to 850. This service can offer advice – through its own considerable range of well-designed literature – on the setting up of self-help groups and subjects as varied as how to work more closely with health visitors and how to acquire and maintain a minibus. Through CaF's own links with other voluntary and statutory agencies, the service can also put parents and others in touch with existing sources of help – and so reinforce rather than duplicate initiatives. It can help individuals to link up too, by putting families whose child has a similar and often rare handicap in touch with each other.

This whole national and local network is strengthened by CaF's newsletter, *Share an Idea*, which goes out to over 1000 groups and individuals, and its large-scale meetings, including the annual 'share a weekend', which draws together parents and children, self-help groups and professional workers for discussions and enjoyment as well.

What CaF aims to do above all is to reach the parents and families who, despite the best intentions of statutory and voluntary organisations, still too often remain isolated – the families who don't think of themselves as joiners or conference-goers. And once they have been contacted, the aim is to help them build their confidence to the point that they can participate in a truly self-help group, and share the expertise that maybe they never thought they had.

There are four things that mark CaF out from many other self-help organisations in the field of disability. The first is that its approach is firmly rooted in the ideals and techniques of community work rather than social work with individuals. It emphasises the involvement of the whole family – including non-handicapped brothers and sisters. It doesn't cater for a specific handicap because it finds that families with a child who is handicapped have so much in common. And it is neighbourhood-based, because what it has found parents want most is a network of local support.

How did CaF grow?

Its approach was developed by its director, Noreen Miller, from her own work in the first project in Wandsworth between 1974 and 1979. She became convinced that a trained community worker – as she is herself – was the best sort of person to act as catalyst, trainer and guide for parents, to encourage them to take responsibility for activities themselves, and to act as a link with different local statutory and voluntary services.

By the end of its first five years as a research project, the Wandsworth scheme – still the largest of CaF's projects – had three flourishing local groups, each with between 50 and 70 members. When the original funding came to an end, there were already other groups in different parts of the country which were interested in developing along the same lines. Contact a Family was launched as a national charity in 1979.

How is CaF organised? The five full-time staff at headquarters in London include the director and her personal assistant and the secretary/book-keeper. The project manager is the person who keeps in close touch with the 10 local projects, and the development officer is the one who fosters that growing network of independent self-help groups.

Locally, each of the 10 CaF projects has its own community worker (two in Wandsworth), and they have their own assistant or assistants. It is their job to maintain and support the group, coordinate new activities and foster links with local statutory and voluntary services.

What unites all this diverse activity is a clear commitment to the single theme that a problem shared is a problem halved – and to the community work approach to translating the slogan into action. What keeps it going and growing, according to Noreen Miller, is a constant seeking after cooperation and partnership – both within and between CaF's own projects and with the many groups and individuals with whom head office is in touch. Quality is maintained through the regular meetings of the trustees and of the staff and the regular supervision and support that the project manager offers the local workers.

But if commitment is one essential in keeping CaF going, the other is cash. In 1979, it had a national budget of some £25,000, with a project budget of £10,500. By 1984/5, those figures had risen to nearly £79,000 and £160,000. Trust funds have provided half the income or more throughout the period; government (DHSS) funding has crept up from about a fifth of the total to a third. Companies have made their contributions to the balance, but CaF's own fund-raising activities remain important.

There is one major problem in CaF's search for financial stability: in 1984, five out of its 10 main project workers were funded through the short-term mechanisms of the Manpower Services Commission. But by then, some of the London groups were able to secure more stable funding through joint-finance from health authorities and social services departments, and this is a pattern which CaF hopes will become more common.

FURTHER INFORMATION: Contact a Family, 16 Strutton Ground, London SW1P 2HP

BUILDING THE NETWORKS: AT THE GRASSROOTS

Contact a Family in Bournemouth is based in an ex-maternity home which acts as a base for other MSC programmes as well. From here, its community worker and two part-time 'secretaries' – who turn out to be the coordinators of volunteers and fund-raising respectively – support and maintain a group which has some 85 member families.

Marylyn Cropley, the coordinator – herself a trained teacher – sees her job as that of enabler, encouraging parents to develop skills and ideas which they themselves feel would benefit them both as individuals and as a group. She knows that families will move in and out of the project depending on their personal commitments, so flexibility is important in its running. What she hopes she is doing is 'helping parents to see the group as part of normal life, to feel no different from any other average family, but still catering for their very special needs'.

In practice, that means a fairly considerable programme of support and social and other activities. CaF started in this area when a mother of twins, one of whom has cerebral palsy, moved here in 1980 and realised how little opportunity there was for parents with handicapped children to meet and support each other, and how little there was, too, in the way of activities that children with handicaps and their non-handicapped brothers and sisters could share. Filling these gaps was a central aim when she and another mother became the project's first coordinators; it still remains so.

Mutual support comes through regular get-togethers for families and outings – the minibus borrowed from other organisations. The need for a 'break' so often expressed by parents has led to regular holiday play-schemes and Saturday clubs for all the children in the families are encouraged too.

The group offers other 'breaks' as well, to whole families – in its holiday caravan, which it also hires out to other CaF groups and any family with a handicapped child, and, most dramatically, in the week-long free holiday it organised with a local hotel. (This turned its entire premises and staff over to CaF and so enabled many families who had never before been away with their handicapped child to find out that this was not only possible, but a huge amount of fun.)

The group's regular provision of support draws on some 40 volunteers, about two-thirds of whom are active at any one time, as drivers, sitters-in, or helpers in tasks as particular, for instance, as reading to blind parents whose child is partially sighted. Volunteers are recruited through the voluntary workers bureau, other voluntary agencies, the media, schools, colleges and word of mouth; they are supported by Julie Riordan, herself the mother of a child with learning difficulties and one of those 'part-time secretaries'. She runs regular open meetings for volunteers, ensures that their enthusiasm is not dissipated by being left without specific tasks, and helps to iron out the difficulties that may arise when neither parents nor volunteers are quite sure of what can and should be offered and asked.

But while the volunteers are essential to the building of support and activities, parents themselves offer it to each other in a quite special way. Quite early on, the group realised that this couldn't be done in a group as large as its own; it found that 'new' families, once the initial contact was made, could easily slip away again unless they got more positive encouragement to become involved. So now, the group is split up, through its link scheme, into 11 'neighbourhoods' and in each of these one parent has the responsibility for ensuring that no family in that small grouping is left out.

CaF also offers its members the chance to help their children learn, in a very distinctive way. This is the home base of CAFCAL, thought to be the first home-based computer-aided learning programme in the country for handicapped children, which was born when the father of a member family started turning his enthusiasm for computers to good account. Other parents became interested – 'it's a fun thing, we really enjoy doing it', as one says – and the scheme has been working since to tailor programmes to specific individual needs among the children. Backed by visits to school to see what teachers were concentrating on, the group has developed, for instance, programmes that help children with coordination, with seeing, hearing, counting and letter recognition. The children enjoy it enormously: for some of them, learning to 'draw a house' by pushing a button may be the first chance they have had to establish such direct control over their environment. There have been dramatic success stories, too, as when one child's letter recognition was reported from school to have improved by as much as 40 per cent. Now the group has acquired 10 home computers – which cost about £250 each including all the trappings – and six of these are available for loan. The aim is to build a basic library of tapes which can be lent across the country to other CaF families.

Finally, CaF has also responded to its members' declared need for more information on different handicaps and the services available. This has been done partly by building links with local voluntary and statutory agencies and partly through membership of an 'official' forum which brings them together to exchange information and views once a quarter. But in 1984, CaF took a stronger initiative than this to spread information and bring people together, when it organised the first-ever open day for all the people involved in providing services for under-fives with special needs in the Bournemouth area, complete with refreshments from the WRVS, an entertainment and a play-space and crêche for children. CaF reckons the day to have been a great success – not just because it attracted over 200 visitors, but because many local service providers actually met for the first time.

To keep CaF in Bournemouth going costs £15,000 a year. Part of this comes from MSC funding for its workers. The rest comes from local fund raising which ropes in a huge variety of local organisations, pubs and clubs and has meant, for instance, that the local army camp has supported an assault course competition. This sort of activity, as Val Berger, the 'secretary' in charge of it all, says, doesn't just mean raising the funds. It is also another way of strengthening links with the local community.

3 EDUCATION

Integration *is* possible. Special educational needs can be met in the ordinary school and to a far greater extent than is currently the practice. There are many pupils in special schools at the moment who could be educated satisfactorily in ordinary schools, given the requisite commitment and resources. So far from damaging the ordinary school in any way, this process can add to its educational strength and enhance provision made for all its pupils.

That was the conclusion of a major government-sponsored study of integration in education towards the end of the 1970s. It showed benefits which ranged from improvements in school buildings and staff facilities, to increased expertise among teachers, to changes in the pupils themselves. Those with special needs gained in self-confidence and independence; others lost their fear of 'differentness' and became more tolerant and mature; some of them, too, gained in self-confidence as they helped their friends who had handicaps. Parents of children with special needs were unanimous that they wanted them to have the ordinary opportunities that regular schools offer. Parents of children who did not have handicaps supported integration once they had been helped to understand what it means. Almost all the 'ordinary' teachers, once they had seen integration at work, supported it as well. And not one of the pupils with special needs the researchers interviewed wanted to go to, or return to, a special school.[1]

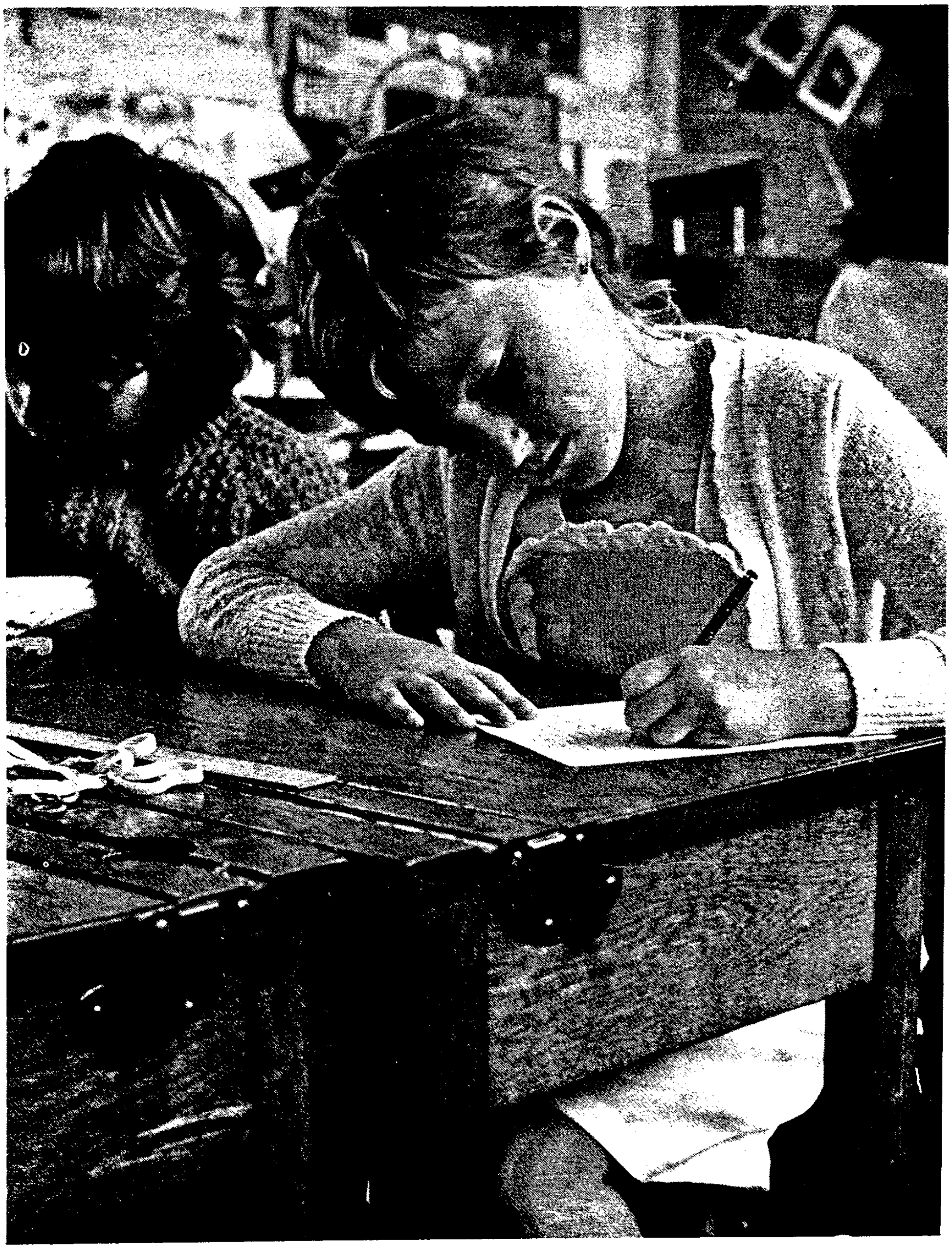
But most of the integrated school experiences that the researchers studied were not for children with moderate or severe learning difficulties – even though they make up over 60 per cent of those categorised as having special educational needs. By then it was becoming more common for those whose difficulties were moderate to be allocated to special classes and centres in ordinary primary and secondary schools. But those whose difficulties were severe – and had only been admitted to the education system at all under the 1970 Education Act – were overwhelmingly likely to end up in the special schools that used to be called ESN(S).

When the Warnock Committee produced the first major government report on special education for 90 years in 1978, it identified integration as 'the central contemporary issue in special education ... earnestly debated far beyond the frontiers of the education service'. By then, CMH, together with MIND, had made its own assessment of the drawbacks to segregated schools for children with mental handicaps, and those were the same then as they are now. Because special schools must draw from a far wider catchment area than ordinary neighbourhood ones, children with mental handicaps are separated from their contemporaries – and both sides suffer from it. The 'special' children become strangers to the social patterns of their own neighbourhood, and live too far from many of their schoolmates in the special school to build alternative ones; they learn that they are 'different' while they are told that they have to learn to live 'as normal a life as possible'. Other local children learn that they are different too, and grow up with a notion of the variety that makes up human society which is far from complete. So the scene is set for a whole generation to grow up with the fears, prejudices and intolerances that have led to abuse of people with mental handicaps in the past.[2]

The 1976 Education Act reiterated a principle that had been enshrined in the law ever since the 1944 Act: that children with special educational needs should, wherever possible, be educated in ordinary schools. But such were the conditions of 'possibility' that local education authorities could, if they so chose, avoid the principle altogether. Special needs were to be met in ordinary schools only if that was compatible with providing the special education that children required, with the 'efficient' education of the ordinary children, and with the 'efficient' use of resources.

The Warnock committee added its own perspective to the debate. It wholeheartedly supported, it said, the development of common provision for all children – in the context of its definition of one in five children as having special educational needs, rather than simply the 2 per cent of all pupils who went to special schools. This blurring of distinctions was, it hoped, a prelude to breaking down the rigid barriers between the 'normal' and the 'special'; it also showed at a stroke that for most pupils with special needs, integration was already a reality. The committee defined its main forms: the locational, where children with special needs shared a campus with others but were effectively separate in their own class or unit; the social, where both sets of pupils came together for out of class activities; and the functional, which meant that they also shared class activities. It paid very great attention to ensuring the quality of that final sort of integration by careful planning and resources to make it work.[3]

Many of the committee's recommendations were enshrined in the 1981 Education Act, which came into full operation three years later. This abolished



the old categories of special school and pupil and introduced complex new procedures for the identification, assessment and placement of children with special educational needs, as well as new rights for parents in that process. It also reiterated the 1976 commitment to integrated education – and the get-out clauses as well.[4]

What has happened since? Very many education authorities, it seems, find that their energy is fully taken up in trying to cope with the hugely complex new bureaucracy of assessment and review of children with special needs. Despite the considerable discussion of integration in the wake of the Warnock report, many authorities seemed reluctant to formulate even a policy of principle on it, let alone start planning for its careful implementation. In fact, the proportion of children in special schools actually rose by 4.8 per cent between 1978 and 1982. Parents' expectations, which had risen in a new way with the promise of greater participation in their children's schooling, and of increased chances of integration as well, sometimes turned to anger and disappointment.[5]

This overall situation contrasts sharply with that in, say, Massachusetts, where there has been a clear legal commitment for a decade and more that children with the whole range of special educational needs have the right to have these met through provision that is free, public and in a setting as close as possible to the ordinary educational mainstream. Chapter 766 – the Massachusetts law whose main provisions are echoed in the federal Education of All Handicapped Children Act of 1975 – introduced important new rights for parents, whose participation in their child's special educational plan is seen as crucial; it has been the basis of a radical reform in the delivery of special education services across the state. By 1985, there were certainly still hiccups in the way the act was implemented; there was still room for debate on exactly how far it was succeeding in bringing children whose special educational needs are most challenging into the mainstream of provision. But British visitors could not fail to be impressed by just how widespread and enthusiastic was the commitment to the principle of integration, among parents, educational staff and administrators and indeed the general public, and by the considerable evidence of imagination and hard work that was going into making that commitment a reality for individual students.[6]

By 1985, though, there were welcome signs that that sort of commitment was beginning to take root in at least some English authorities as well. The clearest statement of principle on integration and assessment of implications for existing special education services came from the Fish report, drawn up for the Inner London Education Authority under the chairmanship of a former member of the special education inspectorate. Its own stance was clear: 'Disabilities and significant difficulties do not diminish the right to equal access to and participation in society ... All those responsible for providing services to children and young people, whether or not they have specific responsibility for those with disabilities and significant difficulties, should accept the aim of integration for all.'

The Fish report put its recommendations firmly in the philosophical context of the equal opportunities policy that the ILEA had already elaborated on race, sex and class. 'Integration', it said, 'is a process, not a state, which requires continued and planned interaction with contemporaries and freedom to associate in different groups.' Special education should be seen as 'a flexible service responsive to individually-assessed needs'.[7]

Just how the Fish report's many and detailed proposals will eventually affect ILEA's special educational provision remains to be seen. Meanwhile, though, there is growing evidence of how integration *is* working for children whose learning difficulties are such as to make them 'typical' candidates for special schools – and that includes children who in the past would have been categorised as ESN(S).* These individual placements are often full-time, especially in infant and primary schools. The one described here isn't. But the experience of Samantha Hulley has been chosen just because her handicaps are so very considerable, and because she shows how, with goodwill, hard work, and little extra cost, even these children can be offered a highly individualised, integrated school programme.

But if that sort of opportunity is to be offered not just to children whose parents are able to put in a lot of hard work, then one-by-one placements aren't going to be enough. The very shape of local schools is going to have to change if all local children with special educational needs are to have the opportunity for integration. The Derbyshire junior and secondary schools described here aren't truly 'comprehensive', in that they don't take in all local children. But what they do show – and in a way that is probably unique in the country – is how regular schools can progressively adapt to offer real integration to children with moderate learning difficulties, and severe ones as well. And that is a beginning of a pattern for the future.

Education, though, isn't something that starts with the first day at infant school and ends with the last day at the secondary. The Warnock committee made increased provision for the under-fives one of its top priorities. The 1981 Education Act lays clear duties on health and education authorities to make early identification and assessment of special educational needs, if the parents agree, and to provide help from this start. The scope of that help had already been laid out in the Warnock report, including the playgroups, opportunity

* Centre for Studies in Integration in Education (CSIE) is a mine of information on current developments. See Appendix B for address.

groups and day nurseries which can and in very many places do offer an integrated experience, as well as the nursery schools which might if they were more widely available for all children.[8]

But the Warnock committee also emphasised what many parents had been asking for years: 'In the earliest years, parents rather than teachers should be regarded, wherever possible, as the main educators of their children.' The Winchester Portage scheme described here shows, in a very specific way, how that recommendation is being put into action.

If the expansion of early education was one of Warnock's top priorities, then the other was an expansion at the other end of the educational spectrum: at school leaving age and beyond. It made many recommendations about careers guidance, preparation for adult life and the provision of a whole variety of further educational experiences. 'Wherever possible', it said, 'young people with special needs should be given the necessary support to enable them to attend ordinary courses of further education.'[9] The number of courses in further education colleges for young people with severe learning difficulties is growing.* But not many of them are as deliberately and carefully working for integration as the one at Kingsway-Princeton College which is described here.

The schemes described in this section don't provide a comprehensive answer to the many and complex questions that special education poses. But they do highlight some of the most exciting developments in the education offered to children and young people whose learning difficulties are severe. They show that these pupils needn't be left out of plans for increased integration. And they show that it is not only they who gain by being brought into the mainstream, but those with whom they work and play as well.

* The National Bureau for Handicapped Students knows about the range of developments for handicapped students aged over 16. See Appendix B for address.

PARENTS AS PARTNERS: FROM THE START

It was like the light at the end of the tunnel. Jacob was my first child, so I didn't know whether he was behaving as he was because that was 'normal' or because he had Down's syndrome. The difficulty was that I kept having to meet professionals during the first few weeks, and all the time I had to put myself out to see them on their own terms, on their own ground – even if I'd been up all night trying to feed Jacob. My home teacher was the first person who met me on Jacob's own terms – she cuddled him and said 'Isn't he lovely?' She brings experience and sympathy. She's a caring and supportive friend *and* a professional.

It's been very stimulating to me to use my intelligence to help Jacob. It's very positive – it cheers you up. It's very fulfilling. When he was six weeks old, his first task was to lie on his back and respond to noises. Now, at nearly three, he's already learned the prepositions 'up' and 'down' through play sessions, and he's

working on 'in' and 'under'. He's going to opportunity group four half days a week. And he's teaching his little twin brother and sister the way he was taught himself!

Jacob's mother is talking about the Portage Home Visiting Service in Winchester, Hampshire, which aims to help parents of pre-school children who have handicaps to teach them everyday life-skills – and where necessary to help parents manage the sort of disruptive behaviours that can get in the way of their child's more useful learning. The scheme draws in a whole variety of helpful professional workers to pool their own skills to help parents. And as it has developed, it has brought to its parents the kind of one-to-one emotional support that they so often say they'd like and still too seldom get.

The Portage approach is essentially a highly structured teaching method; it takes its name from the small town in Wisconsin, USA, where it was first used to help children with mild and moderate handicaps to learn specific skills. The Winchester service brings help to parents (mostly mothers) and children in their own homes and at a time that suits them. This is not just more convenient than expecting them to trail about to clinics and other places of expertise; it also enables parents to work on skills with their children in the place where those skills are most often used, and to tackle problems, for instance with sleeping, that don't arise elsewhere.

The help comes as early as parents are willing to have it – the youngest referral to the Winchester scheme has been three days old – and generally continues until the child goes to school. It comes consistently through the regular weekly visits of the same home teacher. It comes cooperatively, in that parents and home teachers together work out and agree the skills that they want the child to learn. And as time goes on and the parents get more confident, they themselves will increasingly come up with ideas. Because the teaching method is based on finely tuned and often tiny steps towards the acquisition of different skills from a lengthy checklist, it can be adapted to the needs of even the most handicapped child. And because of the way that it is worked out, it is very nearly impossible, if the home teacher knows what he or she is doing, for either parents or their children to fail in what they have set out to do.

This is the theory, and experience in Winchester seems to bear it out. Over 140 families have passed through the scheme since it started in 1976 as a research project under the Wessex Health Care Evaluation Research Team, the first of its kind in the UK. The package it offers seems to be one that parents want. One indication of that is how few home visits are missed: the parent-teachers were not at home when their home teacher called on fewer than 20 occasions in its first five years (or less than one visit in every 300). The scheme reaches the most handicapped children: the exceptional number of deaths and serious illnesses among the children served (eight deaths and 28 long hospital stays among the first 113) is an indication of that. The teaching method succeeds in what it sets out to do: something like 90 per cent of the weekly tasks agreed between home teachers and parents are achieved, and the children can be pre-empted from learning the disruptive skills like head-banging and biting which can be such a bar to their future learning and participation in a wider world.

This way of working suits the home teachers. As one of them, a health visitor, says: 'It's satisfying, because you see something for your work – which you don't always as a health visitor.' It suits parents, too, and not just because it gives them the tools to help their child learn. The Winchester team has found that the relationship of support between them and their home teacher which grows through the very regularity of contact that, say, a social worker, cannot offer, has its spin-offs. Parents will raise family problems that might not otherwise get a hearing and their teacher can help them solve these. And another reason for that might be that the Portage approach sees families who have a handicapped child not as the 'handicapped families' who have dogged so much of the research, but as people who are on the whole extremely skilful in managing their lives, and can be helped to build on this.

Some critics of the Portage method have wondered whether it isn't asking too much of parents to expect them to put aside regular teaching time and fill in work-sheets. Only once, however, has a father in the Winchester scheme raised this concern about his wife; only two parents have declined to join the scheme once introduced to it. As the home teachers point out, 'over-work' of parents isn't really a hazard, because the onus is on the teachers to adapt to individual needs: 'you have to start where people are'. That includes children as well as their parents, for although the original Portage kit is still the basis of the work, there are continuing refinements: one team in Peterborough, for instance, has worked out a further 32 steps on the checklist on motor skills – and these come before the original 'step one', which has to do with the child learning to lift his or her head.

A mother underlines the point: 'You'd be spending regular time with your child, anyway, so you may as well use it in a way that's helpful; you have a theme in your mind so you use it – and the child does the variations.' The fact that 'success' is built into the teaching method, if properly used by the teacher, is clearly important; and parents enjoy, the teachers say, the sense of achievement that comes through the clear evidence in previous work-sheets of how much their child has actually learned.

Critics of the Portage method have wondered, too, whether highly specific skills learned at home can be maintained over time and the learning transferred to other places. The Winchester Portage people answer 'yes' to both these questions on the basis of their own research; and have found a considerable spin-off as well, with up to 50 per cent of additional skills being learned not through the method at all, but incidentally, through 'experience'.

Helping children find ways to use their skills outside their homes is an important part of the Winchester scheme as well. Part of the home teachers' job is to inform parents about playgroups, special nursery centres and other local provision, and to support the children in these so that they build on the skills they have learned at home. The team says that it has been highly gratified by the enthusiasm with which local playgroups have welcomed children with handicaps and extended the Portage teaching into their own, 'non-specialist', settings.

How is the scheme organised?

The Winchester scheme serves around 40 families in its catchment area, which is the health authority's population of some 200,000. Children and their parents are referred by paediatricians, health visitors or, occasionally, other parents. The scheme is also publicised through leaflets in health, social services and education departments.

Each family in the scheme works with their home teacher for an hour a week, agreeing tasks from the Portage checklists, practising these and checking what has gone before. The 10 home teachers are nearly all on part-time secondment from their other, main, jobs in the health service, social services and education departments; it has been a jointly-funded project between these three departments since the original research funding came to an end in 1980. The three health visitors, three teachers (home tutors), three community nurses and two volunteer parents whose expenses are paid by the social services department between them put in some 60 hours a week; an occupational therapist and speech therapist contribute another three hours apiece which they use either in advising the home teachers or working directly with families themselves; the supervisor, Robert Cameron, is an educational psychologist, seconded for five hours a week. These arrangements ensure that the scheme is in the mainstream of local provision. They are also cheap. In 1976, when the original scheme served 15 'research families', it cost £4 a week per family. Now, the cost is £6–£8 a week.

The fact that one of the teachers is a parent who has herself been on the receiving end of the scheme shows, perhaps, how successful it has been for at least one family. It also underlines, as Robert Cameron points out, how a teaching method which is extremely sophisticated in its effects is far from reliant on a great bank of 'professional' expertise in administration. The elements of teaching the Portage method are easily learned: the home teachers have an initial three-day workshop, backed by inservice training.

But the careful monitoring built into the scheme also ensures that further expertise is available. The whole team meets once a fortnight, to exchange the good news and work on any difficulties. It's at these meetings, too, that long-term goals are discussed, to give an agreed curriculum over six months to each family. The team will also discuss any family problems that may have arisen, if the parents agree. Most of these, in fact, never get as far as the meeting, but are resolved by the home teacher and the parents together. But once they have been brought to the team, they remain on the agenda until parents and home teachers agree that they are resolved.

This regular meeting – and one of the few reasons allowed for missing it is a child's birthday party! – is backed by a further one. The three-monthly meeting of the management committee draws together the area psychologist, the adviser in special education, a psychiatrist, a paediatrician, a principal social services area officer, a representative of the voluntary organisations – and Jacob's mother, who was quoted at the start of this description and brings an essential 'consumer perspective'.

Key elements

The key element in getting the service started, according to Robert Cameron, was training and personnel. The key elements in keeping it going are the monitoring and evaluation that come through the fortnightly team meetings, which bring service and consumer feedback, and the three-monthly management meetings, which bring continuing evaluation and future planning.

The way the scheme is managed, he points out, brings further advantages. It ensures that the time and expertise of the 'scarce professionals' is used consistently to help all families, rather than being dissipated to reach some and not others or wasted on tasks which other people, less 'scarce', can do.

Accountability is built into the scheme, too, through this 'positive monitoring' system. Everyone can see clearly whether management team members, supervisor, home teachers and parents themselves have actually carried out the tasks that they have agreed to do. 'This', says Robert Cameron, 'is an interesting point, because it immediately overcomes the parent–professional dichotomy. Both parents and supporting professionals not only have clearly defined roles within the service, but also recognise that each is a vital component of the service model.'

The Portage model has brought its advantages to many other places than Winchester. There are now well over 150 Portage schemes operating in different parts of Britain, with a National Portage Association to back them. The approach has been found useful in meeting some of the needs of the uniquely scattered population of the Scottish highlands. It has been used in hospitals, children's homes, schools, paediatric units, opportunity playgroups and adult training centres too – almost anywhere, in fact, where there are people with learning difficulties who want to learn and people who find this an effective way to help them to do it.

FURTHER INFORMATION:

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Silverhill, Winchester, Hampshire SO23 8AF

Mollie White, National Secretary, National Portage Association, 4 Clifton
Road, Winchester, Hampshire SO22 5BN

INTEGRATION: MEETING INDIVIDUAL NEEDS

On a Friday afternoon, small groups of 9- and 10-year-olds who make up the junior school class are working on different projects. Some are making a variety of solid geometric shapes, others are observing the landscape outside the school and translating what they see into drawings. Some are learning about the properties of yeast, and one of them is Samantha Hulley, who mixes, rolls, shapes and waits for her bread to rise with the rest, joins in the chat and helps with the washing up as well.

Samantha gets on pretty well at school. She is sociable and enjoys her lessons; she particularly likes to go swimming with the class. She has her special friends, who make a point of greeting her when she arrives, and want to sit next to her at meals and play with her during breaks. She has her own and decided views on who she wants to come round to her place after school – which isn't far away, because like her older brothers before her, she goes to the local school.

In nothing of this is there anything very extraordinary for a 10-year-old – except that Samantha has learning difficulties and other handicaps so severe that when she started her school career it was in a special care unit of a special school. She has come on a lot since then. She is highly mobile on her hands and knees or bottom; her sight has improved considerably since she started to see again when she was five; those who know her have few problems in understanding her signed communications. But she cannot stand unaided and must rely on a wheelchair; she is still partially sighted and still finds hand coordination difficult; her vocabulary is limited and she has no speech at all; she needs help to eat and dress and go to the lavatory.

Samantha now spends three sessions a week at Burydale junior school in Stevenage, with her own welfare assistant. For two more sessions, she has her own teacher at Lonsdale, a local school for pupils with physical handicaps. The rest of her school-time she works at home, with her mother, her father, her grandmother, and with anyone else she can rope in.

As far as Burydale school is concerned, this arrangement works. Samantha evidently enjoys her time there. Her class teacher, Sandra Madden, finds no difficulty in helping her to participate in the classroom sessions in ways that will be of value to her. When the rest of the class was set to discovering the mysteries of the equilateral triangle, for instance, Samantha amassed those they cut out and worked on fitting the shapes together. Sometimes she can get even more out of the sessions than the adults suspect: once when the class had been talking about reflections, and Sandra Madden really did wonder what this meant to Samantha, she learned that when Sam went home and looked at herself in a mirror, she immediately made her sign for 'school'.

The educational gains aren't just academic but social as well – and those are for all the children. As Irene Wingham, Sam's welfare assistant says: 'The other children gain so much, and Samantha loves being with them.' Sandra Madden confirms this: 'The children talk to her as an equal, there's no condescension; they want to sit next to her.' She remembers that one time when the class went swimming, there was a child at the baths who had no arms; the class reacted with curiosity but no trace of fear – and that, she reckons, is a measure of what Samantha is bringing to the school by way of increased understanding. Samantha can make her own comment on her social relationships: she has been known to dismiss her welfare assistant at break time so that she can get on with playing with the children who have asked to wheel her about.

Jenny Mackay, the head teacher, has herself noticed a difference in attitudes to Samantha among those children who knew her at the ordinary infant school to which she used to go and those who came to Buryfield from a different school and so know her less well. But she has only once had to intervene when lack of understanding looked like turning into name-calling. And she too emphasises how good it is for the children to have Samantha among them – to help them learn that the world is made up of people with all sorts of differing abilities and that it is the people who matter, not the differences.

For Samantha's parents, the gains are clear. 'We're always meeting her schoolmates out walking, in the shops', says Tom, 'and when the children talk to her, that teaches the adults. She's ever so much part of the locality – and that's because she's in the local school, not separate and different.' 'In front of my eyes, she has benefited', says Bobby: 'I saw a lot of withdrawn children at the special school; they weren't part of this world. I like Samantha being a part of everything – even if it can be a nuisance!'

Working for integration: Samantha's progress

When Samantha was 2½, and first went to the special care unit of the local special school, she couldn't even lift her head; she had only just, after a year of minimal communication, begun to smile again. The brain damage she had sustained when she stopped breathing during an attack of croup had left a normally developing child of 18 months totally dependent; she was quite floppy, blind, and worst of all for her parents, couldn't bear to be cuddled or even touched.

Their aim for her then was 'to make her life pleasant'. They had already been encouraged by joining the Stevenage 'opportunity class', where Samantha was able to mix with non-handicapped as well as handicapped children and her parents were able to learn of individual efforts to enable children to go on living this integrated life as they got older. But that was not something that seemed relevant to Sam. Her parents were delighted that the new special school was going up, so near where they lived; they used to say 'they're building it for Sam!'

When they took her to Great Ormond Street hospital to be registered as blind, however, Bobby saw that there were other ways of working with children whose handicaps were severe. She was impressed by the physiotherapy and thought that she would like to work in the same sort of way with Sam. It became plain that Sam could benefit from joining in activities with children who, although handicapped, were much more able than she was.

So Samantha's educational programme began to expand. By the time she was four, she was going part-time to the special school, and for sessions to the opportunity class, as well as to a weekly nursery group at Great Ormond Street, always with Bobby. It wasn't easy, with two other children then aged five and six, and Tom's work as a social work lecturer to sustain, even if hospital transport to London was a help. But the Hulleys wanted to do anything that seemed to help their daughter, and while they were doing, they were learning more themselves.

'Because I saw so many different ways of working', says Bobby, 'I became more critical. At the special school, they were very kind and always made me very welcome to come and work with Samantha. But I saw how quickly the children there suffered from each other's problems as well as their own. They were either unresponsive to each other or aggressive; Samantha couldn't see or move out of their way; she was very distressed, shrieking all the time and banging her head. I was disappointed, too, in the small amount of time available for physiotherapy and speech therapy, and for individual teaching.'

When she started going as a volunteer to the nearby primary school with one of the brightest children from the special school, she quickly saw how helpful this was to him. When she remarked to the head teacher that it seemed a shame that more children didn't get this chance, she was hardly expecting an invitation to bring Samantha to the school. But when it came, she took it up, and she and Sam started working there twice a week. The staff were always encouraging – to the extent of making it possible for Bobby and Tom to work with a small group of children for half an hour a week, to help Samantha get used to being with other children. Eventually, she was progressing so well that the Hulleys decided she should leave the special school altogether and go part-time to the primary with Bobby, and work at home with her for the rest. The authorities visited and saw no reason why not. Sam went onto the roll at the primary school – 'We felt so good!'

By 1983, when Sam was coming up to her ninth birthday, the Hulleys were thinking that her transfer to junior school was long overdue. She had already been doing some sessions at Burydale with her mother; a volunteer teacher was now going to school with her every morning of the week, so showing that she was not dependent on Bobby for educational help. By now, it seemed important to formalise arrangements: Bobby was pregnant and not well. The Hulleys wrote to the authorities asking for a welfare assistant to work with Sam.

During the silence that followed, they also went back to Great Ormond Street to get their own assessment of their daughter's progress. The psychologist who hadn't seen her for over four years wrote glowingly: Sam had made marked social gains and clearly benefited enormously from her time at primary school; her headbanging and screaming had almost stopped; but she would clearly need one-to-one attention in any school setting. A home visit from the authorities followed. The Hulleys asked for a teacher for Sam for five hours a week and a welfare assistant for ten hours. They got them – the first to be paid from the regular education budget and the second from the special education one.

The search was then on for a junior school. The Hulleys had discussions with four. But it seemed that more work had to be done to convince them that Samantha's eccentric arrangements were feasible. So she, together with her teacher and her welfare assistant, spent half a day a week at her primary school for another year, while she continued to work with Bobby (by now bolstered by a once-weekly visit from a home aide) for the rest of her educational time. Finally, in September 1984, the new arrangements were made: Samantha would spend three sessions a week with her welfare assistant in Burydale junior school, two sessions a week at Lonsdale special school with her teacher, and continue to work at home as well. A formal assessment of her situation under the 1981 Act was being initiated in the Spring of 1985, when it was also agreed that her teacher and welfare assistant would work with her in both school settings.

Working for integration: key elements

When Samantha first started her education, the Hulleys knew little of theories of integration. But they became more and more convinced of its value to her – and to her brothers and all the other children with whom she was in contact – as their own experience broadened and knowledge deepened. They were prepared to put a great deal of time and work into enabling theory to become practice. But, as Bobby emphasises, she has never forced Sam's presence on anyone; she has always (until 1984) been at school with her, ready to withdraw her from the group if she started to disrupt the other children. But she has always been ready, too, to look for ways in which Sam could participate with the other children in the work they were doing; as she found, there are in fact plenty of these once you start investigating what is going on.

But parental determination and hard work can't mean much unless others are prepared to cooperate. The Hulleys speak highly of all the schools with which they've been involved – for their readiness to welcome Bobby to work with Sam, for their openness to experiment. The important thing, the Hulleys have found, is for the school to be willing to adapt to the special needs of a child like Samantha, rather than expecting her simply to 'fit in' to existing patterns.

This is not always easy. Jenny Mackay, the head teacher of Burydale, emphasises the absolute necessity of constant attention to Samantha from her own helper. This is hard work too, as well as rewarding, as Irene Wingham has found: she knows that if the experience is to be successful, she must be constantly talking with Sam and the other children, helping to interpret them to each other, constantly watching for the signs of frustration or distress which mean that Sam needs to withdraw from the group to work on her own.

That work needs to be coordinated, too, especially now that Samantha has three main places of learning and more people than ever before are involved in her education. The arrangement by which Sam's teacher works with her at Lonsdale and her welfare assistant at Burydale isn't ideal: Irene Wingham at least would like to be able to spend time in the other school. At the moment, although Jenny Mackay is responsible for drawing together all those most involved in Sam's education for a termly meeting, most of the day-to-day work of coordination falls to Bobby.

The LEA is not taking Sam's experience as a policy precedent. It shows, though, that it is perfectly possible for a child with severe and multiple handicaps to gain a great deal from life in a regular school – and for the other children to gain as well. And although the support she needs to make the best of her arrangements has until recently been provided principally by her mother, her experience shows too that this need not be so – provided that the authorities are willing to pay for the resources that are needed and the school is open to receiving them. Certainly the expense is hardly enormous. Sam's welfare helper was paid, in 1985, £2.30 an hour and her teacher (or home tutor) £6.36; in addition, the LEA paid some travelling expenses.

Looking to the future

What Tom Hulley wants for his daughter now is full-time education in a regular setting; he is already thinking about Sam's transfer to secondary school. Bobby is less convinced that there is a single solution. Lonsdale special school, she points out, offers the advantages of considerable expertise; Sam is already learning new skills that will be important to her, like working her wheelchair independently. Nor is Bobby sure that full-time education is the best option, at the moment at least; she knows how much Sam has matured since the arrival of her little brother and wouldn't want her to be deprived of the experience of watching him grow up.

But the Hulleys are both determined on one thing: that Samantha should continue to spend part of her educational time at least in a regular school setting, with ‘normal’ children of her own age. ‘People say’, says Bobby, ‘that it will be different at secondary school. But it’s a question of finding ways to involve her. And you’d have to be there to see how to do that, wouldn’t you?’ Tom says: ‘Unless we do the work, we’ll never see what can be done.’ Samantha asks when she can go to the shops, and play with her new doll family, and play recognition games with her picture cards and go back to school and have her friends round and visit the café. And when she’s told that she can’t do them all at once, she just grins and goes on asking until she gets the timetable that offers her most of what she wants.

FURTHER INFORMATION: Tom and Bobby Hulley, 8 Vallowsgate, Stevenage, Hertfordshire

SCHOOLS FOR ALL: JUNIOR SCHOOL

When the first-year pupils took as their term project the theme of ‘communication’, they studied radio, and television, and walkie-talkies and every sort of device that humankind has invented to bring people closer together. On one day, one member of the class was studying the way that sound waves travel. And another was speaking into one end of the telephone that the children had rigged up out of tin cans and bits of string and then rushing to the other end to reply to himself in a different voice.

For Springfield Road junior school in Swadlincote, that is what integration in education is all about, for its declared aim is to ‘allow and encourage children of diverse abilities to work alongside each other in areas of the curriculum for all or part of the day’. That student of sound waves is thought to be one of the brightest pupils in his year. The student of telephonic communication would once have been categorised as ‘educationally subnormal (severe)’ and is now said to have ‘severe learning difficulties’. And they don’t just go to the same school, but spend a good deal of their educational time together as well.

They are not the only ones, either, for about a third of Springfield Road’s pupils – in 1983/4 63 out of around 200 – are classified as having either moderate or severe learning difficulties. At lunchtime, they jostle together in the queue for their meal and share tables and make a din together as children will. After lunch, they share a playground and can join the same clubs, and participate together in games, dancercise, roller-skating or music, either as players or as spectators. The first-year pupils who take the visitor on the tour of the school chat cheerfully and unselfconsciously about this child and that in the classes for children with severe or moderate learning difficulties, and the sometimes funny things that they do and their special friends among them. They are keen to introduce the youngest children and those who have very severe handicaps in the ‘special care unit’ and to tell the sort of stories about them that show they know them well and like what

they know. And everywhere there is the bustle and energy that gatherings of young children will generate. The difference is just that here this involves all sorts of children and not just some.

Building integration: the foundations

The foundations on which Springfield Road was built to become what is probably the most integrated school in the land were not laid with that in mind. In the mid-60s, it became apparent to Derbyshire LEA that it needed new provision for children categorised as 'ESN(M)'.* Rather than build full-scale schools in its areas of largely rural and small town populations, it decided to 'establish small area units at local primary and secondary schools, thus eliminating long travelling distances for pupils which would have been necessary if the alternative course of building larger but fewer special schools had been adopted'. Springfield

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* The postal address of Swadlincote is Staffordshire but the school is administered by Derbyshire education authority.

Road was then an infant and junior school. But when a new infant school opened nearby to take its youngest pupils, space became available. So the new ESN(M) unit for up to 40 children was sited there and opened in 1969. When the 1970 Education Act promised schooling for children hitherto excluded, Springfield Road seemed the right site for them too. The ESN(S) unit for 35 children, including 10 'special care' and nursery places, opened in 1974.

The aim then, though, was little more than what the experts now like to call 'locational integration'. The staff may all have met in the communal staffroom, but the lack of a definite policy of integration from headquarters was echoed by a lack of preparation for staff on what this new hybrid of a school might mean. 'One can question', said the National Foundation for Educational Research in its review of Springfield Road at the end of the 1970s, 'whether this will suffice when the arrangements are as innovative and demanding as these were.'[10] Policy was effectively left to the head teacher, and although the physical distance between the three units was minimal, the place was effectively run as three separate schools. The situation was not easy for the staff. Some of the main school teachers felt they had been 'saddled with the handicapped kids' and that their own children were getting less attention than those in the special units. Some of the 'unit' teachers felt that their colleagues didn't appreciate what they were trying to do: 'They say, "You can't call it teaching"' was one comment. Even within its own terms, Springfield Road was becoming a strange mixture. Although there were no infants in the main school and most infants with special needs in fact went to a special unit at the nearby infant school, it had a nursery group as well as 'special care' children who stayed until they were 16. The lack of suitable special provision nearby meant that 'children with severe learning difficulties' could include those who were not assessed to have these at all, but simply needed a place to go until they could transfer elsewhere at the age of seven. Local screening procedures were such that some children who *did* have special needs didn't transfer to Springfield Road until they were as old as 10, despite the efforts of the ESN(M) unit head towards the end of the 1970s to build closer links with catchment primary schools.

But by the end of the 1970s, Springfield Road had its strengths as well. There were good links with local specialists who came together for the six-weekly review and admission panels for the children whose learning difficulties were severe; three local paediatricians held their clinics in the unit. There had been an active parents' group ever since 1973, who had raised money for a minibus and swimming pool that benefited all the children; there was a toy library and good links between teachers and parents of children in both the 'S' and the 'M' units.

By then, too, there was some interaction between the children from the

different units. Those whose learning difficulties were moderate came to assembly and mixed with the main school at lunch and in the playground; there was some *ad hoc* integration in PE, art and craft, singing and swimming; there had been a small but steady trickle of pupils from the 'M' unit into the main school, either part-time or full-time, ever since the unit opened.

But for the 'S' children, opportunities for integration were more sketchy. Many took their meals separately from the main school; they didn't attend assembly in case they disrupted the proceedings. 'There isn't much you can do about social integration' was the view of one teacher; 'they've not been diagnosed as needing integration but as needing special education' was the view of another. 'When', some of the 'S' children would ask, 'am I going to the proper school?'

NFER suggested that the needs of Springfield's pupils would be better met if the special units functioned as part of the parent school; if there was a flexible exchange of staff and pupils across all parts of the school; and if staff appointments were made to promote integration.

Building integration: the reorganisation

The chance to put these recommendations into practice came in 1982, when there were, by chance, several new staff appointments, including that of Ian Mitchell as head teacher and Anne Jones as his deputy. Both of them are committed to an integration which is not just social but educational as well, and have gradually been increasing its scope.

There are constraints: although the original plan in building the special units was to cut down on travelling time for their pupils, some of them must still travel up to 12 miles each way each day and school transport is such that they arrive after the start of the school day and leave before its end. But all the children now come to assembly as and when they arrive; they are an integral part of the weekly afternoon assembly to which parents and friends are invited, each 'special' group teamed for a term with a different class from the main school so that all pupils have a chance to get to know each other better. 'And no one stares if a child happens to scream or shout out', says Anne Jones, 'it's just accepted.'

Further opportunities for social integration are seized during the course of the day. The introduction of a cafeteria system put an end to segregation during mealtimes by making it possible to use the dining space more economically; and although some of the staff wondered whether the 'special' children would learn to cope, there have been no difficulties at all as they have learned to recognise their 'house colour' and so know when it is their turn to start queueing up. Playtime offers other opportunities, backed by the lunchtime clubs. Expectations of integration aren't unrealistic: Ian Mitchell reckons that children with moderate and severe learning difficulties who don't have behaviour problems mix well with children from the main school, while those from the nursery group get affectionate attention and the majority of children at best co-exist. But as Anne Jones points out, there isn't a school playground in the world where all the children mix with all the others all the time – and 'many children from my main school class ask to go next door to play with a friend from one of the "special" groups'.

In 1982/3, Springfield started to act on the second of NFER's recommendations – the flexible movement of pupils and staff throughout the school. The 'clubs experiment' involved all the teachers and welfare assistants, some parents, all the main school and 'M' unit children and most of those whose learning difficulties are severe. The school was divided into upper and lower and for two one-hour sessions a week over half a term, children opted for one of a whole range of artistic and physical activities – from clay-modelling to cookery, from chess to cycling proficiency. The average number in each group was 16, with one staff member, and the ratio of main school to 'special' children was 4:1.

There were some problems with this: as all the staff were involved, the activity foundered if a staff member was away; some staff felt the curriculum was fragmented and that competitive sports weren't the best vehicle for integration. But Ian Mitchell reckons the experiment worked for some staff and most children: 'it widened the curriculum and highlighted possibilities'.

These were further explored during 1983/4. One of the 'S' classes exchanged rooms with one of the main school ones in a bid to help break down distinctions between groups of children; the curriculum was considerably redesigned to enable children of different abilities to work together for some of their day. During the year, three of the seven main school classes and all the 'unit' children except those designated 'special care' were involved in mixed ability group work for as much as 40 per cent of their time. The next year, the links between all the pupils in the school were stronger yet, and four children classed as having severe learning difficulties were placed full-time in a main school first year class.

How is the curriculum organised?

'Integration', says Ian Mitchell, 'means that there are no subject boundaries, but that within each subject, activities are related to needs. You could say that we have 13 class groups here and so 13 schools; ideally, we should be able to say that there are as many 'schools'' as there are pupils.'

What made the move to mixed ability teaching possible was the decision of the teachers involved to pool their resources and teach as a team within the chosen theme of the term or regular topics. In the school as a whole, these resources amounted in 1984/5 to the head, the deputy and seven teachers for the 'main' school classes; three teachers and two welfare assistants for the 39 children in the 'M' grouping; three teachers, three welfare assistants and one nurse in the 'S' group that included the nursery and 'special care' children – and many volunteer parents and friends and the children themselves.

By judicious blending of these resources, it has become possible for small groupings within the class to work within a chosen theme in the way that suits them best. For some, for instance, studying 'our school and its environment' could mean learning about its history; for others, it could mean observing what went on in and around and translating this into written work or drawings, or simply finding out more about their surroundings. Children could work alone, or together, or with the help of a teacher, welfare assistant or volunteer – but all were learning together about the theme.

By 1984/5, Springfield was showing too that children can do regular 'academic' work in a very mixed ability setting. A group of fourth year pupils, for instance, was learning practical maths in company with the children designated 'special care': while the second group was playing with water, or gaining from copying and talking with the more able children, these ones were, for instance, working on measuring capacity in the water trough or weighing and measuring by helping the nurse do precisely that for the special care children. The two groups shared library time, with the fourth year ones reading to the others or telling them stories. They were also keeping diaries on the progress of the special care children, as part of their own work on language. And one very able fourth year pupil was designing computer programs to help the special care and nursery children.

Members of the two groups were also, during this year, coming together for drama and some physical education, as well as crafts and horse riding. And they spend a great deal of time together at breaks and lunchtimes – with not only girls volunteering to take a turn at pushing the buggies.

Building integration: signs of success

Springfield Road wouldn't claim that it has found 'the' way to work. But as the number of children on the roll of the main school falls in the natural way of things, and so enables main school class numbers to be kept in the low 20s, the opportunities to continue exploring new ways of bringing children together are there. (And the fact that Derbyshire education department can't give relative costs of its special units and other special education provision because of the complexity of the variables indicates at least that it isn't unduly worried about expense.) Springfield Road's plans for 1985/6 include putting two groups of children with moderate learning difficulties permanently with main school classes.

Certainly the experience so far is exciting and heartening. 'Very hard work – but worth it!' is the verdict of the teachers who have been involved in the mixed ability work. 'Working together on a common professional task has widened horizons', says Anne Jones. 'At Springfield, we have mixed ability classes, so all we're in fact doing is extending those mixed ability groups a little wider.' Members of the team trained in special education say that the new way of working has helped them raise their expectations and tackle areas of the curriculum they wouldn't normally have thought of. Overall, the teachers are feeling far more positive towards the children with special needs as an integral and valued part of the school community than they did before the experiments in integration began.

And if things are beginning to work for the teachers, they are working for the

parents as well. Parents of the children in the special units were near-unanimous when Anne Jones asked them their views during the school year 1983/4: they wanted their child to grow up in as normal an environment as possible. Parents of the main school children, more formally surveyed, showed a very positive attitude to what was happening. In 1981, when a similar exercise had been done, 9 per cent of them didn't approve of this mixing of 'special' children in the regular school; a quarter didn't like the thought of their children going into the normal classrooms for some of their lessons and nearly as many didn't approve of their own child helping those with special needs; a fifth didn't think their own child would benefit and a third saw no extra advantages for their child in going to a mixed ability school. By 1983/4, those proportions had fallen to 2, 8, 8, 8 and 11 per cent respectively.

Maybe they had been learning something from their own children. For what seems sure is that while the children from the special unit have often gained noticeably in such skills as, for instance, speech, the main school children are not being held back in their own attainments. And what seems sure as well – and certainly joyfully apparent to the visitor – is the self-confidence, self-respect, awareness of others and skill in cooperation and socialisation that the new way of working has brought to all the children, whether they are categorised as having special needs or not. Main school children have not been frustrated: they are glad, in their mixed groupings, to take time to help others with their work; friendships have developed between children of different abilities, and unsure children especially have been brought out by finding a 'special' friend.

Anne Jones's 1983/4 survey among the children bore out many of the things that had been found in a similar exercise in 1979: that girls were more likely to know the names of some at least of the 'special' unit children, that younger children were more likely to play with them than older ones, that tolerance for them diminished with age. But she found some gains in positive attitudes as well. Perhaps the most heartening finding of all was that very few indeed of the younger children know what to call the 'unit' ones. They weren't 'unit', 'mental', 'spastic' or even 'disabled'. They were just children with their own individual names, like anyone else in the school.

FURTHER INFORMATION: Ian Mitchell, Springfield Road Junior School, Swadlincote, Burton-on-Trent, Staffordshire

SCHOOLS FOR ALL: SECONDARY SCHOOL

A small group of students with severe learning difficulties walks up the hill from their school with their teacher for an afternoon of learning in town. They go into the greengrocer and each chooses and buys some fruit. One goes into the social security office and delivers a form. They pass the fire station, the telephone box, the public lavatories and any number of other local landmarks; they discuss these and recognise the key words painted up or printed on them – a learning which is reinforced by the photos of those same landmarks they have on the cards at school.

There is nothing very special in any of this, perhaps – except that the shops and the landmarks are those which the students and their families and neighbours are constantly visiting and passing, because those students go not to a special school distant from their own neighbourhood, but the same local school as others from their area. And this is immediately apparent to the shopkeepers and passers-by, who recognise them not as belonging to an all-age special school, but by their blazers as belonging to the comprehensive down the hill.

That comprehensive is Pingle, and it is the school to which pupils with moderate and severe learning difficulties transfer at the age of 11 from Springfield Road junior school. One of the three comprehensives which serves Swadlincote's population of 22,000 and its surrounding area, it has over 1100 students. And as some of these have the sort of difficulties in learning which used to classify them as ESN(M) and ESN(S) and others are A level students who have come on for their examination course from the other two local secondary schools, it is probably the most truly 'comprehensive' school, in the range of student ability for which it caters, in the whole of the land.

For all the students with special educational needs, this means an opportunity to be part of a normal school and its expectations. For individuals among them, it means the opportunity to join in integrated social and educational experiences according to their need and ability. And through access to the special provision for these students, it means an extra resource on which any member of the school community can draw as they may benefit.

The foundations of integration

When Joe Bradley came to Pingle school as headmaster from a background in grammar schools and the academic end of comprehensive ones, it was specifically to start building it up from a school which had no provision for A level courses into the one which offered these for the district. But at that time, in 1970, Derbyshire education authority was looking for a place for local secondary students with moderate learning disabilities – in line with its policy of dispersing pupils with special needs among area units rather than gathering them together into a few large schools (see the discussion of Springfield Road school for more details on this policy).* 'I was not sure', Joe Bradley recalls, 'how parents of the ordinary children would feel about this, when I was trying to build up the school for the more able. But I thought we could cope, given the facilities; my own view was that this was a comprehensive school – so there was no more reason to segregate the less able children than there was to segregate the most able: it would have seemed a nonsense.' So the ESN(M) classes began, within the main school building.

Then when the 1970 Education Act demanded a replacement of the all-age junior training centre with primary and secondary school units, Pingle was approached once more, this time to house a unit for older pupils whose learning difficulties were severe. Joe Bradley was more dubious about this, although he saw that the ideology made sense. But he agreed, providing that the students had their own and quite separate unit. This was duly built, close to but quite distinct from the main school building and the first seven students arrived, with one full-time and one part-time teacher, in 1974.

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* The postal address of Pingle School is Staffordshire but it is administered by Derbyshire education authority.

In those days, Joe Bradley reckons, 'everyone was ignorant of what was needed'. Preparation was more or less limited to his own visits to some special schools and staff seminars, meetings with parents and teachers and discussions with existing pupils at the school. Liaison with support services like speech therapy and physiotherapy, educational psychology and social workers was poor, because there was no established pattern of cooperation.

But, as the National Foundation for Educational Research noted when it reviewed Pingle's arrangements for its students with special educational needs at the end of the 1970s, 'there has been a steady and considerable development since the early days'.[10] And although Joe Bradley emphasises that he is 'not a crusader for the mentally handicapped', he reckons that the arrangement is ideal – not universally, but for the particular local circumstances of Swadlincote. There have been gains for the entire school as well. 'There has been a spin-off in staff. More resources are available for not just the least able children but all of them. Whenever there is spread of ability in a school, there are bound to be problems at the bottom end. More expertise at that level, as we now have, helps not just the least able pupils but those in the middle range as well.'

Building towards integration

In 1983/4, Pingle had 20 students whose learning difficulties were severe and just over 60 whose difficulties were moderate. They, together with their teachers and welfare assistants, form part of the school's remedial department, which also caters for a large number of other pupils with special educational needs. One of the aspects of Pingle that NFER noted at the end of the 1970s was that this department enjoyed a higher status than similar ones often do; this has always been a deliberate policy within the school. The department's seven teachers (including head of department) and four welfare assistants enjoy a great deal of autonomy – as do all departmental heads and teams within the school.

The basic organisation of the department is such that the students with severe learning difficulties still spend the bulk of their time in their separate unit, with their three teachers and welfare assistants. Those classed as having moderate difficulties have their own classes and teachers for the first three years; after that, they join other pupils who will not be taking public examinations in a 'core curriculum' that emphasises practical skills and is taught by the main school staff. The remedial students have their own class teacher for the first year and then work with the main school.

Within these basic arrangements, there is considerable flexibility to meet individual needs; the deliberate blurring of categories and use of welfare assistants according to changing needs was something noted by NFER. Although the department does not take in pupils assessed as needing 'special care' – who will stay at Springfield Road until they are old enough to go to the special unit at the local ATC – it has in the past, for instance, taken children who use wheelchairs into the 'ESN(S)' unit and a partially hearing child as well.

Within the basic arrangements, too, there is opportunity for integration into the main body of the school. This is particularly true for the 'remedial' group who spend most of their time there. But those whose learning disabilities are moderate also spend something like half their time working with their main school peers, either in class groups, taken by a subject teacher rather than a special class teacher, or fully integrated for such subjects as music, games and craft.

There is less integration than this for the students whose learning disabilities are severe. The establishment of completely mixed ability classes would not, says Joe Bradley, be appropriate in such a school as Pingle; he prefers to talk of the sort of integration that is appropriate for individuals.

But within these bounds, opportunities for integration for this group have grown over the years. They now no longer take their meals separately, but join the main school – with their own staff – in the cafeteria. Individuals join the main school's groups for games, art, leisure activities, and domestic science; one goes to geography lessons with the 'ESN(M)' group. All members of the group know their way about the main school building and its students know them. They spend their spare time in a variety of ways: some are members of the lunchtime clubs, some join their non-handicapped peers in the playground and a few prefer to stay close to their own unit.

There is some traffic in the other direction as well. Sixth-formers will volunteer to come and help in the special unit, or to go swimming with its students. Sometimes pupils who are finding it too emotionally difficult to cope in the main school will come and spend time in the unit. And its staff have on occasion lent their special expertise to teachers and students in the main school – as, for instance, when one student of the 'core curriculum' who had few reading and writing skills was helped to gain a social sight vocabulary through the methods developed for students in the special unit.

Constraints on building on these beginnings are partly those of attitude. According to Lynne Brown, acting head of the remedial department during 1983/4, main school students react to those with severe learning difficulties 'as in any society: some go out of their way to get to know them, a minority behave badly towards them and the majority are indifferent'. But she does wish that teachers from the main school would do more to acquaint themselves with the unit, its work and the people who teach and learn there.

Other constraints, though, are those of time and personnel. In 1983/4, the three staff and one full-time and one part-time welfare assistant were finding themselves quite overwhelmed with the demands of the 1981 Education Act for statements on and reviews of the individual pupils. Ideally, Lynne Brown says, she would like four staff members and three welfare assistants. In this way, one member of staff could concentrate on liaison with parents and outside specialists – for at the moment, staff have had to drop the arrangement by which two spent half a day a week in the local ATC with which the unit has a link programme for its students. And more welfare assistant time would mean more possibility of negotiating a place in a regular class for a specific subject for the students, because then they could always have the support and backing of their own welfare assistant there.

Nevertheless, Pingle has already shown that integration which goes further than the 'locational' is indeed possible for individual pupils who have severe learning difficulties, and the possibility of building on what is probably a unique experience in English education is there. 'You can't bulldoze', says Lynne Brown, 'but it is happening, in a very small way. We need both the special structures and the movement out of them. We need to formalise the support system for students with special needs. This will come.'

FURTHER INFORMATION: Lynne Brown, Pingle School, Coronation Street, Swadlincote, Burton-on-Trent, Staffordshire

MOVING ON: FURTHER EDUCATION

Oh yes, it's better than school. Well, you can chat up the girls, can't you?

The students saunter through the college to the cafeteria, greeting friends and trying to get in a quick chat-up on the way. After lunch, some of them go to play badminton; another goes to the bank. In the afternoon, they go their separate ways to different courses, or out to get the printing done for the leaflets for the end of term party.

The only really 'special' element in a day in the life of this bunch of students at Kingsway-Princeton College in central London is that all of them have been assessed as having severe learning difficulties and come on to this place of ordinary further education from schools that used to be called ESN(S). And that is how the college wants it to be, for its aims are to develop the abilities and independence of these students and to provide them with the opportunity to participate alongside their contemporaries in ordinary student life. The philosophy that underlies the structure and content of their curriculum is one of integration, and the college sees itself as providing a microcosm of the society in which they will go on to live and work.

The students are on the Gateway 2 course, which runs full-time for two years –

26 hours a week, 34 weeks a year, with Easter and summer programmes of leisure and recreational enjoyments. They join the course after an initial year in the 'link' programme that brings them into the college from their schools in the boroughs of Camden and Islington for a day a week. During that year, they get to know the college and learn what student life will be like; a specialist college tutor helps them bridge the gap between school and college experiences through a carefully structured programme that offers the chance to learn the skills needed to succeed in an integrated setting and includes classes in homecraft, social education, life-skills and yoga. At the end of the year, the Gateway 2 course team join the link students for a week's residential course in Cornwall.

The full-time Gateway 2 programme, which has up to eight students in each of its two years, offers further opportunities for integrated learning. The students have their own 'base-room' in one of the busiest parts of the college, and from this they follow a timetable worked out for their individual needs and preferences. About half their time is spent on 'life-skills' – which may include functional literacy and numeracy and learning to travel about independently. The rest is spent on movement, drama, music, yoga and home economics, which they learn as a group, and in an individual selection of classes from the ordinary college timetable, in which they work alongside other students on subjects as varied as gymnastics and jewellery-making, pottery and – for one young man especially interested in perfecting his reading and writing skills – press studies. During the students' second year, they spend more of their time in getting to know how to use what their local community offers, and sometimes in work experience placements both within and outside the college.

Only the 'life-skills' part of the course is taught by 'special' tutors and in the 'special' setting which is the students' base-room. For the rest of their time, the students are taught by teachers who are specialists in their own field rather than in mental handicap, and in the regular facilities of the college.

This does a lot to help students develop the self-confidence and maturity on which college staff and others so often comment, for they may be not just moving about the college but learning to work with as many as 16 different teachers. It does a lot, too, to ensure that the students are recognised as an integral part of the student population by students and teachers as well.

And that certainly seems so. The games tutor who was running that lunchtime badminton session, for instance, sees no difficulty at all in working out ways to ensure a good game for people with differing levels of skill. The other students in the session find it perfectly ordinary: 'It's a good idea, they get out, they meet people.' As the Gateway 2 team say: 'They just merge in – people forget they're "special", they're just students!'

How did Gateway 2 develop?

In the mid-1970s, Camden social services department asked Kingsway-Princeton – which already had a commitment to providing truly 'comprehensive' further education by supporting students with a range of different disadvantages and disabilities in its courses – to provide a teacher for its adult training centre. After a while, it seemed that a better route would be for the students to come to the teacher in the normal further education setting rather than for the teacher to go to them in the special one; and for them to come at the normal time in their educational career, which is straight from school. So the first pilot 'link' programme started in 1977 and proved successful enough to lead into the first full-time Gateway 2 course the following year, planned by the College, the schools, parents and the social services department.

How is the course organised?

The 'link' and Gateway 2 courses are both part of Kingsway-Princeton's Department of Social and Community Studies, which offers its students general educational and pre-vocational studies. Each of the three groups has its own tutor, and in addition 60 hours' service from 'general duties attendants'. These essential people are the ones who make the integration of individual students into the regular college courses not just possible but rewarding. They accompany them not as 'teachers' but as 'youth workers', ensuring that they get the most possible out of what's going on. And because they are often more or less of an age with the students and either students or ex-students of the college themselves, they also bring them a valuable bridge to wider friendships.

The Gateway 2 students are selected for the initial 'link' course by the college in consultation with their schools, parents, social workers and careers officers. They are tending to leave school later these days; most of them are between 17 and 21 during their college years. There are no minimum academic criteria for joining the course, for essentially students are accepted if it's thought that they will gain independence and maturity from it. They must, though, have enough mobility to be able to negotiate the college stairs, and be able to cope with their personal needs with support if necessary as well as to work in a small group without constant supervision.

The 'link' year is seen by the college very much as an introduction for the students to college life and its demands and a time of continuing assessment. The final decision on whether students will move into the Gateway 2 course is made during a residential week at the end of the year, which they share with some students from other college courses and the Gateway 2 tutors and youth workers. In fact, most students do continue their studies; only occasionally has the college felt that individuals find the life of a busy college too confusing or that they need a more structured and containing environment than it can offer.

The residential component of the course continues: in each of the two Gateway 2 years, staff and students from other college courses join the students and their staff in a week away which offers not just an experience of integrated living but the chance to learn how to participate in group decisions and share domestic work as well.

Key elements

The key elements in getting the Gateway 2 course started, according to the staff, was firm commitment among the agencies concerned to make further education truly comprehensive. The key elements in keeping the course going are the Inner London Education Authority's own commitment to continued further education and the recognition by Kingsway-Princeton that it is of value not just to Gateway 2 students but to the whole college. Close communication and liaison with everyone inside and outside the college who is concerned with the young people is important too. And so are adequate resources.

Liaison is ensured through regular meetings within the college and with schools, social workers and others outside it. Involving the students' parents is seen as particularly important, especially during the 'link' year, when they may find it difficult to envisage their school-child growing into student status and coping with new demands like, for instance, buying their own lunch and travelling unaided. There are usually two meetings a term between college staff and parents during this year, and in addition, each 'link' student has a diary which travels with them between school, home, college, so that everyone knows what is happening and how people feel about the student's progress.

The ensuring of adequate resources for the Gateway 2 course has become more difficult in recent years. It is more expensive than other college courses, which have generally 14 students to each tutor rather than Gateway's eight and don't have the additional cost of the 'general duties attendants' or youth workers (who are paid from the administration budget at something like the same rate as cleaning staff). The economic pressure, however, is felt not so much by Gateway 2 itself as by the general college courses. Their staff are under some pressure to show efficiency and savings – and this in turn means that it is getting harder for them to integrate the Gateway 2 students. It is not possible, according to the staff team, to do more than work to create and maintain a climate of willingness to foster integration; the detailed work on adapting the course structure and teaching methods that they and others would like to see done simply isn't possible.

Economics play their part too in limiting the possibilities for students when their time at Kingsway-Princeton is over. The college does what it can to foster opportunities for continuing adult education (see *Leisure: learning together* for another example of how these can be provided), and to ensure that the students are prepared for work. But for most of them, that work will be offered not on the open market, but in the specialist setting of an adult training centre.

The graduates of the Gateway 2 course will, however, take with them into their social and working life a new maturity, self-confidence and independence. Kingsway-Princeton shows that it is possible to offer students whose learning disabilities are severe a full-time course of further education in a regular setting and a considerable degree of integration. And its experience over the years shows too how much further this could be developed if resources were available, both in colleges and in the wider world to which their students move on.

FURTHER INFORMATION: David Williams, Senior Lecturer, Social and Community Studies Department,
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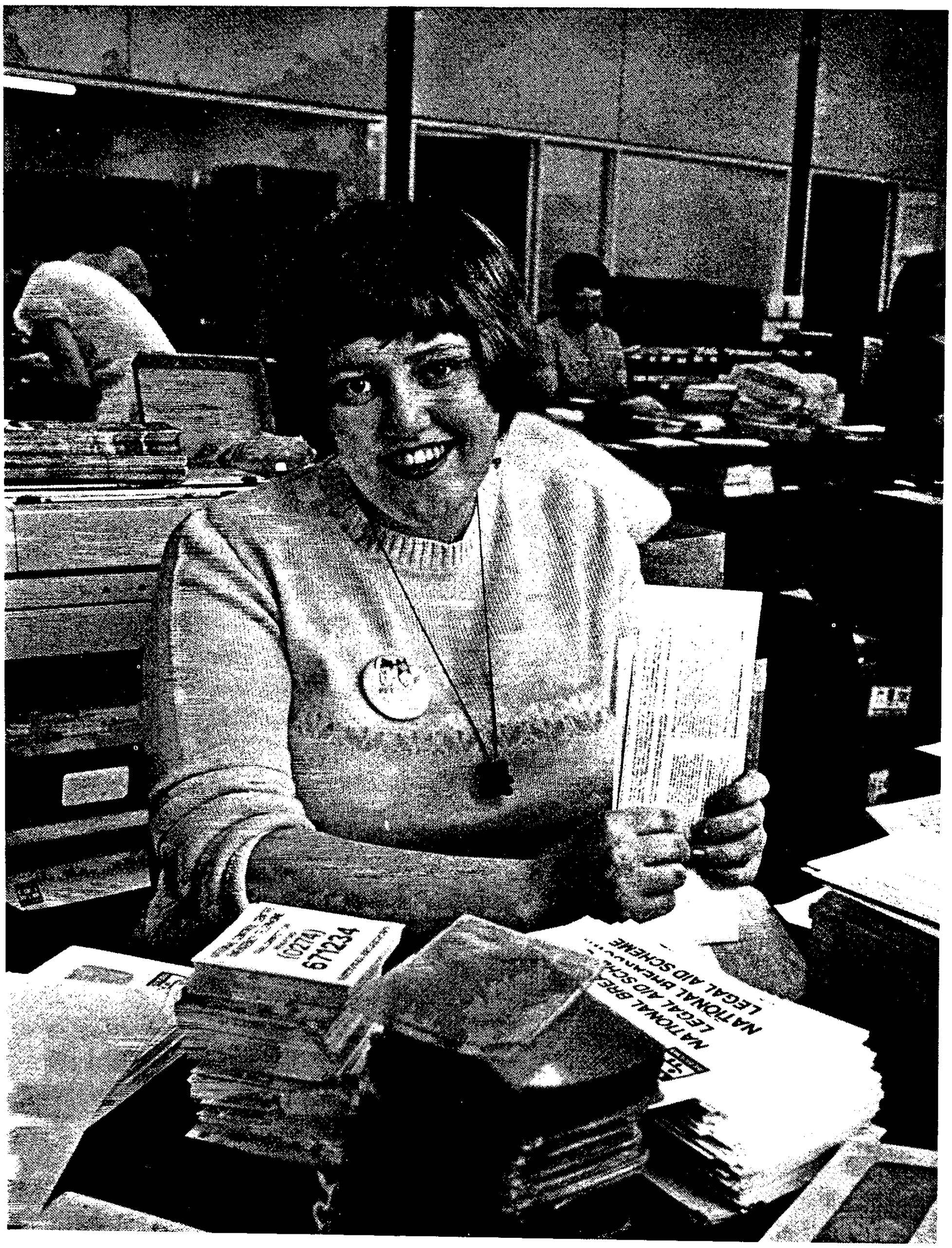
LEGAL AID SCHEME

4 WORK

If we assume that people will never work, then they will not be given the chance to work. It is safer to assume that everyone can do a job of value to the community and which they will value themselves, if they are given adequate help. The only way to learn a real job is to do a real job. You can't learn to swim on dry land. Our main task is to find out what work people want and then identify what help would be needed for them to pursue their choice.

An Ordinary Working Life, King's Fund Centre, 1984

Very many people with mental handicaps say that they want a real job. As the King's Fund project paper *An Ordinary Working Life* underlined, employment means more than money.[1] It offers a structure to, and a measure of control over, our own lives; it offers the chance of relationships; it means having a valued role in our society and a valued self-image too. But if very many people who have mental handicaps say they want the chance of these ordinary satisfactions, what they very often lack is the help to pursue them.

For most of them, the only resource open when they leave school is the local authority adult training centre (ATC) or, as the same places are increasingly called, social education centre. But the question 'Training (or education) for what?' has rarely been satisfactorily answered. The very fact that these establishments are usually under the umbrella of the social services department labelled 'day care' – rather than part of ordinary work-training schemes or educational bodies – immediately takes them, and so the people who attend them, out of the mainstream of their community. The fact that these people are called 'trainees' or 'students' suggests that they are in a state of preparation. But that state, it seems, can too often occupy a working life-span.

The first national survey of ATCs, published in 1977, pointed up just how confused their goals could be. Managers offered between them no fewer than 30 goals for their centres – including work-training, education, 'developing potential to the maximum', occupation and helping workers to move to open employment. But none of these goals was shared by even half the centres. And even within this broad remit, they pursued their aims with only modest success.

In the year of the survey, the centres reckoned that over a third of their workers had the capacity to work 'outside'. But fewer than 4 per cent actually moved to open or sheltered employment and of those who did, only a third found the skills they had acquired in their ATC of any use to them in their job. Nor could the centres claim great success as educational establishments. Many 'trainees', so the survey found, learned the basis of working discipline there. But they were more likely to keep the level of educational skills they had arrived with than to increase it; individual abilities were often not encouraged. 'Meaningful occupation' tended to boil down to unskilled packaging or industrial contract work – the 'dull, repetitive tasks' that people with mental handicaps are so often said to be good at, and which they so often, as perhaps would anyone, find nothing but boring.[2]

In 1977, the National Development Group issued its own blueprint for reform of this scene, which has since become widely accepted. It wanted a change of name for the centres and a clarification of what they were about: they should, it thought, become social education centres and offer 'education in its broadest sense' to their 'students'.

After a period of assessment, the NDG thought, some of these students would move directly to 'advanced work' within the centre. Most, however, would move to its 'development and activity' section, where many would spend a considerable amount of time. This would offer a variety of education and counselling, training in social and leisure skills and 'work experience'. Some students would go to a 'special care' section, part of it having its own staff and facilities.[3]

This model envisaged a 'throughput' of students, with the staff in the 'advanced work' section maintaining close links with local industry and the disablement resettlement officer to ensure that those who could cope with open or sheltered employment should get the chance to do so. But centres, as the Independent Development Council for People with Mental Handicaps pointed out five years later, have found that 'throughput' very hard to achieve. In 1982, with ATCs now full, 'the main problem' confronting them was precisely that.[4] In other words, people are stuck.

What to do? In the previous section, we have seen how people's needs for further education can be met not in a special centre but where other people find their resources for this – in the mainstream of local educational provision. The King's Fund working party on An Ordinary Working Life envisages what might be offered to people once their formal education is over. Its proposals are very different from those of the 'throughput' model, with its assumption that 'students' have to have advanced up a certain ladder of proven ability before they can seek the job they so often say they want. Opportunities for paid employment, it says, should rather be available to all people with mental handicaps, irrespective of their degree of ability, and as a right. The vocational service they are offered should be planned on this premise from the start.[1]

The working party knew that many people would greet the idea that others with severe or even profound handicaps might be able to do a paid job of work with sheer disbelief, especially at a time of such high unemployment, when many feel that if there are jobs to be had at all, they should go to traditional breadwinners.

But the working party had answers to both these objections. It pointed out that there is already a gross imbalance in the way that jobs are distributed: while 86 per cent or so of the general population available for work is employed, probably fewer than 5 per cent of those with severe mental handicaps have paid jobs. 'We question the assumption that a person with handicaps has fewer rights than other people ... We are arguing for the right of people to contribute to meeting society's and people's needs by their efforts.'

Nor did the working party think it unrealistic to extend that right to people whose handicaps are very severe. It knew of people who could be so categorised who confounded even its own expectations by succeeding in paid employment; it came to realise that we are simply not using the many opportunities for shared work that would make that a reality for more. It pointed out that modern educational technology equips us with new skills to teach complex tasks to people hitherto thought unemployable.

That technology has already been put into effect with some very encouraging results. By 1984, for instance, the 13 specialised training programmes, developed from work by Dr Tom Bellamy and colleagues at the University of Oregon, had significantly challenged the myth that people whose handicaps are severe are unemployable. Some 300 people were employed in these programmes, often on very complex and valued tasks, for the electronics industry. Other American initiatives, drawing on the same technology for training, underline the point: for instance, people whose mental handicaps are severe are part of the workforce of a major company which manufactures life-saving defibrilators for hospital and ambulance use; others are working on the intricacies of microfilm processing; highly structured training for other employments also yields its results.[5]

How are opportunities like these to be incorporated into the choices available to people with mental handicaps in this country? The King's Fund working party cites a range of possible job options: 'own job', sheltered workgroups, job attachment, and self-employment among them. But if this sort of choice is to be opened up generally, it emphasises, there needs to be not just a commitment to the right of people with handicaps to work, but the structure of a careful employment or vocational service within which to make it happen.

This may all sound a long way from many of our 'blocked' adult training or social education centres, under-staffed as they so often are. But this chapter describes how one such centre is beginning to move away from traditional ways of doing things to become a 'vocational service' catering for *all* the people it serves within existing financial and staffing constraints.

Two contrasting ways for people with mental handicaps to get jobs are also described. One example is linked to – and the end result of – a structured 'throughput' programme of training for 'real work' within an ATC system. The other has developed alongside a system of social education centres which doesn't place nearly such high priority on preparing people for eventual employment; it shows how 'ordinary' work training and work experience opportunities can be very helpful for people with mental handicaps. Between them, they illustrate some important things: that people with differing degrees of handicap can get jobs if key people are committed to making this happen; that these jobs can be in a variety of often demanding places and be organised in a variety of ways; and, very importantly, that this is possible in areas where the general level of unemployment is extremely high.

There are other ways, too, of opening up choices in employment for people who have a mental handicap. Those working alongside them most often, because of the structures and expectations of local authority 'services', spend their time supervising rather than sharing in that work as equals. But this need not be an inevitable pattern. This section gives two examples of cooperative work, one successfully commercial, the other in a sheltered setting. What unites them is that in both all the workers, whether they have handicaps or not, pool their skills and abilities to produce goods which are highly valued and to create a working environment that puts high store on the less tangible but still important rewards for which any of us would hope from a job of work.

Taken together, these five examples don't amount to a blueprint. But they do show how much more is possible, even within the constraints of present services and the overall economic condition of the country, than many people may have thought. They show the King's Fund working party could have been right when it concluded: 'Low expectations are possibly the biggest barrier to progress in vocational services.' From all five examples, the starting point for opening up choices and chances for employment for people with mental handicaps is clear. And that is a conviction that they, no less than anyone else, have a right to an ordinary working life.

TOWARDS A VOCATIONAL SERVICE

This centre exists to provide experiences, activities and learning opportunities which will help people with mental handicaps to take their place in the mainstream of the community, with appropriate support if necessary.

At first sight, Camperdown Training Centre, on an industrial estate in North Tyneside, isn't much different from many others. Its 115 workers do a lot of industrial contract work; they make wooden bed-frames and run a small print-shop; they all have different degrees of mental handicap.

But then small differences from similar centres begin to stand out. The workers seem to be getting on with the job, rather than moving from workbench to 'education room' to sports activities, and they include some people whose handicaps seem very severe. At lunchtime, the small tables are set out rather more elegantly than they sometimes are elsewhere, each with its own milk-jug and sugar-bowl; a pot of tea is brought to each. The person who shows the visitor round is one of the workers rather than one of the staff; it turns out that it is only because the workers' representatives have agreed to it that the visitor is allowed into the place at all. And the declaration of the centre's aims quoted above, it turns out too, is not some managerial decree, but a statement agreed by all the staff and the workers as well.

Camperdown Training Centre, which opened in 1976 to do what such social services departments establishments traditionally do, is working to transform itself into a 'vocational service'.

Its manager, John Fisher, who came here in 1982, envisages that service as being provided by a team whose central function would be to help all the people who use it to secure employment and to support them in their jobs – whether that meant occasional visiting contact or constant one-to-one presence. Staff would organise training for work and help people find work experience; they would negotiate with employers and set up sheltered industrial groups; they would also build links with local educational facilities, manpower services agencies and anyone who might be helpful to people learning to organise their own recreation and living arrangements.

Such a service, John Fisher reckons, would not cost any more to run than a traditional ATC, with its heavy investment in buildings and equipment rather than in people. It could evolve from the traditional centre and the resources now available to it, provided that the staff had the chance to rethink their role, build on their own skills and get the training and support they might need for the new way of working.

As a start towards this evolution, it could do what Camperdown has been doing itself: look at all the ATC's activities in the light of how and where they might be happening for local people who don't have mental handicaps. 'Only by seeking answers to these questions', says John Fisher, 'will we be in a position to help shape the future of this service. If it is not possible to set up activities on an integrated basis, in valued settings, in mainstream society, then we should see this as our failure.'

Planning for change

Shortly after John Fisher took over as manager, the Camperdown staff took part in a three-day workshop on the principles of normalisation. As a result of this, they drew up a list of 29 issues to be tackled – which ranged from the fairly usual, like review and goal-planning procedures and education and employment opportunities, to the rather less expected, like what to do about the 'soft play area'. These issues are pinned to the wall of John Fisher's office. Some have been resolved. Others remain as the basis of the agenda for change.

At about the time when staff were working towards formulating their own views, the 'trainees' at the centre were beginning to do the same. Soon after John Fisher arrived, he invited each of the seven different 'sections' to send a delegate of their own choosing to a 'workers' council' and offered the services of a member of staff, again of the workers' choosing, to help the council formulate its discussions. After a while, the council decided to dispense with the staff helper, so its deliberations now take place in what John Fisher calls 'a private territory, time and space'. The more able workers, who act as 'guides' to the deliberations rather than officially chairing them, serve on the council for a period of three months; others serve for longer, and so are able to develop their own skills in speaking out for themselves and the sections they represent.

From these beginnings has grown the main decision-making forum for the centre: the joint meeting of staff and workers' council every two weeks. John Fisher brings his own agenda to these meetings too. There is no separate staff meeting at all.

The beginnings of change: abolishing the hierarchies

Camperdown used to operate in a recognisably hierarchical way. Staff were called by their second name, had their own lavatories and their own long dining table, with the normal sort of cutlery and china. 'Trainees' were called by their first name, had their own lavatories and ate off green plastic. The 12 people whose handicaps were most severe and multiple lived a more or less separate life of their own, in their 'special care unit'.

The introduction of first names for everyone, and the change of title from 'trainee' to 'worker' are only the start of the efforts that Camperdown has made to flatten the hierarchies and so increase mutual respect among its people. The separate lavatories have gone. So has the separate staff dining table, and the custom by which staff were served first. China has replaced the green plastic and if there are any breakages, they are paid for out of the budget marked 'educational equipment'. The milk jugs, sugar bowls and pots of tea for each table were the suggestion of the workers' council, because their people were fed up with getting a uniform brew that they couldn't vary according to taste.

These changes do their bit towards creating and reflecting new expectations among both staff and workers, and these are in turn reflected in changes in the way the centre is run. The responsibility of the workers' council for deciding who visits and looking after them when they come is one of these. The opening of all files and personal records to the individuals they are about is another. So is the introduction of telephone extensions in different parts of the centre which anyone can answer if they happen to be around. So too is the bringing of people who have very severe handicaps from their 'special care unit' into the mainstream of the centre's life. For a start, their 'soft play area', which seemed more suitable for small children than for working adults, was sold to a nursery and the proceeds put into buying a hoist for someone who needed very careful lifting. These days, the 'special care' people are in their renamed 'therapy unit' only if they are ill, or if they need occasional physical attention that can't conveniently be provided elsewhere, or if they are having specific therapy from the visiting speech therapists and physiotherapists. Otherwise, they share the normal life of the centre, dispersed through its workforce. And all the workers, including them, are now paid a flat rate of £2.50 a week in place of the payments based on performance which effectively discriminated against people just because they had very severe handicaps. That may not be much – and it's called an 'attendance allowance' to make clear that it's not wages. But at least, as the workers' council agreed, it's fair.

Working for change: opening up and moving out

One of Camperdown's priorities has been to increase the involvement of parents and families, and if he were starting again, John Fisher says, he would certainly invite parents from the start to the fortnightly meetings of staff and workers' council, so that they could be drawn into a better understanding of changes that can sometimes seem bewildering.

But parents have reacted well to the new system of reviews and goal planning for individuals, which takes a team from the centre into their homes rather than bringing them into a formal meeting. And at least 15 or so of the parents are keen enough on what the centre is trying to do to come in and run the place during those fortnightly meetings. A normalisation workshop specifically for the parents has, says John Fisher, been helpful.

If opening up the centre for people to come into it has been one of the aims, then opening up the choices in the way people move out from it has been another.

Camperdown's holiday scheme, for instance, used to be a traditional affair, based on a block-booking for 50 people at a time in a Scarborough hotel. During John Fisher's first summer, a complex programme of short trips for small groups was arranged, which tried to give participants a taste of city, or country or seaside, and sometimes more than one. It was on the basis of this experience that planning for the following year's holidays began; groups coalesced around not so much where people wanted to go as with whom and discussions progressed from there. It took two months to work it all out. But in 1984 (helped by a £6000 social services grant for what John Fisher called '100 weeks of respite care') seven small groups set out for Blackpool, Spain, Scarborough, Ayr and York – and they included half a dozen people who because of their degree of handicap normally didn't qualify for the general holidays at all, but went in a special and separate group.

Working for change: education

'You've stopped all the education and the recreation – all you've got now is work!' was the reaction of one angry parent to the reorganisation of Camperdown's working day.

John Fisher's answer to that is that the centre did indeed used to provide education – in the shape of basic numeracy and literacy for a few of its customers. But while the time of as many as three instructors was given over to their sessions, the other workers in the centre, herded together in large bunches, were offered very little at all. Camperdown is looking for another way. Following its philosophy of asking where and how specific activities would be happening for people if they did not have mental handicaps, it is building its links with ordinary educational establishments in its area.

One of these, an adult education college, already runs a two-year full-time course for 15 young people with mental handicaps after they leave school and before they come on to Camperdown at all. In addition, workers from the centre go out to individually planned and chosen adult education courses from the centre itself. Sometimes a special programme can be set up for them – as for the three Camperdown workers who wanted to learn to budget more effectively and were able to join with three workers from another local training centre to form a class. Sometimes existing 'regular' courses seem relevant, like the one in hair-care to which six workers from Camperdown went for a half a day over a year, with the other half spent in crafts and floristry. Sometimes people join schemes for personal tuition in literacy – like the five who signed up to have a tutor visit them at home in the normal way. Other resources are explored – like the sixth-form college where one young man with a particular interest joined the regular students for their art course, or the local centre for people who are unemployed, where some others go for non-academic courses like dress-making and crafts.

Working for change: employment

'We should not be surprised', says John Fisher, 'that the vast majority of people who attend ATCs, when asked "What would you like to do during the day?" reply: "I would like a real job".' Camperdown is trying, from its traditional beginnings in contract work, to help people find just that.

It has set up a 'pre-employment' group, from which workers go out to job experience on one or two days a week, together with a member of staff. So far, such work has been found in a factory, a hotel, a department store and a printing office. The image fits with the eventual aim: these workers turn up not in the

ATC's minibus, but in the estate car it bought to accord more nearly with the image of regular workers.

Plans for the future include increased opportunities for work experience through closer links with skills centres as well as the possible creation of 'real work' through setting up a separate industrial shop for the centre's existing woodwork.

Organisation for change

The flattening out of hierarchies between staff and workers at Camperdown has been paralleled in the reduction of hierarchy among staff themselves. Each of the eight instructors (and the five staff for the 12 people whose base is the therapy unit) works with his or her own group of around 12 workers and has a high degree of autonomy in that work.

The staff have the responsibility of working out individual plans with each of their workers, looking to their educational needs and supporting them in their work experience as well. They may also, as needed, help individuals to set up house, with the cooperation of a local social worker and occupational therapist. Three of the staff have special responsibility for seeking out work placements and, eventually, employment.

Staff take their own initiatives. They arrange their own cover, for instance, by a colleague or a volunteer, if they need to be out of the centre. They are encouraged to drop into other ATCs when they are on holiday and claim back their expenses later. They make their own direct approaches to the people outside the centre who can help the workers, without going through their manager. 'My job', says John Fisher, 'is to wind people up and send them out and then do the leg-work with the people at the top. Of course there are risks, but you have to take them. All I ask is that the staff inform me of what they are doing.'

In this, they have the support of two assistant managers as well as himself, two auxiliary drivers, three cleaners, three kitchen staff, a driver handyman and three volunteers. Their own expertise and formal training (the Diploma for Teachers of the Mentally Handicapped, for instance, or Certificate of Social Services) is backed by short courses like the one on the principles of normalisation and another on the rudiments of individual programme planning.

Camperdown's aim is to go on working on and refining its agenda for change, constantly looking outwards to see where and how non-handicapped people are doing the things that its workers want to do themselves and looking for ways to support them in the mainstream. It wants to expand the educational opportunities open to its workers, especially those related to work-skills. It hopes to enable its workers whose handicaps are very severe to have more experience of their community with one-to-one support. It wants to encourage volunteers, who might, for instance, set up a befriending service to enable workers to join in regular sports activities in the evenings and at weekends.

'The irony is', says John Fisher, 'that we need to establish a unit that works in order to dismantle it. It is not easy to dismantle an institution when you're living in it!' But that remains the goal, as Camperdown works towards using the resources open to very many ATCs to turn itself into a vocational service.

FURTHER INFORMATION: John Fisher, Camperdown Day Centre, Mylord Crescent, Camperdown Industrial Estate, Killingworth, Tyne and Wear

FINDING A JOB (1)

I enjoy the work – I help with the post and taking it round, and I do a bit of typing. I was at the workshop before, but I packed it in – there wasn't enough money and they weren't my kind of people. I thought 'If I'm here all the time, I'll never get a job'. It was difficult here at first – I do get easily upset if people tell me off. But I didn't last week, did I? It's good here, because people are kind and willing to help.

You've got to be patient, very patient – don't put her under pressure until you know her. But it's worthwhile. She's got a job, she's working and she's enjoying it – and it's nice to see someone doing that.

Carole Patterson works in the postroom at the Bradford headquarters of National Breakdown, the people who rescue your car if it collapses. She is there because one of its directors, Michael Stephenson, heard about the setting up of a local Pathway Employment Service for people with mental handicaps and wondered whether his firm could offer a job. He was clear that it wouldn't help anyone to be over-generous in what he offered; but he reckoned that it would be realistic to propose a vacancy for general duties in the postroom.

Since Carole arrived, her job has grown with her. At first, she helped with franking and bagging mail and taking her turn in packing envelopes for the membership. But as her confidence grew, so did her skills: after 18 months, she was opening and sorting the mail for internal delivery, taking it round and typing labels as well.

She used, as she says herself, to get very upset if things didn't go right or if she wasn't too clear about how a particular job should be done. But she has been able to turn to a helpful and sympathetic workforce. Michael Stephenson wanted them to feel a collective responsibility for helping her find her feet, and reckons that the non-bureaucratic atmosphere of a relatively small workforce of just over 100 people has been helpful. Carole has also found special support from Paul

Allen, her 'foster worker', quoted above, and from a small group of women employees who have helped her not just with day-to-day encouragement but with a whole host of other things, including the sorting out of budgetary and housing difficulties.

Carole is one of 67 people that the Bradford Pathway Employment Service has helped to get either a full-time job or work experience and training since it started in 1982. Of the total, 26 have found employment in areas as various as labouring, domestic or catering and kitchen work and working in a machine shop or as a care assistant to elderly people. Twenty-two have joined 12-month community programmes, which have mostly to do with improving the local environment. Seven more have moved into further education programmes, including industrial training, and four have had work experience – in a big store, a kitchen, a day nursery or a garden. Eight have permanent jobs in sheltered employment. And this job placement has been achieved in a city whose staple industries of textiles and engineering have been badly hit, and where the official unemployment rate at the start of 1985 was nearly 16 per cent of the workforce.

How is Pathway organised?

Pathway in Bradford is part of a national network of such services and the first in the north of England. There are 12 others in different parts of England and Wales, with over 50 more at various stages of negotiation. By the end of 1984, the different Pathway Employment Services had between them found jobs for 493 people with varying degrees of mental, and sometimes additional, handicaps, with an 81.5 per cent 'success' rate in terms of jobs held down. In addition, the services had placed about 175 people in work experience on the open market.

The first Pathway Employment Service was set up by MENCAP in Cardiff in 1975, by its now national director, Valerie Cooper, the brainchild of parents in local South Wales societies. What it fundamentally offered then and offers now is a support service to workers with mental handicap and their employers through the first critical months of employment. Part of that support is professional: the local Pathway employment officer finds the jobs, matches them to the workers and is as available as necessary for advice. Part of the support is financial: Pathway will pay the new worker's wages at whatever is the ordinary going rate, for up to 12 weeks, and also a small honorarium (£5 a week in 1984) to a designated 'foster worker', who will help the new colleague learn work routines and introduce them to the social side of working life.

The introduction of a local Pathway Service is conditional on the local authority accepting the major financial responsibility for it over three or five

years at least. In 1984/5, the Pathway 'package' – which includes the salary of a full-time employment officer, a part-time secretary, payment to foster workers and as necessary to employers – cost £34,732 in the London area and £34,194 outside it.

In practice, these costs can be shared. The Bradford service, for instance – set up at the invitation of the local authority – was funded for its first three years, until 1984/5, under the Urban Programme, which meant that central government picked up 75 per cent of the tab. Other money can be drawn into the service as well: the Manpower Services Commission's job introduction scheme for disabled workers may pick up all or part of the payments to employers during the employee's first 13 weeks. Sometimes employers and foster workers waive their 'fees' altogether.

Once a local service has been set up, it works closely within the national network. There is a six-week national induction for Pathway employment officers, and they all meet together regularly for discussion and evaluation of their work.

Key elements

'In the current economic situation, where the employment of one worker may be critical to the future of the firm, you can't,' says Stephen Middleton, 'appeal to people's social conscience. You have to be sure that you are matching the skills of the workers to the job.'

The finding of jobs and the people to match them falls to him, as Pathway employment officer in Bradford. (This was in 1984. He is now deputy director of the national service.) One way that he finds the jobs is through sheer determination not to miss one. He drops into the job centre every day, and works closely with the disablement resettlement officers there. This cooperation, both sides agree, is essential. It is through the DRO, for instance, that placements can be made in Remploy and other local sheltered employment. Stephen Middleton, for his part, may have the time to visit local employers and negotiate on behalf of a worker that the DROs, with their wider responsibilities to different groups of disabled people, simply don't. His own considerable past experience as personnel officer in the textile industry is an added advantage.

The other way of securing jobs is to persuade employers to open opportunities to rather wider a field of applicants than they may have thought of. The idea of taking them on to the catering strength at the Town Hall, for instance, to work in the day-to-day nourishing of the staff and the occasional more lavish spread put on by the Lord Mayor, is one that has paid dividends. There is a strong commitment within the workforce there to people whose needs for support in their work may be greater than is usual, and from Tony Culley, the chief personnel officer, to offering them further education within their work. One young man, for instance, who came on from a 'community workshop', has proved so adept at learning catering skills – as well as the social ones that come with being in charge of the tea trolley that goes round the offices – that he now has the chance of going to college as a step towards his ultimate ambition of becoming a chef.

The 12-month community programme has also been worked on by Stephen Middleton to include the people for whom he advocates. At first, there was some doubt whether they could cope with work which is tough both physically and socially. But after the jostling within the work-team had settled down, the workers who have come through Pathway have shown themselves to be just as tough as anyone else – and that too, Stephen Middleton reckons, is going to be important to them in their working lives.

He sees the community programme as one way for the people on his books to get themselves a training in work skills and habits – and, importantly, a reference at the end of the year that will stand them in good stead when they apply for a permanent job. This has already paid off for more than one of the CP workers. One young man, for instance, who was thrown out of his first job after he left school for fighting and quickly became classified as 'unemployable' managed to do well during his CP year, and is now employed full-time as a porter in a supermarket.

Stephen Middleton feels strongly that it should not be part of a Pathway employment officer's job to ensure that people get proper work training; with nearly 30 people on his books who need work, he would have more than enough to do in seeking out employment and supporting them in it without this extra responsibility. But ironically, it was at about the time that Pathway started in Bradford that the social services department decided to change the name and the emphasis of its training centres to 'social education'. This means that the pace and nature of the work in them is less adapted than it was to instilling essential work skills and disciplines. So Stephen Middleton finds he must work to ensure that others – like the community programme, and different local workshops as well as the firms who accept people for work experience placements – fill that gap. It is in fact from these settings rather than directly from social education centres that most placements in full-time open employment are made.

Stephen Middleton feels strongly too that Pathway is not in business to usurp the functions of either social workers or employers and their personnel officers, by remaining too closely involved in the lives of the people it places. That isn't to say that he won't visit a workplace every day and chat to both employer and employee if necessary. But as time goes on, he reckons, the support of the worker should increasingly become the responsibility of the workplace itself.

In those first 67 Pathway placements in Bradford, only three can be said to have been 'unsuccessful'. Two workers left because they reckoned they couldn't stand the pace – and for one, that was the result of an extra workload when the workforce was cut. The other was made redundant – but has since found another job. The key factors of identifying supportive employers and colleagues and careful matching of workers' skills to the jobs available seem to be paying off.

FURTHER INFORMATION: Valerie Cooper, National Director, Pathway Employment Service, 169a City Road, Cardiff CF2 3JB

FINDING A JOB (2)

It's interesting – you're out in the open air, you're getting out and meeting people. It was only grass and boulders when we started. Now there's grass, window boxes, the lot. And you earn more. Before, I was at the day centre, doing different things, learning different things. Then I learned to be a gardener. My wife's at the centre now. You don't earn much there. I've learned a lot since I left the hospital; I used to run away from there, I was in the security ward. We used to be in the hostel. But everyone's on top of you there. We're far better off in the flat.

The aim of Newcastle social services department's employment scheme is to find jobs for as many people with mental and other handicaps as possible, either in sheltered groups in ordinary workplaces or on the open market. Since it started placing people in 1979, it has helped 124 people with mental handicaps to find a job.

More than half of them are in regular work – as labourers, domestics, kitchen or catering assistants. The work setting can be a demanding one – like the kitchen of a major hospital, for instance, where one young woman is part of a staff team that reckons to produce, on average, no fewer than 17,500 meals for patients and staff during a working week.

Other workers are on community programmes; a few are in sheltered workshops. But a third of the total are in 'sheltered industrial groups' in which between four and six of them work in a team under supervision and get the union rate for the job they do. Some, like the man quoted above, work as gardeners around eight of the social services department's own residential homes. Others cope with the more than ordinary pressures of working in a meals on wheels kitchen, which may produce, pack and get out on time up to 2000 meals a day. Others again work in the city's environmental health department, helping to keep Newcastle's streets clean; 28 of the 150-strong workforce are employed in this way.

Three of the members of one of those street-cleaning groups can between them clock up 100 years of experience of life in institutions. You can see them and their colleagues pushing their cart round their allotted beat, greeting the shoppers on their way home, getting on with the job with great good humour. When they meet together with their supervisor to unpack their lunch in their fuggy little hut, there's a lot of banter and jokes. No problem. As the supervisor says, 'Well, they've a right to society, the same as anyone else.'

'There are people who got jobs in 1979 who won't speak to me now,' says George Twizell, the employment liaison officer – and that, he reckons, is one mark of his scheme's success in enabling people to feel that they are just part of the ordinary workforce. 'You can see the difference in people as soon as they start work – they begin to think for themselves, make their own way.' In all the years that the scheme has been going, only about 10 people have lost their jobs – and that's in a city where, with unemployment as high as 18.5 per cent of the workforce at the start of 1985, there are plenty of others who might be glad to take them.

Working out: the context

At the end of the 1960s, Newcastle had a single training centre, the Dame Catherine Scott, to serve all of its population who had a mental handicap. Then when the city's boundaries changed in 1974, it 'inherited' another from Northumberland, at Westerhope. Three years later, the Geoffrey Rhodes centre was built in another part of the city again – so it ended up with 400 training places on three separate sites to serve a total population of 277,000.

This seemed to the social services department to offer the opportunity for a new way of working, and its working party came up with the idea of a 'three tier' system of training for people with mental handicaps. The notion of movement through the system was part of their thinking from the start: people were to be offered a 'career structure' whose eventual goal was open employment, and carefully worked-out steps towards it. So the Dame Catherine Scott centre became responsible for intake and initial assessment for everyone in the city reckoned to need special services for those with mental handicaps; people would join it either directly from school or, latterly, from a two-year course at the polytechnic. After a two-month period of assessment, some would move directly to the Westerhope 'intermediate' centre, which would offer training in a combination of social and working skills. Others would stay at the Dame Catherine Scott centre to increase their self-help and social skills until they were ready for this move.

After a period at the Westerhope centre, people would move on to Geoffrey Rhodes when they were assessed as ready for its demands. Here, the regime would be geared as far as possible to the demands of an ordinary working life; people would have to be able to travel independently to qualify for a place, and they would get a rigorous structured training in the skills they needed to get and hold down a job. And from there they would – with the help of George Twizell, who was appointed in 1978 – move into employment.

Work at the centres has developed pretty much according to this pattern, if not quite as neatly as foreseen. For a start, the Geoffrey Rhodes centre became so successful at enabling people to find work that its numbers began to drop; the 'flow' from the other centres was not as steady as had been hoped for. It also became apparent that there was a group of older people in the Dame Catherine Scott centre whose need was not for a 'career structure' towards sheltered or open employment, but for 'meaningful activity' rather than social skills training. So this group has moved, with transport provided, to the Geoffrey Rhodes centre, where its members are dispersed through its workforce in the woodwork, metalwork and pottery sections.

At the same time, the general economic situation has taken its toll on the system's ambitions. About a quarter of the most able workers at the Geoffrey Rhodes centre, George Twizell reckons, could hold down a job. But he remains determined that if there are jobs to be had at all, he will find them.

Working out: the organisation

George Twizell is based at the Geoffrey Rhodes centre and works to its manager. Each week, there is a session of case reviews; he always attends these, together with the parents or other carers of the people involved, and their social workers.

When one of the centre's workers is reckoned to have mastered the skills they need for a more open job, they may then move into an 'extended work situation'. These skills, taught and measured on a points system, have to do with working itself – like punctuality, ability to do the job at an acceptable rate and willingness to put that ability into practice. They have also to do with the other things that workers need to know: how to use the telephone, for instance, and how to behave at an interview; how to call on general helping resources within the community, and to understand the intricacies of tax and union deductions from a pay-packet.

The 'extended work situations' have been set up by George Twizell in a variety of the social services department's own establishments, with the cooperation of the professional advisers and the relevant unions. Workers-in-training may find themselves learning the skills of domestic, kitchen assistant or gardener, by working alongside regular workers and under their supervision; the agreement is that they are to be seen as 'supernumary' rather than as members of the establishment's staff. They work for the hours that they would at Geoffrey Rhodes and they get £4 a week – which is £1 more than the maximum they could earn at the centre itself.

Once the skills needed in these situations are mastered – and George Twizell pays weekly visits to each placement – the workers may, if there is a vacancy, apply for a job on the spot. Or they may move elsewhere, including a place in a 'sheltered industrial group'.

In these groups, they are part of the regular workforce, though working together in groups of not more than six rather than dispersed through it, and under rather closer supervision than they would get as regular employees. They get the union rate for the job they do; the reckoning is that they will be working at 70 per cent of 'normal' capacity. Their wages are administered through their employer who pays for the percentage of work done; manpower services pays 75 per cent of the remainder and the sponsor (in this case the social services department) makes up the rest. (So to make up a wage of £77, for instance, the employer pays £53, manpower services £18 and the sponsor £6.)

From these sheltered groups, workers may move on to regular employment within the organisation – like the men who have been promoted from street-sweeping to the dust-carts – or elsewhere.

Key elements For the first nine months after he was appointed, George Twizell reckons, he did nothing but build contacts – with prospective employers, the unions, job centres and disablement resettlement officers. He emphasises the importance of continuing liaison and strong personal links with all these people; the extended work situations, for instance, would never have been possible without the support of the unions. The fact that in George Twizell there is a single person to whom all the agencies and others can refer is important.

Absolute honesty about the skills and needs of each prospective employee is, he says, important too. The success of the Geoffrey Rhodes centre in imparting the first and identifying the second is seen as crucial – and may be decisive in persuading a prospective employer that people are worth taking on. As one, who manages a very large kitchen, says: 'I was a bit dubious at first, but it was the visit to the centre that reassured me, when I saw how people could handle the demands of a production line.'

In those few cases where workers who have been through this system have lost their jobs, it has invariably been for social reasons rather than an inability to do the tasks required. It may be hard for a father who is himself out of work, for instance, to feel enthusiastic that his son should have the chance that he himself is denied. Yet if parents don't cooperate – by ensuring that their son or daughter gets up early enough to catch the bus in the morning, for instance – then that may seriously jeopardise a working life. So parents are always invited not just to reviews of their son or daughter's progress, but to visit them at their work as well; and George Twizell tries to maintain liaison with them in case of difficulties. Sometimes his efforts are repaid heart-warmingly: he remembers the mother, for instance, who just burst into tears when she visited her son at a workplace to whose status she never thought he'd rise.

It is through his regular weekly visits to the 'extended work' placements that George Twizell can pick up on not just any difficulties in the job itself, but any tensions the worker may be trying to cope with outside it. As people settle into sheltered groups, his visits, though still regular, become less frequent except in

times of special difficulty. There is no need at all, he says, for lengthy follow-up once people are in regular employment. That would add nothing to their lives except a definition as 'different' to the rest of the workforce.

And that is not what the Newcastle scheme is about. The supervisors in the sheltered industrial groups and those who may keep a friendly eye on workers in other situations say the same thing: there's no trouble, they just fit in. For them, it sounds simple: these people are just part of the workforce, with their ups and downs and individual quirks like anyone else. Tony Atkinson, director of the city's environmental health department, underlines the point: 'You take people on at face value and see what they can do. Commitment to the enclave scheme is an attitude of mind – you don't need more than that.' The same could be said of any employer who recognises that people who have mental handicaps can make their own contributions to an ordinary working life.

FURTHER INFORMATION: George Twizell, Employment Liaison Officer, Geoffrey Rhodes Centre, Algernon Road, Newcastle upon Tyne NE6 2UZ

WORKING TOGETHER (1)

When I came here first on the community programme, I'd been out of work for a long time. My confidence was very low; I didn't think I had much to contribute. But during that first year, I realised how much I could learn here. When I decided to stay full-time, it was for selfish reasons! All my working life I'd been dogged by the idea of perfection, of having to do everything perfectly if I was to be accepted. Here I'm among people who accept me not for what I can do, but because I'm me. That's marvellous.

It's good. Too noisy at the ATC. Too many people. Boring. Here? All right.

The working community at The Wedge, right on Norwood High Street in south London, has some 30 members these days. Their shop front shows the variety of work that goes on behind the scenes. A unique sort of reconstituted stone moulding produces a whole range of designs, from lampstands to bird-baths and balustrades to ornaments; one of the designs was included in an exhibition of nativities at the Barbican Arts Centre in 1984. There is hand-weaving; there is rug-making; there is woodwork as well.

The aim of The Wedge is to create a place where people with mental handicaps can develop their capacities as creative workers, by making sense of form and matter, learning responsibility and autonomy, and developing relationships as cooperative members of a working team. About half the workforce have mental handicaps, and there are another five full-time workers besides them. The rest are part-timers, either through the MSC community programme, or volunteers who come for longer or shorter periods of time.

The way the workforce is made up means that The Wedge can offer a highly individualised day to its workers, for its concern is not just to produce high-quality craft goods but to do this in the context of meeting wider individual needs. This in turn means that it can accept and encourage people who might otherwise not get the chance of belonging to a creative working team. One young woman, for instance, came here after six years in a local authority 'intensive support unit'; she found it not easy at all to adapt to working in a group and participating in its life. But now, with careful individual support, she is able not just to follow her own educational programme within the context of the workshop, but to join in the production of some fine weaving as well. One young man doesn't find it at all easy, either, to be with others and follow a sustained activity; but again, with a coherent individual programme, his progress and difficulties carefully recorded each day, he is becoming something of an expert at mixing the ingredients of the stone-work and so participating in the production process.

The Wedge takes a broad view, too, of what constitutes a satisfying working life. There are individual relaxation programmes in the workshop, as well as daily group exercises and movement. Making the tea for the communal breaks and clearing up at the end of the working day becomes an important contribution to the workshop's well-being. The weekly meeting welds it all together, with exchange not just of workshop news and plans but of matters that are important to individuals as well. At one not long ago, for instance, there was talk of the work in hand and orders coming in; but there was also a remembering that one of the workers had been sad to go to a family funeral, that some others had been interested by a lecture on how we live with the anxieties of a nuclear age, that others again had enjoyed visiting another workshop to see what it was doing.

None of this means, though, that The Wedge sees itself as a less than serious working place. It is a member of the Norwood High Street Traders Association and aims to produce its goods in a quantity consistent with its broader aims of individual growth and development. It has sold its wares in some very classy stores indeed, as well as through regular attendance at craft fairs, a growing number of private commissions and the shop itself. Helping with the sales is another important part of working life for the people with handicaps – with the satisfaction not just of seeing the goods valued but of knowing that people get pleasure from them. The most recent addition to the workshop, the woodwork section which opened in spring 1985, immediately landed a contract with Lambeth borough's amenities department for seed-trays and nesting boxes.

How is The Wedge organised?

The Wedge is part of l'Arche in Lambeth – a community where people with mental handicaps and others share their life and work, which is in turn part of the wider network of l'Arche communities in England and Scotland, and indeed across the world. The workers who have handicaps live in one of the l'Arche houses which are scattered through the neighbourhood within ten minutes' walk or so of the workshop; the others have their own living arrangements, independent of l'Arche.

The Wedge is leased from the special trustees of St Thomas' Hospital, who when it started in 1979 put some £27,000 into buying, doing up and initially equipping the workshop and have financed its expansion since to the tune of about £54,000. Other capital expenditures have been met by a variety of donations and grants.

The running costs of The Wedge in 1984/5 amounted to about £57,000. About 60 per cent of this went on salaries for the five full-time non-handicapped

workers, the rest on overheads and payments to the handicapped workers who get the maximum they are allowed by the social security system before their pensions are docked.

The running costs are met from a variety of sources. Sales accounted for around £10,000; the Inner City Partnership funds the majority of the handicapped workers and others are sponsored by individual arrangements with local authorities and, most recently, the hospital they used to live in, under the 'care in the community' financial arrangements. These subsidies worked out, in 1984/5, at rather under £3000 for each handicapped worker.

When The Wedge first opened, there was a lot of discussion in the community about what it should be called.

The Wedge was one of the names that came up. 'That's the right one', said one of the people with handicaps who was going to work there. 'A wedge keeps the door open, doesn't it, so that people can come in and out.'

FURTHER INFORMATION: The Director, The Wedge, 11 Norwood High Street, London SE27

ABOUT L'ARCHE HOMES AND WORKSHOPS: Tim Hollis, l'Arche Secretariat (UK), 14 London Road, Beccles, Suffolk

WORKING TOGETHER (2)

When I left school, I was so depressed, just stuck at home. I couldn't do a damn thing, just counting the little hours round the clock. You feel so tired, the days go so slowly.

Then I went to the centre and learned quite a lot – how to use an electric sewing machine and make soft toys. And then the manager got me this job – and here, one minute it's Monday and the next it's Friday!

I work in the café, help prepare the salads for lunch, working in the shop, go to the bank. The rest of the time I'm bagging up. It's really fun! I quite enjoy it.

Sue Nelson works at the Gillygate Wholefood Bakery, tucked into a beautiful old courtyard in the centre of York, with a mill that produces the only unadulterated flour in the city. The shop sells a whole variety of good foods, including the offerings of the bakery – and you can sit and eat those in the café too. Next door, and the rest of the courtyard, is taken up by Well Workshops which specialises in woodwork and also does picture framing and other crafts. Tucked away in the corner is a shop selling organically grown fruit and vegetables. It feels like a place where you can meet a whole variety of people.

Its hub is the bakery, run as a cooperative. About 20 people are involved in it, half of them full-time; volunteers come and go as well. Since it had its beginnings in 1975, its aim has always been threefold: to operate as a cooperative, owned by its workers; to provide unadulterated food; and to create opportunities for work and employment for people who have been defined as having 'special needs'.

There looks to be plenty of those opportunities in the cooperative's life – from maintaining the place, to serving in the shop and café, to working in the bakery and kitchen, to mastering the weighing and measuring that goes into the bagging up. Two young men who have been defined as having special needs help with the cleaning on Saturdays; another comes in during the week to do a variety of other work. The neighbouring woodwork shop turns out badges, mirrors and coat peg racks with the help of, amongst others, a young woman who used to work in an adult training centre – 'doing boring things like gardening' – and a young man who has spent some time in hospital. Others come and go too, perhaps as volunteers, perhaps for 'work experience', drawn by word of mouth either through friends or because the agencies that are involved in their lives reckon that the Gillygate Bakery is a good place to learn and to share.

One reason for that could be that it is not the sort of place that puts much store on the sort of diagnostic distinctions that separate the 'able' from the 'disabled' in its working life. One of the very reasons that Gill Carrigan, for instance, threw in her job as a teacher and joined the place was that she was tired of the hierarchical structure of the school system and wanted to experience work according to different values. As one of the full-time workers in the cooperative – and the person who pays most special heed to the needs of some of its workers for support and help – she knows that maintaining those values in action isn't always easy and that non-bureaucratic organisation can bring its frustration. She knows too that Gillygate is engaged in a sort of balancing act, for it must continually ensure that the pooled abilities of its workers maintain the place as a going concern.

There have been difficulties in trying to balance commercial criteria against the ideal of providing employment for people with special needs, and it was to expand this side of the work that the Well Workshops were started in 1983. They offer a range of social, work and residential opportunities and are supported by Gillygate, working closely with it. Their role is to support people with special needs in the bakery, offer advice and provide work opportunities in an integrated environment which includes sharing lunchtime and moments of leisure in a communal sitting-room.

But Gillygate is a going concern, through hard work, modest personal rewards if finance is what's counted, and a lot of volunteer energy. It cost the cooperative around £20,000 to buy the premises in 1978 and about the same again to rebuild and equip it. At the present rate of trade, that entire debt should be repaid within two or three years – and that's without any grants or subsidies at all.

How did Gillygate grow?

The bakery stands in Miller's yard, so it is only the latest in a long tradition of its kind. But when Mike Sheppard arrived from Botton Village, one of the Camphill communities, with two friends who had mental handicaps in 1975, it was hardly a going concern. It took a lot of hard work, rebuilding and negotiations to get the place restarted as a bakery after its previous owners had moved out; the city had had it in mind to pull it down for years. But start it did, as a bakery that supplied a local wholefood store, and from the beginning as a business that involved people with mental and other handicaps.

From there, it took a lot more hard work, rebuilding and negotiations to put the business on a firm footing. But in 1978, with the help of friends and a bank

loan, the premises were finally bought. And in that year, too, the Gillygate Wholefood Bakery began trading as an official cooperative.

It has grown ever since. These days, it can mill up to a ton of that unadulterated flour a week, to supply the wholesale trade as well as York Castle Museum (which sells it in its reconstructed Mill) and its own customers. The bakers have six or seven contracts to supply different local restaurants and shops as well as Gillygate's own needs; there is the start of a contract business to nourish guests at weddings, parties and conferences. The Gillygate café, which opened in 1983, draws a brisk lunchtime trade, especially in the summer. The workshops have already, in their first year, found one outlet for woodwork in town and another for badges, as well as selling on the spot.

How is Gillygate organised?

Decisions about the day-to-day running of the place and future policy are taken at the weekly meetings of all the cooperative's members and representatives from Well Workshops. All the full-time workers take home £60.00 a week, and the part-time ones £35.00, with the bakery itself being responsible for national insurance and tax. The hourly rate for more 'casual' workers is £1.50 unless, as sometimes, they are paid by the Manpower Services Commission under the community youth programme or other training schemes; this is the only 'subsidy' the bakery has ever received.

The Well Workshops are an independent, but associated venture, managed by charity and York Invicta, a limited company. Jaspar Gripper, who runs the woodwork shop, also came through Botton Village and is a member of the cooperative.

These days, people tend to stay in the cooperative for two or three years; the original founders have moved on. Some people now come more to see what they can learn from this way of working than to commit themselves long-term; that, according to the more 'permanent' members, makes a difference to the place.

But there are plenty of dreams around the Gillygate courtyard. There is the hope of being able to offer more 'work experience' to people now at adult training centres or on the list for places there. There are hopes, too, of working alongside a housing association with which one member of the cooperative is involved, to offer a place to live to some people who have mental handicaps.

Meanwhile, though, what the Gillygate Bakery has already shown is that it is possible to survive as a business and to get a lot of satisfaction along the way – both as a cooperative and as one which from the start has wanted to offer good and real work to people who otherwise might not get any at all.

FURTHER INFORMATION: Gillygate Wholefood Bakery, Miller's Yard, Gillygate, York YO3 7EB

5 NEW HOMES FOR CHILDREN AND YOUNG PEOPLE

The decision to place a child in an institution on account of mental deficiency is almost never in the child's interest, but it may be in the interests of another child or that of the parents themselves.

Dr Brian Kirman, Fountain Hospital, 1951

The time has come to state unequivocally . . . that large hospitals do not provide a favourable environment for a mentally handicapped child to grow up in . . .

I can think of no more important aim than to try to ensure that all children who do not need specialised health care have the chance to grow up and develop to the best of their potential in their own homes or in small homes in the community.

Patrick Jenkin, Secretary of State for Social Services, 1980

The story of the search for homes for children with mental handicaps who can't, for whatever reason, live with their own families is a long and often wretched one. For most of the postwar period, there has been a single option: a bed in a ward in a mental handicap hospital. For the thousands who have spent their childhood in these places, it has been as if the postwar revolution in child care never happened at all. The fact that they were handicapped obscured the official mind completely to the fact that first and foremost they were children, with any child's need for warmth and affection, individual concern and respect and a stability of relationship. They were offered instead a place in a barracks, extremes of physical and emotional deprivation and the care of ever-changing and overstretched staff. Instead of a concern for their individual future, they were offered an apprenticeship for fitting into the adult wards across the campus.[1]

By the start of the 1970s, when over 7000 children under 16 – and very many more young people over that age – were living in mental handicap hospitals, there seemed little official concern for them. The white paper *Better Services for* *the Mentally Handicapped* made little distinction between the needs of children and those of adults; although it envisaged a halving of hospital places for adults, it thought that children's beds should fall by only 1000, to 6400, with an eventual growth of local authority places to a number short of that.[2]

Yet as the number of children living in mental handicap hospitals seems actually to have risen, to some 8000 in the mid-1970s, the extent of their deprivation began to become shockingly public. By 1979, the Jay committee on mental handicap nursing and care declared the use of hospital wards for children to be totally unacceptable; its 'model of care' envisaged instead that those unable to live with their own families should be found new ones, or a place in a small, local children's home.[3] Its case was overwhelmingly reinforced by the publication of *Children Living in Long-stay Hospitals* – a terrible indictment of a system of warehousing which offered children nothing at all for their happiness, growth or development, and not even the basic medical care which a hospital might have been expected, perhaps, to provide.[4] Pressure increased on government to declare an end to the admission of children to mental handicap hospitals and encourage new homes for those already there; the main organisations concerned in this field formed Exodus to campaign for reform.*

Finally, at the end of 1980, the government responded – and offered £1m, spread over four years, to voluntary organisations who wanted to bring children out of hospital and to match its contribution pound for pound. That initiative has continued, with a further £9m on the same basis promised subsequently. An official circular in 1981 urged regional health authorities to ensure that joint assessments between health and social services were made of all children with mental handicaps in their hospitals. Another circular, two years later, said almost exactly the same thing.

At the end of 1979, there were some 3000 children living in mental handicap hospitals. By 1982, that figure had dropped to nearer 1700. Yet how many of them had found a new home and how many had simply, with the stroke of an administrative pen, ceased to be part of the total because they had had their sixteenth birthday and so become official 'adults', their lives unchanged in any other way? Nobody knows – although in one region at least, 29 of the 32 children who 'left' hospital between 1979 and 1980 turned out merely to have suffered that administrative hypocrisy.[5]

What is certain is that by mid-1985, a Spastics Society survey had found something like 450 children under 16 officially designated as 'long-stay' in mental handicap hospitals and units of 25 places and more in England and Wales. Most of them are in their teens, but some are under 10 and a few are under 5; the survey found that the majority have physical as well as mental handicaps; many

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* See Appendix B for address.

are known to be 'behaviourally disturbed'. What is certain, too, is that new long-stay admissions are being made – four of them at least in the first five months of 1985. What can be suspected is that the true numbers are far larger than the official ones, swelled by the continued blurring between 'long-stay' and 'short-stay' care. Two years after the government initiative was declared, for instance, 'short-stay' in one region meant anything up to two years; in another, there was 'no official time-limit' to it; in a third, some 140 children designated 'short-stay' were actually in hospital long-term.[5]

Whose responsibility is the care and well-being of these children – and the others who might end up in hospitals in future for want of somewhere better to live? Local authorities have put little energy into developing alternative homes; on one estimate, based on their performance during the 1970s, they will *never* reach the targets set for them.[6] Official circulars have spoken of health service responsibility for children 'so severely handicapped that they need residential care in a health setting' – but the lack of clarity about what that means can continue to serve as an excuse for inaction.

And when action does come, it can too often have little to do with the ordinary opportunities of family life. The official circulars have spoken of 'domestic scale health service accommodation' and 'small, homely units'. They have not spoken of ordinary housing, on ordinary streets, or of fostering or adoption.[7] So there are health authorities that make their own interpretations – and plan, for instance, to convert an office to house 10 children, or to build space in a new hospital to house 16 children alongside 72 adults.

Yet it doesn't have to be that way.

Parents For Children has found new families for children who under any existing convention could be said to 'need residential care in a health service setting' – and sometimes, indeed, have had it before finding their new home. Barnardo's professional fostering scheme has done the same for children and young people who have often had to overcome the legacy of many years of institutional living. The Northumberland houses for young people show that a 'domestic scale health service setting' can be translated to mean what any of us would recognise as an ordinary and modest house at the heart of its local community. And they offer a reminder that young people don't stop having needs and aspirations just because they are no longer officially designated as 'children'.

What all three schemes show, in short, is that now and finally there can be no reason why all children and young people with whatever degree of mental handicap should not be offered what was promised the majority of children unable to live with their families something like 40 years ago: affection,

understanding and a care for their future; stability and the opportunity to make the most of their abilities; and a share in a place that is home. And what these schemes show too is that there is every reason to make sure that these are what they get.

ADOPTION

Every kid is different, and Sally is just different in a different way. She's happy and active and loving and annoying – the same as all of them.

Some people say 'Aren't you saints!' But why admire us for something that really pleases us?

Sally Montgomery is 10 and lives with her parents, two sisters and brother in

Southend. When she first arrived, one of the questions that people would ask her parents was whether they'd 'still got her' – with a pretty clear implication that the answer would be 'No'. Eight years on, that particular question doesn't come up so often. But there are still comments enough to show, says Sally's father, that there's people walking about without labels who are far more handicapped than the people they label.

The comments have to do with the fact that Sally has Down's syndrome and was adopted by the Montgomerys when she was just over two and lived in a London children's home. When they first went to visit her there, Archie recalls, he was warned that she'd probably panic to see him, as she wasn't used to men. 'Within 30 seconds she was shuffling towards me on her bottom saying da-da-da. That's it, I said, no more, wrap her up, we'll take her straight away!'

When the Montgomerys first started discussing the possibility of adoption, it wasn't a child with a handicap they had in mind. Nikki was thinking, however, that it would be nice to fill the age gap between Fiona, then a new baby, and Alasdair, who was four, to balance the age difference between him and Catherine, then six. When she saw a photo of a little boy with Down's syndrome in the local paper, under the caption 'Could you adopt this child?', her immediate reaction was 'Yes!' Archie agreed: 'I had always had a special feeling for people with Down's syndrome since I was 15 and realised that the boy who lived up the road was "different".'

They didn't know much about adoption, though, and even less about adopting a child with a handicap. Could working-class people like them adopt, or was this something only for the middle classes? 'Am I allowed to adopt with a baby five months old?' was Nikki's first question at the meeting they went to to find out more. But they were reassured and impressed by the people from the adoption agency, whom they found friendly, intelligent and interested; they liked the way they answered every question put to them and their emphasis on finding parents for particular children rather than simply recruiting 'potential' parents in the abstract.

So they met Sally. After that first visit, Catherine wrote her a letter: 'Dear Sally, I hope you can come on Tuesday with Hilary and Angela and your lugage (*sic*). I have done writeing that you are going to come and I've told all my friends and I've told all the teachers and they are very intrested and they are saying that how kind we are. Lots of love from Catherine.'

If some people thought the Montgomerys were kind, then there were other reactions, too. There were the people who suggested more or less plainly, when they met Sally, that her new parents had been somehow cheated, had her palmed off on them. There was the woman who, when Nicky was out with the children one day, told her how lucky she was to have four – and then hastily added, after a closer look, 'Oh, no, you're not!'. There were the people who would ask 'sympathetically' and sadly after Sally – and not mention the other children at all.

The Montgomerys find all these reactions equally ridiculous. They would count themselves less than conventional, perhaps, being more interested in music and making a living through the craftwork they enjoy than in steady jobs and career prospects. But as far as they're concerned, Sally is simply one of their children, growing up in the rough and tumble of a normally affectionate, normally argumentative family, sharing in everything from the day-to-day to the backpacking holidays. When she first arrived, they recall, she was terrified of the sound of bath water running, the hoover, the washing machine, because she'd never heard them; that sort of thing, her parents learned, was what people mean when they talk about people being 'institutionalised'. These days, she looks to be the most extrovert of the whole family.

There are still instances of name-calling and teasing to cope with from other children. 'They're stupid' says Catherine, who from the start took charge as Sally's special champion – and still ticks her father off when Sally has incurred his wrath for some wickedness. 'Your sister doesn't talk proper' was one child's taunt when Catherine was seven. 'My sister's mentally handicapped – what's your excuse?' was her riposte.

The only regret the Montgomerys have is that Sally goes to a special school rather than the special unit in a regular one they wish existed – because for them what it's all about is helping her, and other children with handicaps, to share in ordinary life. For the same reason, they're not involved in 'special' activities for handicapped children – though they are in encouraging and supporting adoption. And the future? 'We're as concerned for Sally as we are for the others – neither more nor less.'

Sally Montgomery met her family through the London-based agency Parents for Children; she was in fact the second child for whom they found a home. When, back then in 1976, their very first referrals were three babies and toddlers with Down's syndrome, they thought they'd really been plunged in at the deep end, for in those days the Adoption Resource Exchange had never managed to find a family for a single one and, with 30 on its books, had stopped taking any more on.

But it wasn't long before Parents for Children discovered that finding homes for babies with Down's syndrome could actually be fairly easy. By 1984, while other agencies were finding the same, they were placing teenagers as well. By then, in its first eight years, Parents for Children had found new homes for 89 children – all of them reckoned by the authorities who cared for them to be 'hard to place' because they had different handicaps, or were older, or came as part of a family group.

From the start, as the Montgomerys found out, the agency has insisted that its job is to find parents for particular children, rather than children for parents. 'The children's needs are so varied', it explained when it began, 'that we do not see how we could "approve" people in the abstract as potential parents – it makes so much more sense to approve the placement of one particular child with one particular family . . . One of the reasons these children have so far not been placed is because nobody has had the time to make them the top priority and concentrate solely on them. Only by doing that can we succeed.'

The search for parents who could meet the needs of specific children has meant too that Parents for Children has always taken a pretty imaginative view of what constitutes a 'family'. Its first 89 children have gone to live with 67 families – 16 of them single parents (including one man), 14 of them childless. Several couples had already been turned down by other agencies; several parents had been married before or had medical problems that might, in the eyes of another agency, disqualify them.

Of their children, 14 left their first 'new home'. Nine of them found new families; two moved on again, one to a third family. Others were found a variety of different living arrangements in children's or 'special' small homes – and one teenager chose to move out independently. It's a fair bet that if they hadn't met Parents for Children, their childhood would have passed without the degree of individual attention that this has meant.

How did the agency grow?

By the mid-70s, heartening tales were beginning to filter through from adoption agencies in the United States about success in placing even children whose handicaps were severe and multiple with adoptive parents. At the same time, individual instances of equally successful family-finding by local authorities here were showing that, given the time and commitment, the opportunity could be extended to a whole lot more children then living in different institutional settings, including hospitals.

At the suggestion of Parent to Parent Information on Adoption Services, a working party of the main bodies involved in adoption and child care was set up. From its deliberations and with a three-year grant from the Department of Health and Social Security, Parents for Children was born.

How is the agency organised?

From the start, the team of four social workers (including the director) has worked closely and cooperatively together, helped by first one then two secretaries. Each social worker works with a small number of children and families, including any long-term support they may need.

The children are referred by local authorities in London and the home counties – a geographical restriction born of practical necessity. By 1984, the service had been used by 26 authorities; it is up to them to decide which of the children in their care are 'hard to place' and need what the agency offers. Parents are recruited through regular meetings at the London office, and continuing publicity through any manner of medium as well as the adoption business's own channels.

As the general adoption scene has changed over the years (and the carefully documented and disseminated experience of Parents for Children has had a fair bit to do with that), the agency has found that its own work has changed. These days, it is increasingly rare for it to be asked to find a home for a young child; as others find they can do this themselves, those it works with are more likely to be between 8 and 14 years old, with often severe handicaps or emotional disturbances.

This presents new challenges and the Parents for Children team is constantly trying, through its own discussions and studying and self-assessment, to find new responses. It has worked with a group of older children, for instance, to see whether they really do want to embark on family life; it has worked with other agencies on supported alternatives for living. It has also worked with groups of local authority workers, prospective parents and children – rather than individuals – to see whether it could in this way speed up family-finding for a group of very severely handicapped children.

Funding follows the pattern it has had from the start, with about half the income coming from DHSS grants, topped up by smaller ones, and half coming from the placement fees paid by local authorities. In the first year of the agency's life, it cost £25,022 to place eight children – or £3127 per child. Since then, it has become harder to work out 'per user' costs, because these include not just an element for preparation and placement, but an increasing amount for supporting adoptive families. But in 1981, the average cost to Parents for Children for each family served was reckoned at £6700. In 1984/5, when the budget was an estimated £165,000 and as well as new placements there were over 80 families receiving continuing support, that figure had risen to about £8080.

Key factors

The key elements in getting the service started, according to Phillida Sawbridge, its director from the beginning until mid-1985, were financial backing, publicity to attract families and gaining the trust of social services departments. All these remain important – and so is the support of the committee, the commitment of the staff and the visibility of success. To anyone else thinking of working in this field, she'd say, 'Have courage! It can be done.' But don't, she adds, think that finding families or working with children is the difficult part: 'The really challenging bit is working with all the other professionals, coping with local authorities trying to act as parents, and dealing with the varying options or prejudices of perhaps 20 people involved with one child!'

Another considerable challenge to Parents for Children – as well as one of the key factors in its success – is its work to support families once the adoptions have been made. From the start it had tried to build this in – from the quarterly meetings for the parents, to the annual picnic for the families, to regular six-monthly or yearly visits, to far more intensive visiting and support at times of crisis. But as the number of families has grown and the number of workers hasn't, ensuring the support needed as well as making new placements has become increasingly problematical.

In 1983/4, the agency set itself to study this in more depth with the help of a researcher who interviewed 37 of the most complex adoptions it has made. These were of children with a variety of emotional, physical and mental handicaps, now aged between 5 and 18; most had had very difficult early lives; many had had fewer than six months of any sort of family life at all before their adoption, with broken foster placements and frequent moves far from uncommon, and many years of institutional living in hospitals or children's homes as well.

The parents found their life with these often very emotionally damaged children rewarding; they were keen to emphasise how much they could develop and change. But at the same time the pace of that change could seem agonisingly slow, the emotional handicaps of the children very wearing and the job of being their parent far harder than had ever been imagined.

What was clear was that these parents wanted and needed support, not just from their own networks but sometimes from people who knew their child's background and the intricacies of adoption. And while Parents for Children's work was valued, it didn't go nearly far enough. So the agency was, in 1985, planning to expand this, with the appointment of a full-time person to explore the possibilities for strengthening local resources.

'The children we place are not ordinary children', one of Parents for Children's workers has written, 'and we would not want to find them ordinary families, even if there were such families about. The children we place are special because they have special needs and the families who adopt them are special because they have special needs too. "Special" in the sense of being unusual, not better than good, and the need is to give as well as to take from each other.'[8]

FURTHER INFORMATION: Parents for Children, 222 Camden High Street, London NW1

FOSTERING

When she first came, I used to spend so many hours each night sitting on the top stair by the landing that I thought I'd better join the book club! She was up and down so often. The advert said 'Are you thinking of a new career?' It should have said 'a new way of life'! She's been here for 12 months – it feels like for ever and ever.

But she's lovely with it. I'd fight tooth and nail to keep her. She's brought so much into the house, I think we must have been dead before she arrived – she's brought the house alive. No two days are the same – it puts that little bit of excitement into life. You can't not love her.

When Barnardo's in the north west launched its long-term professional fostering scheme for children with severe mental handicaps in 1979, 'everyone knew' that there were those who would always need hospital care, that in any case no one would choose to parent a child with profound and multiple handicaps, and that even if they did, they simply wouldn't be able to cope.

Exactly six years later, in the spring of 1985, the scheme had found long-term foster parents for 47 children. And 'everyone' might be surprised at their characteristics. Most of them are older – around 10 at the time they went to their new home – and have many years of institutional living in hospital and children's homes behind them. Many of them took to their new families very serious difficulties in relating to other people and indeed themselves; for some, the question had been whether they could be contained in a residential home at all; one child at least has been excluded from school for some months because that environment simply couldn't offer what he then needed.

Other children have very severe and multiple handicaps. Two, for instance, have lived in Barnardo's own 'intensive support unit' after their years in hospital. Another little boy arrived from hospital at his foster-mother's with instructions for tube-feeding and a whole complexity of gloomy diagnoses of which 'failure to thrive' was the simplest. Now, at nearly three, that child is not just eating independently but running around and into everything unless you can catch him first. And for every tale of difficulty and hard work, there are tales too of the gains the children have made – of the way they are learning to use the shops instead of tipping the goods on the floor, of the growing communication, of their many new skills, and above all, of the relationships of trust that have grown between them and their foster families. As one foster mother says, there are days when she wonders whether she can go on. 'But I wouldn't give him back. We love him too much. I feel as if I brought him into the world myself'. And only once, after much heart-searching, has a family decided that they could no longer offer what a particular child now needed.

How did the scheme grow?

In 1975, Alan Kendall, divisional director of Barnardo's in the north west, visited a professional fostering scheme for children with severe handicaps in Michigan, USA and was impressed by its achievements. His division was already committed to the right of such children to live within their own community. During the 1970s, it pioneered the concept of 'mixed' children's homes, where non-handicapped children and those whose handicaps were often very severe lived happily together. Later, in Skelmersdale, it introduced a 'core and cluster' model of ordinary housing for children with severe mental handicaps, in which a small, specialist home supported a series of houses where not more than two children lived together with their staff. Since then, with its 'intensive support unit', the division has been showing that even the children whose handicaps are most grievous of all can live and thrive in ordinary houses and share in ordinary local life. By 1979, the division was ready to take that commitment further for some children, while offering its residential services to others for as long as they needed this support. In its first full year, the professional fostering scheme found homes for six children. The annual total has grown steadily since then, until in 1984/5, 18 new placements were made.

How is the scheme organised?

The professional fostering scheme aims to find families within a 25 mile radius of its office in Liverpool for children with mental and multiple handicaps. The children come mostly from Barnardo's own residential homes, but also from other voluntary and local authority provision.

The team of six social workers, with its project leader John Hardy, has established a clear annual cycle of activity. This starts in July, when the team works with residential staff to identify the children who might benefit from living in a family. In October, there is a 'saturation' publicity drive within that 25-mile radius to find the families – using press and radio features, advertising and sometimes television as well.

This annual campaign has consistently been successful in catching people's attention – one year, there were no fewer than 500 responses. Very early on, the team realised that trying to meet all inquirers would take too much energy altogether for the return. So people who respond to the initial invitation to phone for more details get a pack of written material that includes accounts of the work by existing foster parents. If they are then still interested, they can come to an open meeting scheduled for a month after the advertisements have appeared, and meet staff and foster parents.

By now, they will know that this is a *professional* scheme; they will be expected, if they join it, to implement a developmental programme for the child, keep a diary of progress, contribute to six-monthly reviews and liaise with other professional workers as necessary. By December, people will have decided if this is for them, and the process of interviewing and selection takes until March.

The new foster parents then go to a mandatory series of five training sessions, which cover the philosophy of normalisation and integration on which the scheme is built, elements of understanding about mental handicap and child development, and what natural parents of children with severe handicaps may experience. The foster parents meet their child at the end of May and final placements are made in July and August, to allow everyone time to settle down before the new school year begins.

'I wouldn't', one foster mother recalls of this lengthy process, 'go through that again! The social worker asks you such personal things. I was dreading their decision. I thought they'd made a mistake when they said "Yes". But you see the point of it all later – you've got to really want to, or you wouldn't put up with it.'

The foster parents are paid the ordinary boarding out fee (from £22 to £39 a week in 1984/5) and on top of this a professional fee which in that year was £60 a week.

The local authorities in whose care the children officially are – and seven of them currently use the scheme – pay Barnardo's a weekly maintenance fee which goes some way to covering not just the fees to foster parents but the costs of the Barnardo's social workers and psychologists who are involved with them. In 1983/4, when 27 children were fostered, the weekly local authority payment for each was £104.51; the total cost of the scheme was some £206,000, so Barnardo's itself contributed about £61,000. In 1984/5, local authorities paid £115.63 a week for each of 47 children; the total cost of the scheme was £274,668 and Barnardo's contribution was £52,810. In that year, the cost of keeping a child in a Barnardo's residential home in the north west was, on average, abut £290 a week.

Key factors The first two key factors in getting the scheme started and keeping it going are commitment and belief. The belief is in the children's capacity to respond and the foster-parents' willingness to help them do it – and both of these have been shown to be well-founded. The commitment comes from the agency, and its professional team which includes, crucially, the residential workers in the homes from which the children come. It has not always been easy for them to see their children move to a new, and untried, way of life. But as one says: 'having seen the benefits for the children we are more determined than ever to play our part in working with the fostering team in preparing children for family life'.

The commitment comes too, of course, from the foster parents. 'You value something more', says John Hardy, 'if it comes hard – and we do give them a hard time!' For some, commitment may be strengthened by being part of a highly professional team; one foster mother, for instance, emphasises how good it is to be able to measure the skills gained over the months and to plan for growth. For some, too, the money may be helpful – though as another foster mother who knows very well the costs of constantly replacing clothes and furniture says succinctly: 'If you're looking for profit, forget it; it's a very, very expensive business.' But if anything unites the foster parents – who have their own young families, or now adult families, or no other children at all – it is, John Hardy reckons, that they like children and don't mind hard work.

The support they get in this is another crucial factor in the scheme's success. When a child is placed, his or her Barnardo's social worker becomes the worker with the family. In the early days, there will be weekly visits, reducing to never fewer than one a month. A 'key' residential worker who knows the child is also available to the family, and families know that they can phone either of these, or the project leader, at any time of the day or night – whether to rejoice, to vent frustration or simply to chat. One of Barnardo's psychologists completes the team gathered round each child – which is responsible, with the foster parent, for drawing up and agreeing the individual developmental plans. Support also comes through the monthly training sessions for the foster parents.

And finally, the availability of 21 days of short-term care is built into the scheme. This may be pretty essential if, to take just one dramatic instance, the foster-child wakes each day at 4 am, and manages to keep that pattern going for three whole years. The short-term care may be offered by the residential home from which the child has come – which delights the staff there – or by foster parents, or in residential staff's own home. Its essence is flexibility to meet individual family needs.

The scheme is not yet perfect! There is more work to be done, John Hardy reckons, in enabling the delicate relationships between natural and foster parents to be more often as helpful to the child as the best already are. There is work to be done too to assure the future of the children once they pass beyond the age of 21, when fostering arrangements for children with special needs come to an official end.

In one case at least, a young woman has continued to live with her foster family, with the help of a DHSS board and lodging allowance, her own pension and a payment from the local authority for the professional help she receives. Barnardo's hopes that this will become a pattern, so that all the young adults who have grown up in the scheme can continue to live as it believes they should –

in the close relationships and ordinary communities to which they have a right.

FURTHER INFORMATION: John Hardy, Barnardo's, 7 Lineside Close, Liverpool L25 2UD

CREATING A FUTURE

When it came to Stephen, the sceptics said that 'community care' would be impossible. Here was a young man, they said, who was 'bound to fail'. His aggressive behaviour towards his surroundings and other people simply couldn't be tolerated outside the protective environment of a hospital ward.

That was in 1982, when Stephen was preparing to move into an ordinary small house in Seaton Delaval in Northumberland, together with two others who had been living on a children's ward at Northgate hospital. Life certainly hasn't been without its incidents since, for either him or those with whom he shares a home. He still finds it painful to share staff attention with others. He can still be very moody and bad-tempered. He has been working at home with a tutor because his school excluded him – not surprisingly, perhaps, when he was placed with – and irritated by – children much younger and less energetic than he is.

But Stephen's bedroom these days isn't the bare place with a mattress on the floor that it has been at times in the past. He doesn't feel the need to bash the place up any longer. Since his temporal lobe epilepsy has been diagnosed – which it wasn't during his years in hospital – and his drugs adjusted and even reduced in dosage, he has become much calmer. He helps about the house without hazard to its normal scattering of bric a brac. He loves going to the beach with staff, some three miles away, and rollerskating. He has spent a happy seaside holiday. He is learning to use public transport. He is doing, in fact, a fair number of things that are normal enough for an 18 year old. Even on the most sober and unemotional of psychologists' measurements, he has made enormous gains.

Stephen is one of 12 young people who have moved out of the Northumberland children's ward at Northgate hospital since 1981, into ordinary small houses run by Northumberland health authority. Each and every one of them was deemed to need permanent 'health care' because of the severity of their handicaps. The ward they lived in has now been closed altogether.

The plan to offer them as ordinary a life as possible in their own community was carefully drawn up by the then principal nursing officer, psychologist, social worker and others at Northgate itself. From the start, the intent was that the young people should not be shifted in a group to a 'hostel'. Instead, they should move to ordinary houses in their own home areas. None of the young people who lived on the ward would be excluded because of the severity of their handicap; if that's where they lived, then they would be eligible to move to a new home. The first five children moved into a terraced house in Ashington in 1981;

the house in Seaton Delaval opened the following year and the four remaining young people moved to a housing estate in Berwick the year after that.

'I thought I knew the kids well', says one of the care-staff who used to work with them in Northgate, 'but now I'm learning new things about them all the time.' She's not the only one who is learning.

The staff in the Ashington house, which has been going the longest, have a quick way of summing up the progress over the years: these days, it only takes two care-staff, not three, to help the young people get up and ready for school – and on some days they can even start tidying the house before the children leave.

Now that Melanie is 12, she can understand far more of what's going on – she gets really excited, for instance, when her food is being cut up for her. She has learned to eat far more easily and to sit in a chair, too – which means that she can share mealtimes with the others round the table, instead of being slowly and separately fed. Medina, at 17, is becoming quite a young lady, now that she can wash her own hair and is learning to cook; the local special school, which was dubious, has finally agreed that she can go there. Jane, who celebrated her 18th birthday with a huge party and a vote in the local elections, now takes herself to college in Newcastle; she's still involved with the local guides, which she joined when she moved to the house. James has a teenager's passion for disco-dancing and can get about a fair amount on his own now, without holding onto someone's arm. Keith, who can't see and has profound and multiple mental and physical disabilities, is making progress too. He can discriminate enough now to register sadness when his brother leaves after a visit as well as delight when something pleases him; he moves his lips when someone suggests a drink. Like all the young people, he goes out and about in his local community; his favourite outing is to the Indian take-away to pick up a curry.

When the young people first moved into the house, Melanie's mother for one had her doubts. It had never entered her head, she said, that her daughter, who had been in the hospital since she was 18 months old, would ever leave it. Who would cook and wash and clean and prepare the meals – and still have time for the children?

It didn't take her long to change her mind. She would have been bitter, she said not long after the move, if her daughter had been left behind. The nicest thing about the house? The smell of baking that met you when you went in. Very different, after all, from the smell of disinfectant on that hospital ward.

How are the houses organised?

All three households remain under the health authority's administration. It rents the houses from local housing authorities; the young people are still officially designated as 'patients' of Northgate. Their staff – eight to each house, including

the home leader – are reckoned as part of the hospital's nursing complement and under the department of community nursing, whose head spends two-thirds of her time with the houses' affairs. The home leaders are, in fact, trained and experienced nurses who have worked at Northgate and are paid as 'charge nurses'. The others are paid as 'nursing assistants' and are mostly recruited from the immediate neighbourhoods, without any nursing experience at all.

There is nothing in the houses to suggest the hospital connection. There are none of the traditional hierarchies: the house leaders take their turn on duty with everyone else and there is no separate domestic staff. There's no separate night staff either: people just take their turn to sleep in their house. (People still ask: 'But what if one of the young people were epileptic?' The standard answer in Ashington is: 'Well, four of them are!' No problem.) The cooking, catering, cleaning and creation of an idiosyncratic home are the job of the care-staff and the young people between them; they have a budget which also covers minor household repairs.

The major financial costs are carried directly by the health authority. It has spent some £42,500 on decorating, furnishing and adapting the three houses. In 1985, it cost some £12,000 a year for each young person living in them. That compares with £10,500 a year for someone to live in Northgate.

If the young people were officially discharged from Northgate's care, these figures would look rather different. Then, they would be able to pay their own way – from their entitlement to disability and other benefits.

Key factors

'They get to be your extended family – and so it can be mentally wearing sometimes, because it's like leaving your own family when you go off duty. It's a way of life, not a job!'

The care-staff's affection for and individual attention to each of the young people is unmissable. You can hear it in the discussions about whether the pain and fright of having her ears pierced is worth it to Medina in terms of the ego-boost; in the thought that went into diverting James's attention from playing with machines that suffered, to playing with fruit machines that even yielded dividends. The fact that half the original Ashington staff are still there five years later – and the rest, who mostly left to marry, still good friends – says something about the level of job satisfaction. As one of them says, comparing this way of working with different experiences of hospitals: 'It's just so much more relaxed. You can give so much more. With 30 trying to get your attention in hospital, you couldn't do anything. You felt useless. Here, it's just completely different.'

Staff training has come mostly in the three-week orientation courses before the three houses opened (which, as is recognised, leaves a questionmark over further training and even the induction of new staff). These courses emphasised not just normal child development and the 'special' developmental and historical factors around mental handicap, but the biographies and needs of the individual young people, together with their family and other social context.[9]

These two concerns have been maintained ever since. Individual programme plans have from the start been drawn up for each young person in cooperation with specialist staff at Northgate, and reviewed every six months; each has a 'key worker' or even two. From the start, too, the Northgate social workers have put a lot of energy into strengthening and sometimes re-creating links between each young person and their family – with sometimes dramatic effect as relationships have been rewardingly reforged.

The fact that the young people have moved back to their own home area has been very important in this. Local housing has also paid handsome dividends in terms of staffing and community contacts. The recruitment of local people doesn't just make it easier to run a flexible rota that can cope more easily with sickness or crises; it builds in a ready-made community of welcome and support for the young people through the care-staff's own networks. There is only one drawback to this determination that the young people should return to their own locality and it is a fairly major one: the third house, in Berwick, is a clear hour's drive and more from Northgate, and it suffers from the isolation.

Its staff, however, like those in the other two houses, have the support of regular meetings. The head of the community nursing service meets all three home leaders every month and the staff of each household every six weeks. Every six weeks, too, the 'community support team' – made up of the Northgate psychologist, senior social worker, and the head of community nursing – meet with all the staff. Immediate support, if needed, comes from the community nursing service.

What about Clive?

The fourth member of the Berwick household is Clive. Since shortly after the house opened, however, he has been living back in Northgate.

It was not easy for him, the team says now, to adjust to life in a small household. He had always been someone who needed to run about a lot. One day, when he ran out of the house, he knocked over a small child. He was readmitted to Northgate.

The other people in the house have missed him. Once the fuss had died down, the relatives of the child – who was not seriously hurt – expressed their support for the idea of Clive's return. The neighbours agreed. His mother is very sad. Twice a week she makes the lengthy journey from Berwick to visit him.

Clive has not reacted well to being back in hospital. It has become harder, not easier, to find the way to enable him to return to his home. The team which works with the young people sees no intrinsic reason why he should not. The difficulty is to find enough resources to give him the support he needs.

What about the future?

One thing has been clear from the start: the three houses are home for the young people who live in them until either they themselves decide to move on or it becomes evident that something more suited to their needs can be offered.

But the team is clear too that the houses are only a starting point. No one, they say, should be fixed on the idea that the story ends with them. Already there are questions about whether all the young people are best suited. Stephen, for instance, has made it very clear that he prefers the company of staff alone to life shared with even two other young people. Would it be possible for him to take a

flat with staff and community service volunteers? Jane and Susan (who lives in the household in Berwick) are both very capable young women. Will they soon, like many others of their age, want to move into a place of their own? And who knows what the others may want and need as they continue to grow and change?

Michael is now 21. When he was 18 months old, the doctor told his mother that an institutional life was the only one possible for him. He went to live in Northgate when he was 7.

These days, he goes on one day a week to a local college and on to a pub lunch. The staff have introduced him to that because he doesn't at all enjoy the adult training centre. And when Michael is roused, he can be quite bad-tempered.

But now the occasions for temper are a whole lot fewer than they were. Michael's physical disabilities are still severe; he's still doubly incontinent. But now he has a wheelchair which enables him to get to the nearby shops, the social club of which he's a member and the pub. He also has a wheelchair which fits into the boot of the car, so he can easily go further afield. The lift shaft installed in his home that goes straight from his bedroom to the living room makes it easier for him to get about inside as well.

Michael used to scream a lot – not being able to communicate through speech – when anyone so much as touched his hands. Now his care-staff can hold his hands to help him learn the art of eating, and he's pleased to be eating ordinary food instead of the 'soft' diet he used to be fed. His epilepsy is much better controlled now than it used to be; major fits are rare. He still gets very tense, but less than he did; his visits to the local sports centre where he uses the pool help in that. He has twice been on holiday to Spain – where the staff so took to him that they installed a ramp for him.

'He's got his own life now', says Lorraine, his mother. 'Before he was like a rosebud – and now he has blossomed. When he was in Northgate, I used to feel I had to have him home every three weeks. Now, if I don't see him for a fortnight, I just don't worry. And when I do want to see him, I sometimes feel I'm going to have to make an appointment, just to be sure he'll be in!

'It used to be a problem for me, looking back – to see what could and should have been. I wasn't planning for him when he was in hospital – but I am now.

'His life has so much shape now. He's so aware of everything. You drive him past his pub and he turns his head. He's savouring the different things in life – the things we take for granted.'

FURTHER INFORMATION: Neil Robinson, Unit Administrator, Northgate Hospital, Morpeth,
Northumberland NE61 3BP

6 HOUSING

We want to live like other people in flats and houses... We want to live by ourselves or with friends who treat us as equals. We want to have a choice of who we live with.

For the first time in my life, I can open my own front door with my own key and know that this is home.

We see the provisions of a home-life as the central core around which many other services – training, education, rehabilitation, medical treatment – must be woven. 'Residence' is not simply something tacked on to specialised professional work. It is the very core of that work and must be recognised as a service in itself.

An Ordinary Life, King's Fund Centre, 1980

Of all the debates over the future shape of services to people with mental handicaps during the past 15 years, the one that has created most controversy is the one over where they live. This isn't perhaps surprising. The movement for reform grew out of revulsion at the living conditions in the hospitals that most people away from their own families were forced to call 'home'; the professional and often personal stake of a generation of carers has been challenged. And it is when 'community care' begins to sound like 'a house in *my* street' that the challenge is brought home to us all.

It is a very fundamental one. It is easier, perhaps, to tolerate the thought of mass unemployment than it is to live comfortably with the idea of large scale homelessness. To live without a home is to live without roots, for our home is the place of our security and the base of our exploration, the place where we can express and develop our own personality, where we can find our privacy and our closest relationships. It is our stake in our own community, the place from which we meet the neighbours and tradespeople around us and to which we return for comfort when the world outside seems confusing and hostile. Or if it isn't, then we wish it was. To be homeless in this society, not to have a place to call our own, is a very fearful way to be.

People with mental handicaps are beginning to claim that place of their own. Those who have left the hospitals very seldom want to return. 'My business is to get away, right away altogether so I can forget about all my lifetime in the past. You can't help thinking about it, because you're still in the same county as the hospital where you was. You must get right away, so you could forget it. I'm looking forward to the future, that's what my ambition is, to get things organised if I can.' And again: 'Well, I do go back to see people, I go on my old ward. But I make sure I don't spend too long there.'[1]

For some people, the local authority hostel which was the main residential investment of the 1970s after the endless upgrading of the hospitals, offers a good way of life. 'I couldn't live outside because matron said I'm better off here. You see, I've got no worries. We get all our meals cooked and we are well looked after.' For others, life in these large places – 24 beds being the standard model – has brought enormous difficulties. 'You can go into a hostel and be hospitalised if you're in a hostel – no freedom, like a little animal or dog. If they say you got to go to bed, you've got to go, you can't go on your own, you're not independent or anything. You come in and they take it all away.' People who have lived in hostels very often speak of just how hard it is to live with rules you have not made, with the large group of unchosen others which makes those rules almost an inevitability, with the lack of privacy that economics and size of group make unavoidable.

People are saying that they want to move on – to marry, to set up their own place, to move in with a small group of friends. Increasingly, that's possible for them through local authority and housing initiatives and the experience can be a good one. 'I can come and go when I like, have a cup of tea when I want it, and I don't have anyone saying have this, have that, and I don't have to ask.' But sometimes the price of independence can be very high: 'I live in a one-room flat . . . there's no one to talk to . . . I get lonely. I want to live some place where I can have people to talk to.' When people do find that, they can enjoy it: 'for the company, soon go crazy on your own. We have a good laugh together, in the evenings we make a pot of tea and sit here together.'

Sometimes, too, the world outside can seem a welcoming one; people are finding that they can become 'good neighbours' and establish bonds of mutual support with those who live nearby. But, as one survey of 35 people living 'independently' found, isolation and loneliness remain a major problem for these pioneers.[2] And that problem can get worse, not better, when people are living in a larger establishment whose difference from 'ordinary' patterns of life is clear. 'We have no complaints', says a neighbour of a local authority hostel. 'I think it is well organised; they aren't rowdy. We really don't know it's there. There's no

invasion of our privacy.' To live 'in the community' is not automatically to be part of it.[3]

The challenge is clear. People who have mental handicaps are going to need a whole variety of living opportunities in their communities and a whole variety of support. They are not, either, going always to settle 'once for all'; a 'residential service' will need to cater for individuals and be flexible to changing aspirations and circumstances. And if that is true for those who can most easily express those for themselves, then it is as true for those to whom we often lack the skills to listen: there can, in justice, be no exclusion of the people whose handicaps are most severe.

And as we build the service, we need to find ways of honouring individual choice and offering people a sense of security. It's not easy when planning for a 'group' to remember that people's lives are not reducible to dots on a map to be moved as convenient. Yet the effects on individuals of being shifted about because it makes sense in service terms – or increasingly because it fits with a policy of exploiting the private market – can't perhaps be overestimated. 'I wish I could feel certain that I'd seen the last of those places' says one ex-hospital resident – and reminds us of how much harder it may be to establish your own life when there has been little in its patterns to encourage you to believe they are your own.

Or again: 'I was put into a hospital when my mother died. Nobody told me why I was being put in a hospital or asked me if I wanted to go. I didn't like it there. You were not given choices and there were too many rules; they also treated you like a child. I don't like changes, so when I was taken from the hospital and put into a hostel I was very unhappy and my behaviour became worse, so I was put back into hospital again. No one bothered to ask me why I behaved like that and I felt a failure again.

'When I was moved to Roehill House, the staff there did not say I would go back to hospital if I was naughty, and I was to begin with, because no one had asked me if I wanted to move. The staff are all my friends at Roehill House and we have three meetings a week to talk about our problems with them . . . I am very happy there and they are all my friends.'[4] So can the search for a place that feels like home be made harder by the providers' best intentions.

Finally, a 'residential service' is not one that stops with the provision of housing and support to live there. It is one that helps those who use it to reach out from that base to enjoy the opportunities their community has on offer, to make links of friendship and to explore. That, after all, is what living in the community is all about.

By the mid 1980s, there were some exciting pointers along the way to this. *An Ordinary Life* offers a clarity of principle and practice from which to start. It outlines the components of a comprehensive residential service which uses ordinary housing and varies the support according to individual need. It establishes a fundamental principle: that services should go to people and not people to services, that support should be flexible to meeting individual need where people are rather than expecting them to change their place of residence according to 'types' of building on offer.[5]

How is such a service to be managed? One working model, adapted from the Eastern Nebraska Community Office of Retardation's pioneering work towards a comprehensive residential service, has become known as 'core and cluster'.

This provides a 'core' which is the centre of support to a whole variety of 'clustered' living arrangements around it, from single-person to shared households, from couples to families with a mentally handicapped person living at home.

One of the joys of this model is that when properly used, it limits the number of disrupting moves that people are obliged to make as their needs for support change; it is the staff who do the adapting, managed from the 'core' which may, for instance, be in the headquarters of the local mental handicap team or part of an information centre. One of the dangers of the model is that 'core' has been taken to be synonymous with 'community unit', hostel or hospital. This may be convenient for existing patterns of service, but it is not what it is about.[6]

What it may be about is shown by the Wells Road service, which is working towards a local residential service that is truly comprehensive in meeting the variety of needs that the people on its patch may have. NIMROD offers another approach to providing a comprehensive local residential service. Both of them underline what 'comprehensive' means: it means that everyone who has a mental handicap in the area must be supported in their living arrangements, including those now at home in their families, who in the past have often been denied any support, and in future may need a whole lot more.[7]

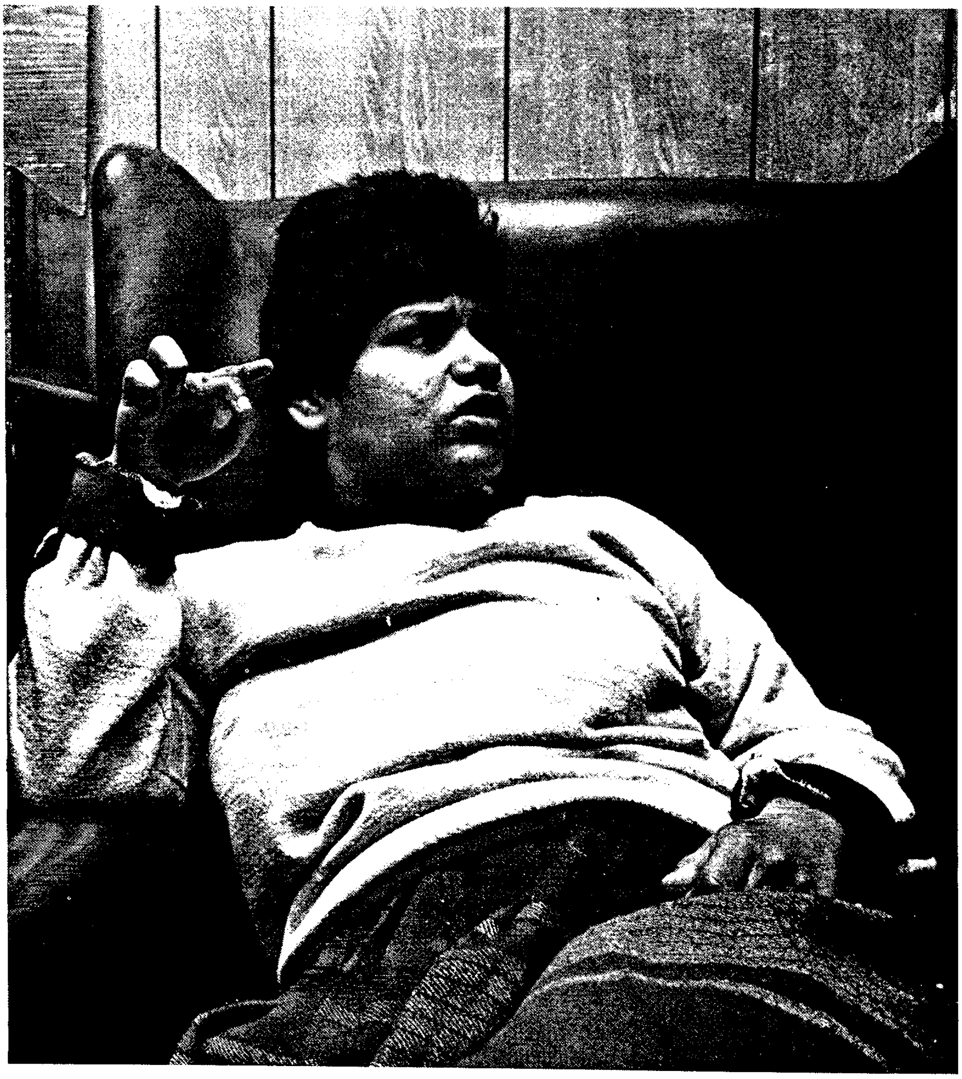
The other services described in this section look in more detail at what some of the components of a comprehensive residential service may be. Hasland is a 'homefinding' service – and offers the support to make that much more than simply the provision of a list of vacant housing. The Cambridge network of group homes shows how people can share their lives with people who will help them explore their community. The very individual supports offered to Maria and George show that living like other people in the community is not a privilege to be earned, but a right to be enjoyed, irrespective of ability and need.

There is still a way to go before we can say that we have found the outlines of a residential service which can be adapted to every local circumstance. But what these examples show is that people who have very considerable needs as well a those who are more able *can* find individual support in a place of their own and the sort of housing that any of us would recognise as perfectly ordinary. And that is the very basis of an ordinary community life.

MEETING INDIVIDUAL NEEDS: MARIA

Maria Kingswell is the tenant of a council maisonnette in the London Borough of Greenwich. Her life now is fuller than it has ever been during her 23 years, between her programme at the local training centre each weekday and the housekeeping and leisure activities she shares with friends. She enjoys shopping – and most particularly eating the food afterwards. She goes to the pub and visits the houses of friends, sometimes at the other end of the country; she has shared in a whole variety of activities, from going to the local fair to visiting Greenham Common to joining in marches and rallies. She has been on holiday in Germany and Spain and, as the photos in her album show, that suited her very well indeed.

Seven years ago, when Maria first came to live in the special children's home



run by Greenwich social services department, she was used to spending her days strapped into a wheelchair. She had lived in institutions for all the 16 years of her life – first a hospital, then a voluntary children's home. Very little was known about her developmental history; although she was officially in the borough's care, the information in her file was extremely scanty. Certainly, though, she was a very handicapped young woman: incontinent, without speech, apparently without much comprehension and relating to other people hardly at all.

Maria came to the urgent attention of the social services department when the voluntary home in which she'd been living said they couldn't keep her any longer. Three years later, Greenwich's own special children's home also felt it was time she moved on. Neither of the borough's hostels for adults with mental handicaps felt they could take her in. By now it was apparent that she could walk perfectly well but one of her problems was said to be 'hyperactivity'; her behaviour was showing other difficult features and she still seemed to have little understanding or communication. She needed, the hostels felt, a degree of one to one attention that they were simply unable to give her.

Still less, the social services department felt, was she likely to get that attention on the mental handicap hospital ward which seemed the only possible alternative. So, 'out of desperation, really', her social worker, June Bulgin, and the department's then principal care officer, Catherine Briscoe, started to work on meeting Maria's particular needs in a way which was certainly unique then and, as far as they know, remains so for someone with so considerable a degree of handicap.

When they started discussing the possibility that Maria should have her own flat, supported by volunteers, there were plenty of sceptics. For a start, residential workers felt, 'you must have experienced people'. There were murmurings about exploitation of volunteers and the inherent unsuitability of male carers sharing a house with a young woman. There were queries from the DHSS about the insecure position of the carers if Maria held the tenancy. But in May 1982, Maria moved into her maisonnette and there she has lived ever since. She has learned to use the lavatory and is beginning to make a few Maketon signs. And as someone who knows her well puts it: 'Now you can tell when she's happy and when she's sad – even though it's still hard to know why. And she's much happier than she was, no doubt of that.'

How is Maria supported?

Marie lives with one community service volunteer and one 'carer' in her three bedroomed maisonnette; another two CSVs also work with her. Two members of the social services department's 'bank staff' offer emergency backup. The CSVs each work a 40-hour week, and the 'carer' a nominal twelve. Between them, they ensure that Maria has the constant companionship and help she needs.

The team has the backing of June Bulgin, Maria's own social worker, the head of the special care unit she goes to at the local training centre and her key worker there. They meet with the carer and the CSVs once a week to iron out any problems and discuss Maria's programme. In addition, June Bulgin is at the other end of the phone in case of emergency.

Maria's financial support comes from her benefit entitlement: supplementary benefit, the higher level of attendance allowance and mobility allowance between them amounted to some £75 a week in 1985. This covers household expenses. The 'carer' lives rent-free in lieu of payment. The community service volunteers work under their organisation's usual arrangements: they get 'pocket money' of some £55 a month, a food allowance and free accommodation (in a separate flat rented for them from a housing association). Their costs are paid by the social services department from its budget for 'out of borough placements'.

Key factors

The key factors in making Maria's household work for her and those who share it with her are, says June Bulgin, commitment and enthusiasm: from the social services department itself, and from the CSVs and the carers.

If she were to start the scheme over again, she would pay even greater attention to the sustaining of both. The time and energy demanded of the social services department, she says, should be budgeted for clearly from the very start, not, as here, simply tacked onto an already full work-load. And help from relief staff should be built in, rather than added only when the need for them had already been proved. In retrospect, too, a larger house would have made life easier; there is little room for manoeuvre in Maria's maisonnette, and living-out arrangements for two of the CSVs are not ideal.

Supporting them in their work is clearly crucial to the scheme's success. The volunteers who live and work with Maria are not chosen by the social services department but – as is its usual practice – by CSV itself. Sometimes this can bring difficulties; more than one volunteer has said that if they'd known more about what the job entailed, they would not have come. Support can be needed at different levels, as June Bulgin points out: few young people know much about running a fairly large household; there can also be the sort of emotional upsets that aren't uncommon among a group of young people thrown together not just in a strange city but in circumstances which are very demanding.

The CSVs get a short 'introduction' to Maria and the work, through time spent at the training centre and in discussion. For one at least, this has proved inadequate: 'you're just thrown in at the deep end'. In spite of a rota that ensures a long weekend off each month as well as a day and two evenings free in a week, working with Maria can be physically and emotionally draining. There can be differences of view between staff at the centre and the CSVs about how her needs can best be met.

The volunteers generally stay – as again is CSV's usual practice – for between four and six months. This raises questions of continuity in Maria's life, and it was to try to build this in that the scheme began with two longer-term 'carers' and two CSVs. This worked well for the first 18 months, when the 'carers' were a graduate trying to make his way on the stage and a German occupational therapist who wanted to gain experience and perfect his English at the same time. Since then, it has proved harder to find people to take on the job of 'carer', in spite of June Bulgin's trawling of university careers offices; the change to three CSVs and one 'carer' is a necessary response.

Yet with all the ups and downs and hiccups, the arrangments bring their satisfactions. For Maria, they bring a breadth of experience and a participation in the lifestyle of her contemporaries that very many people whose handicaps are less severe than hers are still far from being offered. They bring, too, a quality of emotional support which, as one close observer says, simply can't be faulted.

For the volunteers, there's not just the satisfaction of living in a way that's different and challenging, but emotional reward as well. The fact that the relief staff include former CSVs who know Maria well says something about the attachments that can form; other volunteers keep in touch with her as well. 'It's good when you see Maria happy and manage to stimulate her', as one CSV says; 'When you see her in a good mood, it makes all the foul tempers worthwhile.' For the carer, there's the interest of working to create a community life and the constant stimulus of working with Maria herself: 'I really enjoy it, comparing Maria with us and trying to hypothesise why she acts as she does.'

About the worth of the scheme, June Bulgin has no doubts at all. 'It's so exciting to do something different. Maria's alternatives were awful; there's the reward of knowing that she's benefiting. It stops you getting tunnel vision about what can work for people with mental handicaps. If it works for her, then it could work for many others.'

And so it has already proved for another young woman, who was living at home with her elderly parents. When her mother died, two CSVs were recruited to help support her and her father. When he too died, the CSVs continued to help her and so enabled her to continue to live in her own family home. Like Maria, she now has her own council tenancy – and the help she needs to enjoy it.

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MEETING INDIVIDUAL NEEDS: GEORGE

George Munnerley was the sort that people call a character, the sort of whom they say there aren't many left. A local policeman once flagged down the car he was travelling in, not because of some heinous traffic offence, but just because he hadn't seen him for a while and wanted to say hello. For nearly 50 years, George lived in the Old Swan area of Liverpool with his family, pushing his woodcart and scrounging his chances in the streets. For his last nine years, he lived in the l'Arche community for people with mental handicaps and their assistants, just a couple of miles up the road. When he died, in March 1985, there were about 200 people at his funeral – from his first community and his second, friends and neighbours all.

George was not a happy man when he moved to l'Arche, some 18 months after the death of his father. He didn't think much of the community meals, preferring what he could scavenge for himself. He didn't reckon much to regular standards of hygiene, either. He didn't, above all, find many signs at all that life could bring its enjoyments. His anxious torrents of negativity could drive you fairly to distraction; he really did once keep them flowing for 72 solid hours without a break.

But gradually George began to see that life needn't be so grim. He grew a beard and started to look good. The nightly battle of the bath, the struggle to get those clothes to the laundry, became things he could play with and enjoy. In more and more of the photos in his house's albums – taken at home, on outings, on holiday – he's laughing. In the l'Arche workshop up the road, he had his firm place as local historian, the one who could tell the much younger people what things used to be like in the area. He even started to talk of l'Arche as 'home'.

In the spring of 1984, George's friends there started to worry that he was getting unduly tired. The doctors ran all the possible tests; they found nothing seriously wrong and prescribed iron pills for anaemia. Seven months later, he suddenly became very unwell. This time, the doctors found he had stomach cancer and an operation was decided on.

Those three weeks in hospital were hardest time of all for George. He was terrified of being ill; he was above all terrified that he wasn't coming home. He turned down the meals and refused the baths and the kind hospital staff didn't find him easy to understand.

L'Arche pitched in. Both the handicapped people and the assistants visited constantly. Assistants washed him and gave him his bath – with the ward TV turned up to drown the roars of indignation. Two of them went with him right down to the operating theatre. What they couldn't and wouldn't do was to answer his questions by assuring him that he hadn't got cancer and that he was sure to get better. From the start, they were clear that George – and everyone else in the community – should know the truth, through as many discussions as it took to get the message across. What they could and did do was to reassure him that he would be coming home.

There was never any doubt about that. It was discovered that the cancer had spread to George's liver. It was only, the community were told, a matter of time – though how long that would be, what with George amazing everyone by trying to struggle out of bed to go to the lavatory only two days after the operation, no one could say for sure. L'Arche's GP, who had been a friend of the community for years, was convinced that they could cope – which brought its own injection of confidence to a group of young assistants, few of whom had any nursing experience at all and all of whom were already pretty fully stretched by the demands of community life with severely handicapped people.

When George came home, he found his bed had been put, as a temporary measure, in the living room. He liked the arrangement. And so there he stayed, while the life of the household went on around him. He would get up late and potter about – until one day, when no one was in the room with him, he just put on his cap and coat and set off up the road to the workshops. In the evenings, when George decided he was tired, the others just continued their ordinary pursuits around his bed. At every point, they took their cues from him; it was he who set the pace of his life.

Just over a month after he came home, George had his 58th birthday. The party, his house decided, would be the one he'd always wanted. It was open house all day, with Laurel and Hardy films and cream cakes and visits from friends within l'Arche and outside it, including his brother and sister-in-law, who were now in close touch and came often. In the evening, there was a feast of truly Rabelasian dimensions, with all the crudest and rudest and most scatalogical presents and sketches that could be dreamed up. George was propped up in his bed in the midst of it and laughed maybe more than he'd ever done before – while even people who don't normally find that sort of thing funny at all laughed with him.

A few weeks later, George decided that life was now too energetic for him in the living room, and he moved to a room of his own. He began to get weaker. The GP came daily, and latterly a district nurse. The doses of morphine got stronger; George slept a lot more.

But there isn't much distance between a sickroom and the rest of life in an ordinary, active, terraced household. In those days, it seems, George's room became the place where everyone wanted to be. Friends from l'Arche's other two houses, as well as his own and workshop, came to chat or simply – for many of them don't communicate through speech – to be with him. So did neighbours and the pastor and members of the Baptist church to which he'd belonged for something like 30 years. His brother and sister-in-law continued to come and stay for several nights a week, and became very much part of the household.

Before his illness, George was terrified of sickness and death. He had a particular loathing of the local undertaker: 'He's not going to get my money', he'd say. But as his own death got nearer, he gradually began to accept it. 'Who will have my job?', he'd ask; 'Who will put the milk-bottles out?' – giving up his own responsibilities one by one.

But he still didn't want, not at all, to go 'down the hole in a box'. When he was told that *he* wouldn't, even though his body would, he began to think, and then muttered about 'glass'. Eventually, they realised what he wanted and brought him a mirror. He looked at his face in it for long minutes, then said: 'It's alright now'. He even, towards the end, stopped rubbishing any mention of God or heaven – as he had always done – and got to saying that was alright too.

George died early in the morning of 29 March 1985. In keeping with the local Roman Catholic culture to which many of l'Arche's members belong, the office for the dead was said around his body and every member of the community was there. In keeping with that culture, too, there was an all-night vigil round his coffin in the house the night before his funeral. It was preceded by a slap-up fry-up – sausages, black pudding, beans, the lot – because that is what George himself would have reckoned a good one, and a procession in which everyone put a flower on his body. The funeral was at his own Baptist church, and very many of those 200 people came back to l'Arche for the baked meats.

'It wasn't too hard really', says Danny Hammell, one of the assistants who was closest to George throughout his illness, 'because you knew where he was – here with all of us'. Three months on, the assistants can reflect that in a sense they and George were lucky: the strain of organising the rotas of constant presence was fairly short-lived and never did caring for George become the physically distressing task it might have been.

But three months on, the community can recognise that it hasn't been too easy, either. For some of the handicapped people, the reality of death and its rituals, so closely shared, has brought angry echoes of other deaths which they were not helped to mourn; several of them were not even allowed to go to their own parents' funerals and so until George died had little idea of what death meant. For some, three months is hardly time enough to heal the wound left by the loss of a good friend. 'Oh, my wonderful prince, he's gone!' cried Irene Woods when she heard the news. 'He was my best friend, I think about him, I miss him', she says now. 'It just drained me completely, drained me for weeks, to see him dead', say Kenny Iddon. 'Only today I was saying how he'd have enjoyed the stunt-car show. We had some good laughs when he was around. I loved him, myself.'

But George's illness and death has brought some other things too. For some of the handicapped people, there is now, perhaps, the chance to complete the unfinished grieving for their parents. For some of them, and for assistants too, there has been the chance – ever since that first decision for honesty was made – to explore their own fears of cancer and of death. For some, there has been the chance to reflect on how much they do believe in an afterlife. For many, there has been the chance to realise that death need not, after all, be terrible.

There have been some gifts to l'Arche as a community as well. Some of these have to do with its place in its neighbourhood, with the realisation of how many people there are around to offer support and friendship. Some have to do with the community's internal life, and the very real bonding among its members that George's illness and death has created. 'We were an adolescent community before', says Sue Jones, its director. 'Now, we're adult. You can't go through something like that without growing up.'

L'Arche in Liverpool is part of the same national – and international – network of houses and work opportunities as The Wedge (see pages 99–102). 'We believe', says the international charter, 'that each person, whether handicapped or not, has a unique and mysterious value. The handicapped person is a complete human being and as such has the right to life, to care, to education and to work. We also believe that a person who is wounded in his capacity for autonomy and in his mind is capable of great love, which the spirit of God can call forth, and we believe that God loves him in a special way because of his very poverty.'

In 1985, the Liverpool community was 'home' for 14 people with mental handicaps and 18 assistants, including director, house leaders and work leader. Some of these are salaried, some are volunteers who work for board, lodging and pocket money. Twelve other assistants, full-time and part-time, are funded by the MSC to work in the craft shop and the small market garden.

The three houses are rented from a local social services agency and a housing association. The workshop belongs to l'Arche, bought and converted at a cost of some £27,000 through the Inner City Partnership. Capital expenditure on the houses has come from l'Arche central funds and some local grants.

In 1985, it cost between £120 and £85 a week for a handicapped person to live in one of the Liverpool houses. These costs are met by Liverpool social services department for one house, and DHSS benefits to which residents are entitled in the other two. The workshop assistants are funded by the Manpower Services Commission, for a year each.

FURTHER INFORMATION ABOUT L'ARCHE IN LIVERPOOL: Sue Jones, Director, l'Arche, 127 Prescot Road, Newsham Park, Liverpool 6

ABOUT L'ARCHE IN THE UK: Tim Hollis, l'Arche Secretariat (UK), 14 London Road, Beccles, Suffolk

A HOMEFINDING SERVICE

Betty and Frank Glover have a flat on the edge of Chesterfield in Derbyshire, in a housing association development for people who have retired. They are clearly very pleased indeed with it and with each other. A flock of cards wishing them well on their wedding anniversary is carefully tended and proudly shown to the visitor – together with Frank's new shirt and shoes, bought on a recent special outing.

The Glovers fit cheerfully into their small community. There are greetings and chat as they show you about its communal rooms; they seem to know everyone and the warden, it's said, wishes he had more tenants like them. Back in their own flat, a neighbour knocks on the door: if Betty is going to the corner shop, could she buy some sugar for her? Betty is pleased to. She knows a lot about elderly people, having worked for some time in a nursing home. Now she's taking early retirement, to keep company with Frank, who has already retired from his job at the training centre. 'He's 15 years older than me, you see. Mustn't wear him out!' They laugh delightedly. Frank and Betty have known each other for over a decade. When they met, she lived in a hospital and he in a group home. When she moved out into another group home, they started seeing each other regularly. But marriage? For many people, it hardly seemed a serious proposition. They were, after all, mentally handicapped.

But when the two of them made it clear that marriage was what they wanted, the Hasland Community Living Assessment and Training Unit didn't see why not. It invited them to stay for a short period, to work out what they might need to learn if they were to set up home together, to help them learn it, and to assess any further support that might be useful. Then one of the Hasland workers started house-hunting on their behalf. A flat in the development they now live in seemed appropriate, as Frank was then nearing retirement. It had the added advantage of being in a part of town they both knew well. When they visited, they liked it. So they moved in, married and now live with the support of that same Hasland worker and a visitor from a voluntary organisation.

Hasland Community Living Assessment and Training Unit started in 1981, with the aim of providing people with mental handicaps an opportunity to lead an ordinary life in their community, through accommodation and support. It helps them to find a place to live and, through highly individualised attention, to acquire the skills they'll need to make the most of it. And it works always from what its customers themselves say they want.

Since it started, Hasland has worked with 62 people, for 28 of whom it has found alternative accommodation and/or support. Although it sees itself as offering essentially short-term, transitional arrangements, it is still in active touch with 18 of them.

How is Hasland organised?

Hasland was set up by Derbyshire social services, jointly funded by the department and the health authority. It serves the north east of the county; there are other, similar units to serve the rest. Because it is trying to provide a local service, Hasland works chiefly with people who live in and around Chesterfield – in whose population of some 96,000 people, a detailed survey has shown, there are just over 300 adults defined as having severe mental handicaps. This includes over 40 living in local authority hostels; it does not include the population of a large mental handicap hospital.

Hasland's base is a pair of converted adjoining houses that used to belong to the police. This is the office base, as well as the main centre for day-training programmes and a residential resource. There are six workers: a coordinator, who is a member of the social services area management team, a social work assistant and a senior instructor (all full-time); and a social worker, occupational therapist and clerk (all part-time).

In addition, Hasland has an annual budget to cover the cost of keeping its base going, paying bus fares and lunch allowances for its customers, training expenses and teaching materials; in 1985/6 this amounted to £10,000. The unit can also apply for capital amounts to meet the needs of the individuals it serves: to alter, decorate and furnish their houses, for instance, and to cover the rent for a short period if this is necessary to secure a property. In 1984/5, the unit spent some £15,000 on behalf of 11 people.

How does Hasland work?

There is no quick answer to that, because the essence of the unit's work is that it responds to individuals. Its basic resource is its pair of houses and its staff, who have to a large extend shed their professional labels to work with the customers as needed, and who ensure close cooperation through their weekly half-day meetings.

Their clients can be referred by any of the other agencies involved with them – or indeed, by themselves. So far, nearly all the people with whom Hasland has worked were, when it met them, living either in a local authority hostel or at home with their parents. Hasland knows from the survey material that overall the second group includes no fewer than 32 people who can be said to be at 'high risk', because their parents or other carers are elderly and will soon be needing support themselves; as in most other parts of the country, there simply isn't enough alternative accommodation to meet these increasingly urgent needs.

So Hasland works partly as a home-finding agency, cooperating with voluntary organisations (United Response in particular) and housing associations, as well as with the local housing department and its own social services. But if finding housing is one part of the job, the other is enabling people to live well in it.

Each of Hasland's clients has an individual programme plan, drawn up in consultation with them and anyone else involved in their lives whom they agree to have along. Usually the plan runs for an initial six months, and according to its aims, individuals may come to Hasland for a day a week to perfect a variety of domestic and social skills; work with a member of Hasland's staff in their ATC, hostel or parental home; or come to live in at Hasland for a short period of time. Sometimes there are group activities as well – like the small 'communications group' that met weekly in the house of the Hasland social worker, to discuss themes like trust and to learn to put across their own views more confidently.

The variety of help that Hasland provides leads to a variety of individual solutions. People have been helped to move into small group homes from a local authority hostel; others have moved into a similar setting or a council flat from their parental home. Sometimes, Hasland's intervention has enabled someone to remain in their current home when they were in danger of losing it – like the man who seemed to be finding independent living in a council flat too difficult until he came into Hasland's residential unit to strengthen his coping skills.

Once people have moved into their new home, the continuing support they get will again vary. Here, Hasland works with United Response, which has its own team of visiting staff as well as full-time residential carers. It now also draws on the social services department's own peripatetic support team, which is designed to ensure that support can vary according to what people need rather than being pitched at a notional 'average' level; it now employs 11 support workers in 10 different living situations. Together with the Hasland staff's own possible interventions, these resources make it possible to offer a flexible, personal service. As the Hasland staff point out, this flexibility is crucial: there is nothing to say, after all, that people's needs and wishes won't change over time and so demand a different response.

Key factors

The key factor in getting Hasland started, according to its coordinator, was the social services department's interest in normalisation and individual programme planning. It was very keen to show how people with mental handicaps could live an ordinary life within their community.

This commitment remains strong and has been important in keeping Hasland able to work as it wants to, with emphasis on one-to-one relationships between particular clients and individual members of staff. The access to ordinary housing and to a variety of networks of support has been important too.

The final element in the Hasland service is its relationship with others who are working with its clients. With parents, for instance, it maintains a close link, with contact once a week. But there are some questions, too, particularly about the links between Hasland and other social services provision. How far should it see itself as a resource to the workers in ATCs and hostels, with whom its clients spend far more of their time than with Hasland? How far, alternatively, should it insist that its prime purpose is to work directly with individual clients?

On one thing, however, the Hasland staff are clear. What their work is about is providing a bridge from those specialist services to the mainstream of life. 'How can we help people with mental handicaps to integrate if we don't integrate ourselves?'

FURTHER INFORMATION: Unit Coordinator, Hasland Community Living Assessment and Training Unit, 55/57 Mansfield Road, Hasland, Chesterfield, Derbyshire

LIVING TOGETHER

You learn to do things, I've changed in lots of ways since I've been here. I do cooking and cleaning. I do more writing. I write poetry.

I don't argue as much as I used to.

All your notions about 'the mentally handicapped' go out of the window. There aren't 'normal' people and 'mentally handicapped people'. There's just a continuum of people.

I liked it as soon as I walked in. It puts things in perspective. I'd never regret it.

We all look after each other. It doesn't make any difference that we're students and they're not.

Shirley, Jim, Roger, Julian and Kate live together in a converted pub in Cambridge, not very far from the city centre.* They share the household chores and all take a hand with the marketing and cooking. Sometimes they do things together and sometimes they don't, because they all have their own work and interests.

Jim works part-time in a milk-bottle factory and a lot of the rest of his energy goes on working with his video equipment. Since Shirley packed in her job at a local training centre, she has been able to put more time into her writing and

*This was in 1984. The students move on and Shirley now has her own bedsitter. But the essentials of the scheme remain the same; another handicapped person will move in.

perfecting her cooking, as well as into her passion for the disco. The others pursue their own interests, and work for their university degrees.

The house they share is part of the city division of Cambridgeshire social services department's network of group homes for people with mental handicaps, which has been growing since 1977. Its aim since the start has been to train, supervise and support people who are able to live with only visiting staff help in their movement towards independent living. By 1984, there were 17 people in this network, living either in small groups or, in three cases, in their own flats. Shirley and Jim, now in their late 20s, have been sharing a house with students since 1978.

How is the service organised?

The person in charge of this network of supported housing is the 'group homes officer' for Cambridge social services. Working with him are a team of part-time 'care assistants', who between them put in some 70 hours a week of visiting support to the different households; they also work with Cambridge's hostels for people with mental handicaps, as a move towards providing a more integrated residential service. The network also includes 'befrienders', recruited through the university's Students Community Action organisation, the local volunteer bureau and Community Service Volunteers.

Different students have shared that converted pub with Shirley and Jim ever since one of the senior officers in social services got to hear of a similar arrangement in Cardiff. The students, too, are found through Student Community Action. Some may come, like Julian, who is studying social and political science, because this way of life gives a practical expression to their own interests and concerns. Others, like Kate, may come because they simply need a place to live – and, like her, find the experience rewarding. They stay for an academic year which often spills over into the long vacation; when this isn't possible, the care assistants who work with Jim and Shirley provide the summer support themselves.

Between them, the students and the care assistants offer both the opportunity of a shared lifestyle and the chance to learn new and specific domestic, budgeting and other skills. Just what that can mean is worked out at the staff meetings with the students that happen once a week at the start of the year and about once a fortnight later. These meetings also help to maintain the quality of the service, together with regular consultation with Jim and Shirley (as with all the other people living in the different group homes), and the quarterly meetings of all the statutory and voluntary organisations involved in the lives of the city's people with mental handicaps.

The group homes and supported tenancies are in places rented from the local housing department and housing associations. The converted pub belongs to the social services department, and the students and handicapped people pay £15 or so a week rent. The support services are not separately costed by the social services department. But its care assistants (who used to be salaried 'care officers') are currently paid the home help rate of £1.30 an hour.

Key factors There are, says Elena Moses (the group home officer until 1984), two key factors in maintaining the service. The first is the determination of the staff – especially in face of the demoralisation caused by what's seen as the downgrading of the care assistants' status. The second, specific to the shared household, is continuing support to the students.

Living together isn't always easy – any more than it would be, as Kate points out, in any shared household when you come home tired from work and find the place in chaos and the meal not ready. The cooking may not always be brilliant: Jim and the others still remember with something like awe his original mixture of fish fingers, bread and butter and scrambled eggs, all churned up together into a sort of orange mess. It isn't always that a household lives without friction, either: Shirley was glad, she says, to be able to talk to the social worker when she just didn't get on with one of the students in a past year. Originally, there was a third person with a mental handicap sharing the house, but when they moved on to their own place, it was reckoned that a smaller group worked better. This can, though, bring its own tensions; as Elena Moses says, a smaller household enables relationships to deepen more easily, but it also brings any emotional difficulties to the surface.

The students emphasise the importance of the social services department's help. This can be at a purely practical level, in the putting up of shelves and the mending of a broken lavatory for instance. They value the care assistants' work: their help in helping to organise cooking and cleaning routines can 'take a bit of pressure off us'. More deeply, their role in helping Shirley and Jim to learn specific skills leaves the students more free to concentrate on their particular job of living as equals, rather than doubling as 'teachers'. As one of them puts it: 'Competence is not the issue. It is creating an environment of respect that is the real question.'

And that is what the household is about – for all its members. There have from time to time been predictions from college staff that the work of the students would be bound to suffer from this lifestyle, and sometimes the students have had to work hard to convince them of their choice. But as Kate points out, it's actually easier to organise your work between your own household and the libraries than it is to make a space among the distractions of living in college. The exam results over the years bear her out: all the students who have lived this way have done very well.

What Elena Moses would love, she says, is the opportunity to include more shared households like this one in Cambridge's group home network. It's not finding the housing that's the problem, nor yet the seeking out of tenants. It is simply that the social services department is not able to put any more money into building the team of supporting care assistants who would make further expansion a possibility. 'But', she says, 'that is what the people with mental handicaps want – the chance to share normal life with other people.'

FURTHER INFORMATION: Group Homes Officer, Social Services Department, County Hall, Hobson Street, Cambridge CB1 1NL

HOUSING IN CONTEXT: TOWARDS A COMPREHENSIVE LOCAL SERVICE (1)

Before Mary moved into her new home with three other women, she had lived at home with her parents for all of her 27 years. She went to the adult training centre and had regular short-term care in a mental handicap hospital. In her free time, she enjoyed making woolly pom-poms, watching TV and helping about the house, as well as going out for a drive with her father and visiting her married sister.

After three months in her new home – just half a mile down the road from her parents' – Mary still sees her family regularly, and still enjoys her other activities. She has developed new interests, too. She likes to listen to music and go to dances and a local social club; she goes to the pub and local places of interest with a member of staff or a volunteer. She spends less time, these days, in her own room and more in chatting with other people.

When Sarah moved to her own home, she was 78 and had been living in a mental handicap hospital for 31 years. During all that time, she had never had a room of her own, but lived in 'units' with 30 beds or more in dormitories and a communal living area. Her only recorded contact with family or friends was her weekly visit from her brother, who died before she left the hospital. Her only outings were by bus with other members of the 'unit' and group holidays with them once a year.

When Sarah moved into her own home, it was discovered that she had a cousin living in a hostel in another part of the city. That cousin has now moved to live with her, and the two of them have regular visits from Sarah's sister-in-law. Sarah goes shopping with staff members, and out for a drive once a week. She has taken up drawing in addition to the crocheting that was her hobby in hospital and has acquired a budgie she's teaching to talk. She was offered the chance of a holiday, but she decided not to go. She's quite interested, though, in

the idea of visiting Blackpool again, which she remembers from a time when she was much younger.[8]

Mary and Sarah both live in an ordinary house in the west part of Cardiff, run by NIMROD as part of its pioneering effort to build a comprehensive local service for everyone with a mental handicap who lives in, or originates from that part of the city. It reckons that that means some 150 children and adults in its 10 square mile patch, 84 of them living there with their parents and 66 living in hospitals or other residential places outside its limits but with family links to it. By 1985, all of them had been offered, and most were getting, at least some of its services.

These include support to individuals living with their families and the offer of short-term care. They include opportunities to learn the skills which make for greater independence, worked out for each individual through their own programme plan, which is overseen by their own 'key worker' and reviewed every six months. And they include a residential service which uses ordinary housing. In mid-1985, that provided a home for 31 people, who lived in a total of five staffed houses, two group houses (one of them shared with a student) and three flats, scattered through the NIMROD area.

These houses are home for people who have spent often very many years in hospital or other institutional accommodation, as well as a smaller number who have moved from their family home. No one whose place of origin is this part of Cardiff is reckoned to be 'too handicapped' to receive the services that NIMROD can provide (though some may be counted 'too able'); some of the people living in the houses have a degree of handicap more severe than that of people who remain in hospital. NIMROD's aim is 'to promote the health, safety and human rights of each handicapped person, and to ensure that each is helped to live and behave as normally as possible' – and that it tries to do for everyone eligible to receive what it is there to offer.

How did NIMROD begin?

NIMROD stands for New Ideas for the Care of Mentally Retarded People in Ordinary Dwellings. It had its first beginnings in a report from the South Glamorgan Community Health Council, which had seized on the new ideas beginning to filter in from the United States during the mid-1970s about how opportunities for community living could be offered even to people whose handicaps were severe. The CHC started to campaign for these to be put into action in its area. In 1977, the Welsh Office set up a working party whose members included representatives of the South Glamorgan health authority and county council, Cardiff city council and the Mental Handicap in Wales Applied Research Unit. Out of their deliberations came the plans for NIMROD, designed as a pilot project which would be exhaustively researched during its first seven years, at the end of which it would be handed over to the county council. The service started in 1979, under the joint responsibility of the health authority, the county council and the Welsh Office in collaboration with the city council.

How is NIMROD organised?

The NIMROD area is divided into four 'communities', each with a population of some 15,000. Each has its own community care manager, who is responsible for the NIMROD services on the patch. These include the staffed houses, each with its own senior care worker and team of part-time and full-time care workers – about 50 in all. They also include the group house, if the 'community' has one. These houses are supported by the community care workers, two to each 'community', who also support families with handicapped people at home and are responsible for the training those people may need.

The community care managers and domiciliary teams are based at the NIMROD centre, two large converted houses which are completely separate from any of NIMROD's own housing. This resource centre runs an advice and information service as well as a 24-hour telephone line for customers who want help outside office hours. It has meeting rooms and a library; it is the base for the 45 or so volunteers. The service's two part-time and one full-time social workers are based here, and so are the senior clinical psychologist and part-time speech therapist (shared with the health authority). The whole operation is coordinated by Shirley Mathieson, who has been with NIMROD from its start and has the status of an assistant director of social services. She is accountable to a steering group representing the county council, health authority and Welsh Office, together with the city council and applied research unit. This group reports to the management committee whose members represent the three authorities.

In 1984/5, NIMROD's whole operation cost about £663,360; in 1985/6 the sum was budgeted at £870,070. These costs are met by the Welsh Office, the health authority and the county council under a formula which tapers off the first's commitment over seven years until the third is wholly responsible. In 1979/80, the Welsh Office met 90 per cent of the costs; in 1986/7, it should be meeting none of them. The health authority is contributing 10 per cent of the costs throughout the pilot phase. Most of the houses have been purchased by the county council and rented by NIMROD.

Financial comparisons between NIMROD and other services aren't easy to make, especially because NIMROD is not yet fully operational. But in 1983/4, the cost of its services 'per client week' to people living in their family home was reckoned at some £29. The people who live in NIMROD housing contribute to the costs through their social security entitlement. In the same year, these worked out 'per client week' at some £266 in a staffed house and £71 in a group house. This compared with £240 per 'resident week' in Ely hospital, which serves Cardiff, and £85 in a 35-place South Glamorgan county council hostel.[9]

Key factors One key element in getting NIMROD started, according to Shirley Mathieson, was having a clear description of the model of service. Another was a distinctive identity made possible by a small, committed staff group working from their own clearly identifiable base, separate from either social services or the health authority. A third was the support of a steering and management group who were themselves committed to making NIMROD happen.

Key elements in maintaining a service of high standard include the formal monitoring by the applied research unit, regular staff meetings and consultation with service users. They include the careful selection and induction training of staff, as well as their on-going education.[10] They include the commitment to regularly-reviewed written individual plans for each client, drawn up with the client and his or her family, and the practitioners involved. 'This', says Shirley Mathieson, 'enables service staff to work collaboratively and helps to prevent omissions and overlap.'

Finally, 'everyone needs to be working to a clearly-stated philosophy – that means elected members, practitioners, managers, clients and their families. All staff need to be prepared to work very very hard, and to take criticism and other knocks in the knowledge that community care works!'

Key issues It is some of NIMROD's greatest strengths – especially the clarity of its purpose and identity and the determination of its staff to maintain the highest possible quality – which have also given it some of its biggest headaches.

When NIMROD started, its planners knew what they anticipated and what they wanted to provide. They anticipated 150 customers, 60 of whom would need NIMROD housing. This would be neatly divided between the four 'communities' and as neatly phased in during the early years of the service. Staffing levels were set; each house was going to cater for five or six people from the 'community' it served.

Not surprisingly, real life has got in the way of the neatness of the plans. Not everyone who is eligible wants NIMROD's services, for a start; some people – or more often their relatives - have elected to stay put in their existing accommodation rather than move into the community. New children are identified; older clients die; families move about from one 'community' to another or even out of the NIMROD area; others move in. In 1983, there were no fewer than 40 such changes in the NIMROD population.

This means that the strict geographical division of the service can get dented. More seriously, it can mean that plans which looked reasonable at the service's start now sometimes look inadequate. It has been clear for some time that the number of houses originally envisaged won't be nearly enough to cater for all the people who will eventually need somewhere to live. Already, it is clear that the staffing levels built into the plan can put very heavy strain on care assistants. The allocating of people to houses within their 'community' of origin can constrain efforts to build households by compatibility and create a balance of abilities and needs within each. For some people, it's clear, a group of five or six is too large. The one resident who has returned to hospital, to have his medication adjusted, has remained there permanently, at his relatives' request. It's becoming more and more apparent that if the needs of all potential customers are to be met, NIMROD needs a range of housing possibilities which are more flexible than the simple 'either–or' of staffed house or group home which is built into the plan.

It has made some progress towards this, ironically because the staffed house for the fourth community proved so hard to find. In mid-1985, and quite seriously behind schedule, it opened instead two flats in a terraced house for one and two people, and a third flat for two more, all rented from housing associations. The Welsh Office has responded to requests for extra care worker hours, too, and for an additional staffed, rather than group, house. But as economic constraints get tighter in Wales as elsewhere, this sort of flexibility is not easy to wrest from a pre-budgeted plan.

The clear and separate identity of NIMROD – and its rather privileged position in the eyes of other service-providers – has brought its difficulties too. Its social workers and psychologists are meticulous in trying to ensure that the six-monthly reviews of the individual plans for each client are done on time, and achieve a high degree of success in this. But there are relatively few of them to be 'key workers' to so many. A greater involvement of other workers – from the social services department, for instance – could help. But though relationships are gradually building, NIMROD remains fairly isolated from other community services.

Those services are not always adequate either to meet the needs that NIMROD has defined. It was built into the plan from the start that NIMROD would not provide day services; these would come instead from existing day centres. In fact, each person living in a NIMROD house and some living at home as well have one 'training day' a week on which they work with NIMROD staff on their individual goals. That means more work for NIMROD staff. Other appropriate day services, however, remain in short supply

Finally, NIMROD has discovered that the more you do, the more you want to do. It wants an accommodation officer, for instance, to develop alternative supported housing. It wants a volunteer organiser. It needs to work on the short-term care which it should be providing with local families and as yet has barely started to develop. There is no money for extra posts.

So NIMROD raises issues about how far ahead plans can be made and in what detail, and about the compatibility of forward thinking for a group and flexibility to the newly-discovered and changing needs of individuals. It raises issues about how a 'special' service can work with existing ones and spread its expertise to create a larger overall resource.

But what NIMROD shows too is that it is entirely possible to build a community service for people with mental handicaps which is truly comprehensive in its refusal to reject any of the people it is designed to serve. It shows how much those people gain by being part of such a service. And, as its feedback from families, both formal and informal, shows, they wouldn't be without it.

FURTHER INFORMATION:

NIMROD, The White Houses, 40/42 Cowbridge Road East, Canton, Cardiff CF1 9DU

The Mental Handicap in Wales Applied Research Unit has a wealth of research information on aspects of NIMROD's development and service, including a series of 'annual reports'. Available from the unit at: 44–46 Cowbridge Road East, Canton, Cardiff CF1 9DU

HOUSING IN CONTEXT: TOWARDS A COMPREHENSIVE LOCAL SERVICE (2)

At first, I didn't see that the service would be any good for Susie. It was talking about people living in houses right on the main road! – that just didn't seem possible for my daughter. I'm a very sceptical sort of a person, too, and the social worker we had before wasn't much good. It was hard to say how you really felt. But now I can see the possibility of Susie having her own home, logically if not emotionally. Just to know the service is there is a relief, because otherwise the only alternative would have been a hospital – and I'm dead against that. And the meetings we have are so positive compared with others, which always emphasised the things Susie *couldn't* do and just left me low and exhausted. The two most important things about the service for me are that I can now look at things from Susie's point of view and that I know the long-term future is not going to be such a problem as I imagined. After beating our heads against the wall for so many years, we began to think that only *we* could sort things out. Now we realise that things *can* be done by other people.

Susie Jones is 20 years old now, and she can get about much more easily than she used to; she can even climb stairs if she has some help. She's having her eyes checked and some physiotherapy; she's learning to put her energy into play instead of just shaking her hands about. These days she gets the incontinence supplies she needs without the hassle that used to take up so much of her parents' energy. There's the prospect that she'll be found her own volunteer who will expand her interests and offer her parents a break as well. As her mother says, a lot of these things could have been possible in the past: it was just that it seemed so very hard to get them together.

They are coming together for Susie and her parents through their community support worker and the Wells Road Service in the south part of Bristol, where they live. This started in 1983 with the aim of offering comprehensive community support for adults with mental handicaps who live in a clearly defined area of the city. There are, it reckons, some 70 people eligible for its help within its population of 3,500, and another 40 who come from its area but now live in hospitals and hostels outside it. Its aim is to serve them all, because it believes that everyone with a mental handicap, no matter how severe, has the same human value as anyone else and so the same rights. These include the right to live in their own community and to be helped to enjoy what it offers, through the greatest possible individual development and independence.

Wells Road tries to respond in two ways. The first is by helping individuals to find a network of community support. This may include ensuring that existing services work better for them. It may include setting up new services where none exist and then persuading mainstream agencies to take them over – like the living skills programme which is now run by a college of further education and has developed as a 'taster' class to introduce students to the ordinary adult education system. It may mean helping people to explore local leisure opportunities and linking them with a volunteer who will help them enjoy these. By 1985, two years after it started, Wells Road was helping some 50 people in these sorts of ways.

The second component of its service is 'home-making'. Many of the people it is now supporting in their family homes, it knows, will need to move as their parents get older; there are also those from the area but living outside it who need the chance to return. The service envisages the development of a whole range of housing, in which its support can vary from 24-hour staff presence to just an occasional visit. It opened its first two staffed houses, each for three people, half of them from their family homes and half from different institutions, in early 1983 and helped two people move into a council house one year later. By 1986, 16 people will be supported in homes of their own.

Like NIMROD, the Wells Road Service uses regularly reviewed individual programme plans, drawn up in cooperation with each person, their family and other people closely involved in their lives, as the basis of what it offers. Like NIMROD, too, its development is being researched and evaluated – this time by a team at the Department of Mental Health at Bristol University, with funds from the Joseph Rowntree Memorial Trust and the regional health authority. Like NIMROD, it is concerned that the service should focus on those with the greatest needs. So no adult would be rejected by the service because they were 'too handicapped' or because their behaviour was 'too difficult'. Some people, though, are in a sense 'too able' and may be better served elsewhere.

But unlike NIMROD, Wells Road has not started as a 'special' and separately-funded service. It is part of Bristol and Weston Health Authority's long-term plan to improve the lives of people with severe mental handicaps in its area. And unlike NIMROD, Wells Road is not growing according to a predetermined plan. It is developing, it hopes, to be as flexible as possible to individual and changing needs.

This means, as one of its workers says, that the more you do, the more you find to do. 'But we wrote into all the job descriptions that people would have to be flexible and adaptable – and it's exciting!'

How did Wells Road begin?

After research at the University of Bristol's department of mental health detailed the shortage of services in south Bristol, a project team was set up which included a psychiatrist, health administrator, principal social worker, parent, director of nursing services and research worker. The health authority's original thinking was much influenced by the notion of a 24 place 'community unit' which would act as a 'core' around which a 'cluster' of housing and other services might develop; a 50 room mansion well outside the south Bristol catchment area, which the health authority already owned, was proposed as the residential and administrative 'core'.

But at this time too, the King's Fund working party was producing its important document *An Ordinary Life*. The plans for Wells Road took up its recommendations, and the mansion was rejected as completely unsuitable.

Once the outlines of the service were set, every person known to be eligible for what it might offer was personally approached to see whether they and their families might be interested. Other contacts were made through the social services department, GPs, health visitors, schools and training centres and community mental handicap nurses. As the service began to get established, more referrals have come through word of mouth. Initial fears that its workers might be swamped with demand turned out to be unfounded. In the early days, it was rather a question of them persuading the families of people whose handicaps were very severe, who had learned over the years to keep their expectations of services low, that the service *did* have something to offer them.

How is the service organised?

Wells Road takes its name from the street in which its first two staffed houses are sited. The base for the service is quite separate from these, in a nearby Portakabin in the grounds of a health clinic – a very different arrangement from the base in the 50 room mansion that was originally proposed.

The coordinator of the service, Daphne Vaughan, is responsible to the health authority's unit administrator for mental handicap. The network of support services is developed and maintained by three community support workers (one of them part-time) who work in close liaison with social workers, community nurses and other key agencies. The CSWs act as 'key workers' in the individual programme planning for each person who uses the service. The home leader and six residential support workers currently take care of the homemaking component of the service, with the back up of a small pool of relief staff to help cope with times of crisis and staff shortage. The number of residential staff is set to expand dramatically in 1985 to support the planned new houses.

The team is completed by a part-time secretary, and a psychologist who is jointly funded by health and social services; and by the half dozen or so volunteers who work with individuals. A local community programme with churches in the area has brought the appointment of neighbourhood workers who help people with handicaps enjoy their leisure time; some half dozen are now working individually, introducing people to local facilities, playing football, using buses, visiting pubs and other activities.

The service cost £106,000 in its first year; the budget for 1985/6 is £114,000. The health authority put £104,000 into buying, altering and furnishing the first two staffed houses and a further £5,000 into buying the Portakabin. The third house is rented by its occupants from the housing authority; the people who live in the staffed houses also pay rent out of their social security entitlement.

Key factors

The key factors in getting Wells Road started, according to Daphne Vaughan, were the determination of the original team, the openness of the health service administration to what were, after all, untried new ideas, and the additional interest of the research component, which was built in from the start. The key factors in keeping it going are determination, enthusiasm and a real belief in the principles behind the service. The staff have all been to a workshop on the implications of normalisation. Their formal induction period has been strengthened by a commitment to regular inservice training days and the opportunity to attend workshops organised by other agencies.

There's another key factor to the Wells Road service, and that's its flexibility.

When it started, for instance, it was committed to the interpretation of 'core and cluster' that saw the residential 'core' as providing a training base from which people would move on as they acquired the skills to live with less than full-time staff support. Two people did in fact move on from the staffed houses to their own home, helped by a well planned network of support. But that experience showed the staff team just how disruptive to carefully-built neighbourhood links and individual patterns of life this philosophy of 'throughput' could be. So the aim of the Wells Road service has now become clearer: people are to be helped as far as possible to find a home which will be theirs for as long as they choose, with staff support that varies according to their changing needs.

Just how flexible Wells Road will be able to remain as it grows has yet to be tested; it will be learning as it goes along. Already, though, it has shown that people with very severe degrees of handicaps can be helped to find richer lives in their own community. Families have felt welcome, and easy about visiting their relatives' new home. People's horizons have been widened by holidays abroad, bicycle riding, skittle playing – as well as more routine but still new activities like shopping. Wells Road has been able to offer some people the chance to return to their own home area. Its research has already shed some light on how you select, train and support staff, and should, over the years, give information on 'quality of life', social integration, costs and service operation.[11]

Already, too, Wells Road is part of what will grow into a wider network of such schemes throughout the Bristol and Weston health district. It will be one of 10 localities established throughout the district, all working to its model, which over the next seven or eight years will ensure that *all* people with a severe mental handicap are offered a range of housing and support rather than hospital care, and that two mental handicap hospitals will be closed.

The health authority has put aside £1m extra to get this ambitious plan off the ground. It will be working in close cooperation with social services to ensure daytime opportunities for the people who will be returning home. As the health authority's mental handicap unit and Bristol Community Health Council say in their joint statement about the plan: 'What is proposed is something quite new. It is not just a health service scheme: it entails a degree of cooperation between health services, social services, the education services and voluntary organisations to create a "shared service" in a way which has not been seen before. It would be equally astonishing if everything went exactly as planned, and if nothing new was learnt as progress is made. The approach has to be a flexible one, but the final objective is clear – to provide the most normal, dignified and stimulating environment possible for all those who have to live with a mental handicap.'

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ABOUT BRISTOL AND WESTON HEALTH AUTHORITY'S PLAN:	Clive Baish, Unit Administrator, Farleigh Hospital, Flax Bourton, Bristol BS19 3QZ

7 LEISURE

We have the right to go into the community when we please and do the same things as other people do.

We need friends. We should have more places where we can meet people and make friends and do things.

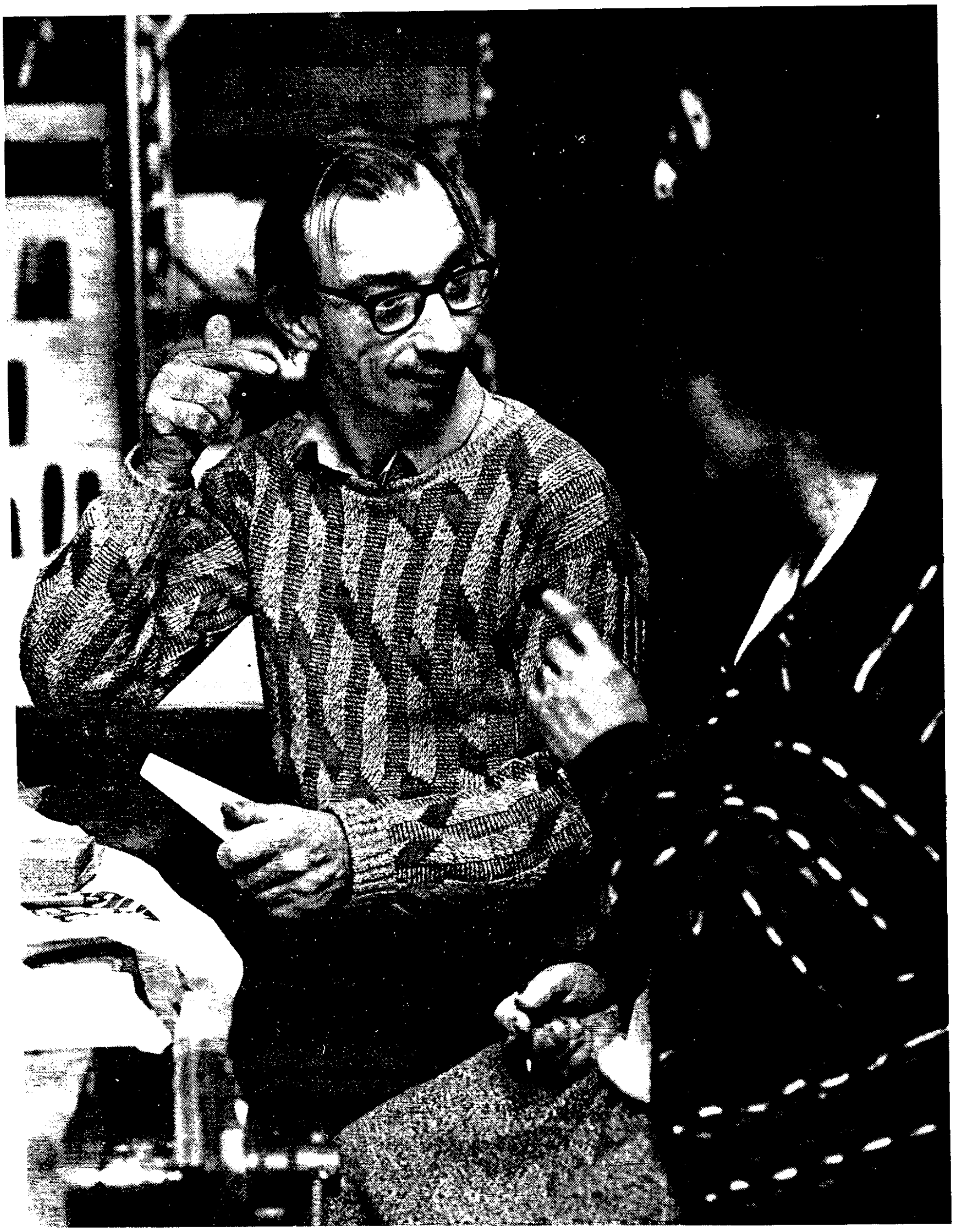
We want to mix with all sorts of people.

We believe that people shouldn't just stay at home and feel sorry for themselves and ask for pity; there's a beautiful world out there and we want to be part of it!

I like aeroplanes and football. I go to London airport on a Saturday by bus and watch all the aircraft landing and taking off... My favourite team is Queen's Park Rangers. When they were promoted, it was the happiest day of my life. I go to two Gateway clubs, I also go to another club which is in a school, we do gym there. I enjoy shopping on my own and use the buses and trains. Sometimes my friend comes with me. The only problem is, he keeps having fits. I'm getting a bit tired of going to hospital with him, but I know what to do when it happens so I can make sure he will be alright.

Those statements come from people with mental handicaps who live as far apart as Australia, the USA and Britain. They at least seem to have a pretty clear idea of what leisure time is about and how they want to use it. They might agree with Professor Joan Bicknell's emphasis on the importance of leisure activities as offering the chance to learn new skills and to make links with the community. They might agree with her that 'above all, leisure pursuits give the chance of fun and enjoyment, friendship, opportunities for risk taking, for making choices, for experiencing the excitement of achieving, and the awareness of imminent danger . . . Leisure for us and for mentally handicapped people is the "black and white" of life and helps to get rid of some of the pale shades of grey that otherwise too easily creep in.'[1]

Yet for many people with mental handicaps, there can be a lot of grey about. There are studies enough to show just how solitary and passive a lot of their



leisure can be. Many of us may choose to sit in front of the television for a large proportion of our free time, but that is rather different, perhaps, from feeling that there is little else we could do. People with mental handicaps who live at home, whether they are adults or adolescents, can find it rare that they have a friend with whom to share their leisure; spending time with the family can mean that activities are the sort that parents choose and not those that most people of their own age enjoy. Even when people have a 'special' friend, like well over half the teenagers interviewed in one study, visits may be rare.[2]

For many people, this pattern is broken only by excursions into the sort of leisure activity that goes to something like the other extreme: the 'organised' club-night or outing, which gathers large numbers of people together for some pre-arranged activities, not because they necessarily share the same interests, or are even in the same age-group, nor yet because they have made any sort of positive choice to meet up, but simply because they are all 'mentally handicapped'. Going to the club may bring a welcome break in the routine. It may also, as one study has pointed out, be an experience which is impersonal, because of the lack of opportunities for individual initiative and one-to-one relationship; segregated from the regular community and its activities; and lacking in opportunities for individual choice.[3]

This pattern of mostly unchosen dull routine punctuated by mostly unchosen large group activities may equally describe the leisure time activity of people who live in hostels or homes. Rules about what time people come in at night may be one constraint on activities; lack of confidence to explore the community may be another. The problem is seen as serious; there is much talk about the dangers of 'isolation' among the people moving into the new patterns of community living. There is also talk about the 'full and varied' social life that large-group living can, by contrast, provide. But perhaps those who see this as an argument for retaining some variant of the mental handicap hospital have not read the study that shows just how unfull and unvaried life on the ward can be for those whose handicaps are very severe.[4] Perhaps they haven't reflected on the difference between 'full' and 'fulfilling', or heard the views of hospital residents who went along to those cinema shows and hospital dances, always with the same people, because the alternative was to do nothing much at all.[5]

Yet it doesn't have to be that way, as one study of 50 people who have left mental handicap hospitals has found. Between them, they enjoyed a whole host of home-based leisure activities, from watching TV and listening to the radio and music, to reading, gardening, knitting, winemaking and beyond. They like going out to clubs, Women's Institute meetings, pubs and cafes and churches; they like the cinema and bingo and walking and window-shopping and trips by coach and train. The opportunities for leisure are there. Why can't more people have the chance to make their choice among them?

There may be an inherent difficulty. If leisure time is time that is 'not obligated' as one expert has it, and leisure activities are those which are 'not obligatory', then for most people 'leisure' is fairly readily defined as something that happens at evenings and weekends. But for 'outsiders' – those without work – the definition isn't at all evident; they in fact cease to have any leisure at all.[6] The point may sound abstruse – until we remember just how hard it is for many people living with long-term unemployment to maintain any sense of 'working' and 'non-working' time and so to organise it creatively.

Very many people with mental handicaps – also outsiders by reason of their long-term unemployment – aren't helped by what is offered them instead of jobs. Their training centre day is punctuated by what other people call 'leisure' activities: sport, discos, unpaid craftwork. Confusion can be confounded by the turning of 'leisure' into therapy. As Alison Wertheimer points out, 'gardening' is what we do in our garden, 'a job' may be what we do in someone else's garden, but 'horticultural therapy' is what we're offered if we have a mental handicap.[7] These confusions of purpose might matter less if they were seen as helping people acquire the skills thát would help them into the mainstream of their community's leisure pursuits. Too often, though, all they seem to do is to remove them further from them.

The justifications for this don't take much seeking: as Alison Wertheimer also points out, they may be built into the very fabric of the segregated leisure provision so often on offer. People with mental handicaps, it's said, won't be as 'good at' ordinary leisure activities as others, so it's unfair to expose them to these; they won't know how to behave properly in regular settings; they might even drive the 'normal' users out by their presence! The list of objections to enabling people with severe mental handicaps to share their leisure with and among people who don't have those handicaps can be multiplied.

The three examples of leisure shared in the community described here show just how empty these justifications are.

In its own determined efforts to move from fairly traditional 'mass' leisure provision to an encouragement of individual choice, Outreach is showing one way in which people with mental handicaps can be encouraged to make the most of ordinary pursuits – with a lot of enjoyment along the way, for both them and those who share these pursuits.

Islington Links underlines the point. It shows how an ordinary community resource – in this case, the wealth of adult education – can be opened up to welcome people who often have severe mental handicaps. It is showing too just

how wide a range of talents and interests they and their friends want to explore. (Are we surprised?)

Path maybe brings a different nuance: for many of its company, 'work' rather than 'leisure' is ideally what it is about. The whole question of the participation of people with disabilities in the arts – whether as audience or performers, amateurs or professionals – has, as the Attenborough committee pointed out in its 1985 report, been shamefully neglected at almost every level where it could be encouraged. Yet, as the committee says: 'The arts are for everyone. To some degree, it is within everyone's capacity to reinterpret their own experience, and to share in the experience of others, by involvement in the world of art . . . Active involvement is best of all, where people, as individuals or in a group, are themselves engaged in creating something. But absorption in the work of other artists, can itself be a creative act. The arts have to be worked at, and thought about, and the results can sometimes be very disturbing. But the rewards and satisfactions should be there for all to secure, in whatever way is best suited to each person's individual interests and circumstances.'[8] We can only hope that everyone, from the Arts Council to the smallest amateur company, takes the committee's far-reaching recommendations on board. Meanwhile, Path is showing the rewards of an active participation in artistic work for people with all sorts of disabilities, in a theatre which is no more marked 'disabled-only' than 'disabled people need not apply'.

Each of these three examples of people at play together across the bounds of labels – Outreach, Links and Path – is making three fairly fundamental points. The first that through their individual choices of how they spend their leisure, people can find an expression of 'who they are' that labels have too often obscured. The second is that in doing this they are finding themselves a 'community' that depends not at all on those labels, not simply on geographical location, but on shared interests and enjoyments. And the third is that it is within such a 'community' that the seeds of friendship are to be found. Which of us, released from the demands of working roles and expectations, does not turn to leisure in the hope of finding precisely that?

REACHING OUT

It used to be just games on a Monday night. We just used to be sitting, playing dominoes. Then people started going out, not just stuck cooped up. That's very good.

We only ever went out to the pub. Now you can do your own things. It's much better.

The social activities offered by Outreach for Jewish Youth in Greater Manchester used to be fairly predictable. Monday night was club night – in a basement room in a synagogue where, as one of its workers recalls, the evening's entertainment was worked out by helpers before the club members arrived, each table neatly laid with its games of snakes and ladders, ludo or dominoes. There were occasional club outings, planned well in advance: so they had to be, for they were large-scale affairs for as many people as could be crammed into the transport.

Outreach's Monday night is very different now. The club members still meet at the synagogue – but this is only their base. Small groups of three or four have worked out their own programme, which runs for a month before they change it; a couple of volunteers and maybe a staff member work with them to encourage them to come up with suggestions that are both possible and adventurous and to underline that they really do have the possibility of choice. So on Monday nights, club members and volunteers go about the city – to sample activities as varied as yoga and rollerskating, as well as simpler pleasures like sharing a meal or drink.

Some people, who aren't as clubbable as that, simply use the Monday night meeting to link up with a friend and go for a meal. And that is fine by Outreach too, for it has put a lot of work into seeing how the principles of normalisation could apply to what it does, and its aim these days is to help people exercise as much freedom of choice as they can as they learn to integrate further into the life of their community. These days, its workers and volunteers see themselves as advocates and friends who will help people acquire the skills to do that rather than entertainers and organisers of leisure.

How did Outreach grow?

The organisation started in 1977, when a group of people involved in some of Manchester's Jewish social agencies felt that more could be done within their community to help young people with special needs. Its first aims were to promote detached community work with handicapped young Jewish people and to offer individual support and counselling to parents and young people, in cooperation with other Jewish agencies.

Outreach's own early surveys among potential users of such a service confirmed that something of the sort was needed. Most of the young people interviewed had no friends, and no one to go out with except their parents and siblings. Many did not know what sort of social activities were available for their own age group; some were either unwilling to go about or socialise on their own, or prevented from doing so by their parents. Parents, for their part, felt that the statutory services had been of little help; they knew little of what might be available for their children (mostly adolescent or into young adulthood); they wanted more support from their own community.

The social club was one response to these needs, together with a parents' group and an effort to recruit volunteers and establish closer contacts with other Jewish organisations in Manchester. When Outreach started, it was serving eight young people who all lived with their families. Now it is in touch with something like 120 young people – not a few of whom aren't Jewish and many of whom live in local authority hostels or other places independent of their families – as well as with parents. It currently works with some 65 people.

What Outreach offers can vary a fair amount when it takes into account the individual preferences and needs among its customers. Apart from the Monday night 'club', there is a weekly group of adolescents who are coming to grips with the complex business of moving from childhood to an adulthood which will be as independent as possible. There is a weekly education programme in a Jewish community centre which includes further education in what it has to offer its community: the special programme here includes sport and crafts as well as the chance for individuals to learn basic literacy and numeracy, social skills and hygiene. Outreach helpers also help members to participate in different further and adult education classes.

There are group holidays as well, and family counselling. There is the chance of individual help in matters as various as dealing with the welfare bureaucracy and statutory agencies, and learning to travel a bus route independently. Outreach also runs its own small residential service in cooperation with a Jewish housing association, and that can bring its own needs for counselling and support. 'It's fantastic, they're very understanding, help us if we can't do things', as one young resident there says. 'It was hard to move away from my mother, though. But she broke down far worse than I did.'

How is Outreach organised?

The often very individual sorts of help and advocacy that Outreach offers its customers are possible because it has a very large 'staff' of some 25 volunteers and seven 'social education' workers. In addition to them, its office serves as a base for 14 residential support workers, a volunteer organiser, four administrative staff and a core worker, and a director.

The running costs when Outreach started were some £9,000 a year. They are now about ten times as great. Funding comes from a whole mixture of sources: urban aid, a DHSS grant for the volunteer work, Outreach's own fund-raising and the Manpower Services Commission, which funds the 'social education' and residential support workers.

The growth of Outreach from a fairly traditional social agency to one whose emphasis is increasingly on advocacy and enabling in the context of normalisation has not been without its anxieties either. As one volunteer puts it: 'Some of the older volunteers wondered what on earth all this talk of normalisation was about – their worry was that they would lose their social club.'

But as he also says, experience has shown that a commitment to normalisation has actually meant an extension of the club's activities and possibilities, and a greater reward for volunteers in helping individuals to learn more about how to go about their communities and make the best use they can of what's on offer. 'We've never looked back. You can see people who would never talk, never do anything, emerging as real people. You go out with a group and you know you're not "needed". It's the best! It's electric!'

FURTHER INFORMATION: Outreach, 393 Bury New Road, Salford M7 9BT

LEARNING TOGETHER

I couldn't go to keep fit on my own. I'd have lost my way, talked to strangers. Mum wouldn't let me out. Now I can go with Susan. I like it. I've learned exercises – helps to keep my weight down!

I've learned to swim. Now I'd like to try other things, sport and things like that. I like to go with someone and I like to go on my own and make friends. I like both.

The handicaps created for people with disabilities by the attitudes and beliefs of non-disabled people are contributory factors to the debate on 'integration'. Integration should not be regarded as an all or nothing affair, but a process of increasing involvement of people with disabilities in the life of the community. The danger of not actively supporting that process may be that nothing happens.

Why volunteer? It's nice to help someone. And I wanted to do pottery, but I was new in the area and I didn't fancy going on my own.

The people who belong to the Islington adult education Links scheme in North London can take advantage of a whole wealth of evening courses, from winemaking to women's woodwork, from creative dance to cooking, from screen printing to sports and beyond. The courses are part of Islington Adult Education Institute's regular menu, and by 1985, some 80 people were going to them through Links.

About half of them are labelled as having learning disabilities* by their attendance at an adult training centre or the fact that they live in a hostel. Not a few of them aren't able to talk much; very many of them would not be able to go to the courses of their choice at all if they didn't have some help in getting there and back. The other half of the Links people are the volunteers who help them do that through individual 'pairings', work alongside them in the courses that they themselves also want to take and as time goes on very often build up friendships with them that go beyond the evenings they share.

Sometimes, some of the Links people may find that the precise course they want isn't on the Islington Institute schedule. So they have asked for, and got, special short courses on women's self-defence and welfare rights, basic home repairs and first aid. And that is part of the Links service, too, for if two of its aims are to enable people with learning disabilities to participate in ordinary adult education classes and to help interaction grow between them and others, then a third is to encourage and enable them to make informed choices of their own. As one of those who chose the first aid course explained: 'I don't want to go running to a staff person for every little thing.'

The Links scheme started in 1981, the first of its kind in the country, as part of a two year research project dreamed up by Maurice Collins (now MENCAP regional chairman) and funded by MENCAP. At the start, there were 10 students and 10 volunteers in Islington, and about the same number in the London borough of Hillingdon. The first setting was then, as it is now, geared to the integration of students into regular adult education courses; the second compared 'special' courses set up alongside mainstream provision.

The evaluation of the scheme[9] showed just how positive an experience of adult education could be for handicapped people, their volunteers and their tutors, and how friendships could build through the contact. No clear differences between the 'separate' and 'mainstream' groups, the researchers found, emerged from interviews. But in practice, the mainstream model offered a far less sheltered environment: 'If the aim of the project is viewed in terms of increasing

*'People with learning disabilities' is Islington's official term for those who are more usually said to have a mental handicap. It was adopted partly at least at the instigation of people in the borough who are on the receiving end of the label.

the awareness of the other students and providing the opportunity for the handicapped students to participate in the same environment as other students, mainstream classes are probably more appropriate than special classes.' Mainstreaming also, of course, as the researchers pointed out, offers a broader range of subjects and saves the costs of new provisions, though demanding more coordinator time.

At the end of the research period, both boroughs took on the provision themselves. Now the Islington scheme is part of the regular adult education scene, with outreach into the borough's three adult training centres, further education college and special school for pupils with severe learning disabilities as well.

How does Links grow?

Islington's education coordinator for students with learning disabilities is Jacquie Billis, who coordinated the original research project and is quoted at the start of this section. These days, half her salary comes from Islington's social services budget and half from the Inner London Education Authority. This, she says, puts her in a unique position to bridge the many services involved, both statutory and voluntary, at grassroots level. Her brief is to recruit, train and support volunteers, and to help develop existing special classes in response to students' interests, as well as to create new ones.

She keeps in touch with the students through close links with their staff in local training centres and hostels, and their families – and through regular meetings with the students themselves. At these, she discusses with them the courses on offer and the ones they would like to see added; she is available to advise not just the Links students, but the growing number who choose to make their own, independent arrangements with adult education courses.

Volunteers are recruited through leaflets in Islington's adult and further education establishments, publicity in London's media, and word of mouth. Jacquie Billis interviews each applicant and organises a visit for them to a day centre if they can manage this; she goes with them to 'their' potential student's home or hostel. No volunteer is signed up without further discussions with the student, their family or staff and the applicant themselves. There is then the 'preparation' of weekly meetings (which later become monthly). Support and counselling for the volunteers are an essential part of Jacquie Billis's job, especially as some of them have had little if any experience with people with learning disabilities: 'We need to tackle and reverse the "Does he take sugar?" syndrome.'

As the scheme has grown, it's become increasingly important to find ways of supporting it that don't depend so much on the coordinator herself. In 1985, a

part-time volunteer coordinator was appointed, funded through MENCAP by the DHSS opportunities for volunteers programme. But in addition, what has happened as the scheme has grown is that the students and volunteers have themselves taken on more of the work of support. New volunteers don't have just Jacquie's phone number, but that of a more 'experienced' colleague. Students don't just meet with her, but voice their own views and concerns through a student's committee, made up of two members from each of the training centres. The creation of the joint student/volunteer support group has been another step; its job is not just to support volunters but to develop more formally the opportunities for shared enjoyment of theatre, cinema, visits to galleries and restaurants that individual 'pairs' of student and volunteer have already seized.

The other side of the coordinator's role is to develop new opportunities in adult education for people with learning disabilities. Jacquie Billis meets regularly with the heads of the three ATCs and the social services department's principal officer for mental handicap to discuss new ways of using day-care in the borough – whether this is by introducing a yoga class for people with severe handicaps or finding a part-time tutor for intensive literacy work with a small group who have asked for this. As coordinator, Jacquie is also a coopted member of Islington's Mental Handicap Team, and so ensures that educational matters aren't forgotten in its discussions.

Finally, the Links scheme is having its effect on the borough's school for pupils with severe learning disabilities. Some pupils in their last year there are attending ordinary classes; another group, whose handicaps are more severe, are learning alongside sixth formers at the borough's sixth form centre. Students from Links have visited the further education college where there is a special course for students with learning disabilities to discuss adult education opportunities with them, so that they too can begin to widen their ability to make informed choices for the future.

Key Factors

The key factors in getting Links off the ground may have been the idea, the research grant, the willingness of Islington Adult Education Institute to cooperate and the first volunteers. The key factors in getting it organised may have been consultation with the users, clarification of the roles of the many different organisational and individual participants and the building of structures by the coordinator. But the key factor in keeping Links not just going but growing, says Jacquie Billis, is the coordinator's close and regular contact with the very many people and agencies involved.

Some parents and hostel staff have been doubtful about the scheme's value for individuals. 'Should male volunteers be paired with women students?' is a question still sometimes worriedly asked (though in practice, most of the volunteers are women). More generally, parents may be concerned at the thought of their daughter being abroad at night in the inner city. 'But won't people in the classes be cruel?' is also a worry that still comes up.

Of that, there has been little sign. There are the 'regular' students who deliberately avoid the Link ones – but they keep on coming to the classes nevertheless. There are the tutors into whose classes Jacquie Billis would not encourage a student, whether because the other members are chiefly elderly and the Links students are not, or because the tutors themselves aren't the best teachers of their subject on offer.

From the tutors – who are invited to regular meetings, and occasional special topic ones as well – there has been little overt opposition. Partly this has to do with the ethos of the Islington Adult Education Institute itself: like all the borough's services, it has a declared concern for the rights of different minorities, and from the start the Links scheme has been seen in this perspective rather than as a 'welfare project'.

But individual tutors too have had their concerns – about whether they themselves can 'cope' with people defined as 'learning disabled'; about whether those people will have the degree of comprehension needed to benefit; about whether they will demand too much attention, or get into trouble, especially with tools they may never have met before. But as one women's woodwork tutor says cheerfully: 'There are plenty of others in this class who are baffled by it all at the start! We don't have time to wonder about any particular member of the class – we're all here to get on with the work and enjoy it. And we like having the Links student – she's a joker!'

Only twice have Links students ever been withdrawn from the regular course of their choice and offered a 'special' one instead. In both cases, this was because their behaviour was such as to interfere with the work of others – in one case through not knowing when people wanted to chat and when they wanted to get on with their work in peace and in the other through really needing more one-to-one attention from the tutor than it was possible to offer. 'Integration', as Jacquie Billis puts it, 'has to mean that both sides have an equal crack of the whip.'

And increasingly, that equality is what the Links scheme is about. To students, volunteers and tutors it offers the chance for a new dimension to their learning and the chance of new friendships and experiences as well. It offers the chance to explode some myths about 'these people' called learning disabled: very often, the surprise for volunteers and tutors has been to discover how 'able' they are. And for those students in particular, Links offers the chance not just to participate in new ways in their community, but to know that their experiences and views are having their effect on the future shape of adult education and day services in the borough.

'I'm sorry', a Links student once said politely but firmly to her volunteer in their class, 'but you just don't do it that way.' She was right, too. For Jacquie Billis that exchange conveyed the essence of what Links is trying to achieve. The student had recognised her own ability – and found the confidence to express that. The volunteer was set to thinking about how often people with learning disabilities feel able to correct others when they are wrong, and so about wider issues of relationship between the 'able' and the 'disabled' world. Links is about integration that is a two-way process of learning.

FURTHER INFORMATION: Jacquie Billis, Education Coordinator for students with learning disabilities, Islington Adult Education Institute, Shepperton Road, London N1 3DH

CREATING TOGETHER

I like mixing with people. It gives me a chance to act, to be with everyone else – and that's something it's been hard to do, because I'm disabled. To me, it's a dream come true. It's everything I've dreamed of.

I think it's good, because it's acting. And you get paid.

It keeps me in touch with the theatre; I can keep up my professional skills. I've learned a lot. If the others have learned about theatre from those of us who are

professional, then I have learned too, about their way of life. People say it's 'therapy' for them. If it is, then we all need therapy.

When Path Productions put on A Midsummer Night's Dream in 1984 in central London, one of the beautiful young lovers was played by Kim Woolfe, whose dearest wish is to be a professional actress, but who has found that the fact that she gets about in a wheelchair has debarred her from even amateur companies. Bottom the Weaver was played through sign by Issy Schlisselmann, himelf profoundly deaf, and in words by Edward Jones – highly professional actors, both of them, and finding through Path another opportunity to work for the breaking down of the barriers that surround deafness. The other tradesmen – if such things are for these purposes to be totted up – had between them a rich variety of sensory and mental handicaps, and were distinguished mostly for their fine comic timing. Puck was a gifted dancer and comedian – who happens to have Down's syndrome. There was, said one London critic, 'a good deal of purposeful and innovative humour . . . Very watchable theatre'.

The above sort of singling out of people by handicap is hardly Path's way. Its concern is neither to offer the chance of an 'outing' for the talents of people with disabilities nor to evoke the theatre of polemic to make a political point about disability in today's society. What it aims to do is rather to provide theatrical entertainment of a professional standard, integrating the talents of able-bodied and physically and mentally disabled participants in a way that makes for a new sort of theatrical experience. 'We hope we are bringing a new dimension to theatre, both for our handicapped performers and also for our able-bodied participants and our audiences.'

Path stands for Practical Arts and Theatre with the Handicapped. It was formed in 1981, the International Year of Disabled People, by a small group of people professionally involved in the theatre, and by the start of 1985 had put on five major productions in central London. It began with a bang: a spectacular new musical version of Anderson's tale The Tinderbox, with a cast of 50, including children from a special school for pupils with severe physical disabilities. This opened at Sevenoaks School in Kent and drew a capacity audience for its one-night stand at The Mermaid. 'A marvellous facility', said *The Times Educational Supplement*, 'for debunking disability and maximising ability.'

Since then, Path has played once at the Young Vic and more recently secured a contract for two seasons a year at the Jeanetta Cochrane. Its productions have ranged in tone from the sombre to the spectacular, in cast from the small-scale to gigantic enough to make the nightly squeezing of performers into dressing-room and available transport something like a miracle. Miranda's Dream evoked the changing nuances of the father-daughter relationships in Shakespeare's work through word and original music; Two Plays of Passion from medieval China brought an unaccustomed starkness of emotion which contrasted sharply with the light and shade and interplay of illusion and reality of The Dream. In January 1985, a cast of over 60 – including for the first time players from the dance and music programmes for people with mental handicaps at the City Literary Institute's creative education programme – re-created A Christmas Carol. 'These productions', said the Attenborough report in 1985, 'have been found to generate a warmly cooperative atmosphere in the audience, as well as in the company, and conventional audience attitudes to disabled people, including those who are mentally handicapped, are being successfully challenged.'[8]

How does Path work?

Path in essence falls into a venerable tradition of family theatre. Its artistic director, Jane Kingshill, is by trade a professional designer who has worked with the English National Opera and, more recently, as a creator of exhibitions, including the Alice centennial celebrations at Longleat and Hatfield House. Both she and her son Danny, Path's musical director, work part-time with people who have mental handicaps, at the City Literary Institute and elsewhere. This blend of professional activities is reflected in Path's approaches. People with mental handicaps, for instance, have participated in designing its shows – and some of the costumes for The Dream were designed by Elizabeth Montgomery of Motley, one of the most distinguished names of British theatre in the past half-century. People with mental handicaps have been involved in Path's musical interpretations – and Miranda's Dream was able to give a first performance to some haunting professional settings of Shakespeare's songs.

The family connection goes further. The Tinderbox was written by Katie Fischel, sister to Danny Kingshill, and wife to Jonathan Fischel, who chairs the trust that administers Path. By good fortune, his father-in-law Peter is a lawyer and also a member of the Path trust. To complete the roll-call, Sophie Kingshill, daughter to Jane and Peter, is a regular member of the Path company – and so are other young people who have worked together since childhood, many of whom have now come to the age of professional theatrical aspiration.

It is from this family nucleus and links of friendship – most importantly with the professional directors Keith Rubidge and Kevin Robinson – that Path has grown. Its concern, though, is always to extend its boundaries further. One instance of that is its approach to a special school to enlist two young blind boys for a Christmas Carol.

Path counts itself fortunate to have the showcase of the GLC's Jeanetta

Cochrane Theatre, not far from London's west end, for its twice-yearly seasons; costs here are minimal. Thanks to the London Borough of Camden's adult training centre, too, it has a regular rehearsal space – not readily found, especially given the particular needs of the Path company for wheelchair access and warmth. But even with this help, finances remain a matter of hard work.

Each of Path's major productions have run at a deficit of some £2,500–£3,000. Audiences,who have recently numbered about 1,000 for each production, bring in only about a third of the sums that Path needs. Costs for large companies are high – even when most people get only out of pocket expenses and the professional members could probably command higher fees elsewhere. Path must seek funds for each production through charitable trusts and individual supporters. So far, it has managed to find them.

Meanwhile, it is trying to extend its activities in two ways. It hopes to set up a small touring company to bring its way of working to a wider audience. And it is trying to encourage more openings for actors with different disabilities in mainstream theatre. A special fund in memory of one of its first actresses, who died after a long illness, will offer financial help with, for instance, drama lessons and audition expenses. Already some major drama schools have given hopeful indications of their willingness to audition actors who happen to have a disability.

'Path is not and never has been', says Jane Kingshill, 'drama therapy. It is rather an attempt to enlarge the scope of orthodox drama a little by using talents which would otherwise remain hidden, and sharing certain kinds of discovery and achievement with audiences who might not otherwise get a chance to understand handicaps as a potential human plus, not a minus.'

Nevertheless, there are stories enough of what Path has brought to individual performers. As one critic has noted: 'If the handicapped actors benefit, so do the non-handicapped. The experience of the work, and the very obvious tenderness that exists within the group, is not usual:' Path can bring the chance to build self-confidence and the ability to make oneself heard, and the skills of concentration, time-keeping and even using public transport. As one 'mentally disturbed' player says of himself: 'The confrontation helps you. It's a challenge to go on stage – and I need that. I love working with all of them.'

The way isn't always easy. The demands of welding such disparate casts into a whole may leave the 'able' actors feeling that they're left too much to fend for themselves. Professional expectations of normal discipline may sometimes be sorely tried.

Yet what Path offers its performers is the chance to be open to the unexpected, and to explore further what theatrical communication may mean.

And what it offers its audiences can be an experience that goes deeper than many more sophisticated approaches.

'Not being able to see or hear or walk, never to be treated as a grown-up member of society', says Jane Kingshill, 'makes it harder, not easier, to achieve anything anywhere. But this minus can be accompanied by a plus to which non-handicapped people have no access, and which in itself makes a powerful dramatic impact. At such times the paraphenalia of disability – the wheelchair, the sign language, the extra importance of touch and the vivid, often painful intensity of appearance – becomes symbols of something we all have in common. They demonstrate the vulnerability and courage of the human spirit in a way that seems larger than life – that seems, in fact, theatre. We in Path maintain that handicap can actually add to the legitimate vocabulary of theatre as a whole.'

FURTHER INFORMATION: Path Productions, 38a Duncan Terrace, London, N1 8AL

8 SELF-ADVOCACY

The General Assembly of the United Nations have a declaration of rights for disabled people that says:

> **'Disabled people have the inherent right to respect for their human dignity. 'Disabled people, whatever the origin, nature or seriousness of their handicap, have the same fundamental rights as their fellow citizens, which implies first and foremost the right to enjoy a decent life as normal and full as possible.'**

The most important of these is our right to respect for our human dignity. We will fight until everyone knows this and understands this.

We are on the move towards a better understanding and nothing placed in our way will stop us.

Constitution of the Avro Adult Training Centre Council

A new voice is beginning to make itself heard in our midst, and demanding that we should listen. It is the voice of persons with mental handicap.

Until now, others have spoken for them, in the belief that they would lack the skills to speak for themselves.

Our task now is to listen to them, to help them to participate as equals in the life of the community and to provide them with the opportunity to make meaningful choices.

Participation in family and community life: a position paper, International League of Societies for Persons with Mental Handicap, 1984

People who have been defined as having a mental handicap are finding their voice. They are speaking out about the conditions of their lives – about how and where they live, learn, work and spend their leisure time. Increasingly, they are no longer content to let others decide these things for them. They are becoming their own advocates, and those of others also defined as mentally handicapped. They have a movement of their own: it is called self-advocacy.

The movement is international. In the USA, where it began in the 1970s, people defined as 'mentally retarded' have built a nation-wide network of groups called People First – because from the start they have wanted everyone to see the person first, and the handicap only second. In New Zealand, people called 'intellectually handicapped' are electing their own regional network of representatives across the country. In Australia, 'intellectually disadvantaged citizens' have held a national conference on housing. In Britain, the number of committees of people called 'mentally handicapped' in social education or adult training centres has grown dramatically during the 1980s; by 1985, a People First network was beginning to spread.*

From their national bases, people are meeting across the world. In 1983, the International League of Societies for Persons with Mental Handicap* made sure that some 30 self-advocates from different countries, who between them spoke seven different languages, not only met together but were able to play their part in its International Congress proceedings. In 1984, People First of Washington state in the USA organised the first international conference for self-advocates and their advisers.* Some 200 people came – from 24 American states, from Canada, from Australia and from Britain. 'Are you willing to speak up? Are you willing to spreak out?' asked the People First state president, Betty Sutton. They were!

The challenge is clear. People who have traditionally been seen as passive recipients of services are now increasingly asking those who provide and staff them to listen to what they have to say about what's on offer. They are asking for a new relationship of partnership and equality in place of the old hierarchies. And they are asking for a sometimes radically different shape of service.

People are talking about housing:

We need to be given the choice of where to live. Most adults do not live at home with ageing parents from choice, so why should we?

We would like ordinary housing such as you all live in.

We need more group homes so we can get the chance to show what we can do and live like anyone else ... Lots of us could live on our own with a bit of teaching and help.

People are talking about work:

I did work experience for a long time and I didn't get paid anything. I think

*See Appendix B for addresses of these organisations.

that if you have learned to do a job and you are doing a job, you should get paid for it.

We would like adult training centres to be more like colleges, with all the choice any student is entitled to, and to be able at the end to hold a qualification. This would help us to be able to get a job.

Why can't people get jobs? If we do get them they're shitty jobs. We want a proper trade and a proper job.

They are talking about their place in the world:

We should do more things with people who are not handicapped, so that they would get to know us.

We like to mix and try our best. We don't want to be shut in, like in a cage. We want to learn to do things for ourselves.

The public should be made more aware of handicap. After all, there are three kinds of handicap – able bodied, mentally handicapped and physically handicapped people and each of us suffers from one of these types.

They are talking too about taking their place in the structures where decisions that affect their lives are made. Participants at the ILSMH's Nairobi programme felt that more people with mental handicaps should be invited to serve on committees; each national and local association should, they said, have people with mental handicaps on their board. 'We should not become members of boards and committees only because we are mentally handicapped. We must be allowed to take part in debate. A non-handicapped board member should assist a new member who is mentally handicapped.[1]

So self-advocacy, as Bonnie Shoultz, co-author of *We Can Speak for Ourselves*, has said, is a profoundly political movement. 'It means that the experience and thoughts of people with mental retardation will become directly available to decision-makers. It means that service recipients will evaluate the quality of those services and make efforts to improve them. It may mean that they will disagree with the administrators and express their agreement. It may mean that they will demand to be taught how to solve problems affecting the services they received.'[2]

The welding of a political strength among members of a minority group has never been easy. It is not easy for people to speak up when others – parents, staff, planners – have for so long spoken for them. 'Everyone is shy at first to bring points up, what to say as well as being shy. Those who have difficulty will be helped along by the group who will be patient . . . You need to be given time and encouragement. The more chances to speak you get, the easier it is.[3]

It is not easy, either, to learn the skills of running and participating in meetings, or to move beyond individual concerns to group ones. As one leader of an English group has said: 'Chairing the group can be difficult, depending on what happens in the week. Sometimes too much time is spent talking about individuals rather than more general things.' But, as he went on: 'I myself have learned how to deal with people more fairly and to be more democratic and less selfish since I have been chairing some of the meetings. The group gives trainees more independence and more responsibility. We have to depend on the staff less. I have got to know them better, as I have had to talk over problems with them.'[4]

But what if the staff don't listen, or the group doesn't have an adviser who can tread the delicate balance between helping its members learn new skills and 'taking over' or 'manipulating'? A survey of self-advocacy groups in adult training centres across England found that nine per cent of centres had had a committee or group which had folded. These groups, it seemed, had not lived up to expectations. Lack of trainee skill, failure of the group to act representatively and the introduction of 'trivial material' all seemed to have contributed to this; groups without staff support seemed particularly vulnerable.[5]

There's a need for training materials for self-advocates and their advisers; these are beginning slowly to be built up in Britain, though there is a way to go before they are as plentiful as those available in the United States.[6] But there's a need too for receptiveness to the movement. Self-advocacy has drawn its critics aplenty, and their objections seem uncannily similar in whatever country they are voiced.

'But we've been doing *that*', say some parents and staff, 'for years!' Or, as the reviewer of *We Can Speak for Ourselves* in a British social work journal put it: 'Much of this will be obvious to professionals working in the field.' These critics forget, perhaps, that the single most constant theme of self-advocates is precisely that they are neither encouraged to give their views nor listened to when they try to.

'They're just an elite', say the critics. 'They don't speak for all handicapped people at all. It's just political manipulation.' When it comes to the challenge of self-advocacy, it seems, the 'able' world can develop a scrupulous concern for the ideals of democracy – forgetting, perhaps, that in any community democracy means that a few politically active people represent the majority who are not politically active at all. They forget, perhaps, that the whole history of the group of people called 'mentally handicapped' has been one of being 'manipulated' into a position of powerlessness by political, economic and social structures.

'But *those* people', the critics say, 'aren't really handicapped at all – *ours* could never get up and make public speeches!' They forget, perhaps, that self-advocacy in its fundamental sense is not just about public statements, but about the building of self-determination in individual lives, and that that can be helped or hindered for anyone. 'Like independence and risk', as Bonnie Shoultz has put it, 'self-advocacy is relative to the situation of the individual practising it. The person who assertively expresses a concern to a staff person, even non-verbally, may be practising as significant an act of self-advocacy as another who speaks knowledgeably to a legislator.'

And as the ILSMH position paper on participation emphasises, the start of that self-determination has its roots in the earliest days of family life, in the way in which children who have a handicap are encouraged or discouraged in their equal participation. 'The obstacles to greater participatin and self-expression do not lie entirely with persons with mental handicap. They spring partly from the low expectations of others, even those with a life-time experience as family members or professionals.'

Where expectations are not low, where people called mentally handicapped are encouraged and their views actively sought, then exciting things can happen.

Take, for instance, this indictment of California's traditional system of services for people called mentally retarded: 'When all other factors are the same, including type and degree of biological impairment, the evidence seems very strong that the ones who have been able to lead the most normal lives are those who have been helped to the greatest extent *outside* of the traditional service system. The task force suggests a new phrase to be used to sum up the nature and effect of what we have been calling the traditional system of services for the mentally retarded: "the retarding environment".'

This conclusion comes after a statewide tour of assessment, and interviews with 150 service-users and their families and professional staff. It is part of a weighty report which not only dissects the present state of services, but makes many well-argued recommendations for reform. It was written by People First of California at the request of the state's Developmental Disabilities Council. Each member of its task force had first-hand experience of services provided to people called mentally retarded; they drew on 'able' help only in the writing of the final report and organising their exhaustive schedule of visits.[7]

It is a long way from California, perhaps, to the adult training centres in Britain where most self-advocacy activity is based. It is as long a way from the California Developmental Disabilities Council's foresight, perhaps, to some current British attitudes. There is certainly some openness. 'We don't like the words "mental handicap". We're people like anyone else' said the self-advocates in the London borough of Islington. And the borough has now officially changed its label to 'people with learning disabilities', as the self-advocates suggested.

But there is entrenchment, too. 'We don't like the symbol you use', a group of self-advocates from Essex told MENCAP in 1983. 'The little boy makes people think we are lost, lonely, sad, miserable and pathetic. We are not! We can't change people's minds about us if you carry on showing us up to the public. We want people to see us doing lots of different things. The little boy makes them think we just want to have a good cry all the time.' It got a dusty answer.[8]

Where is the limit of 'acceptable' self-determination? Self-advocates, it is beginning to seem, may be applauded and even encouraged as long as they stick with the 'safe' issues like sugar in tea and matters of minor administration. But the story may be different when they start to challenge the policies on which services are based. The issue is one that would be recognised by any minority group which is trying to establish its rights and so alter existing power structures.

How can the self-advocacy movement build its greatest strength? Is a base in existing service provision the best one for the future, or is the power structure there so weighted in favour of the providers that self-advocates are bound to run into trouble? In the USA, the philosophy has been clear from the start that self-advocacy needs to be established independently of any service structure.

What is the best role for 'supporters'? Many local CMH groups, for instance, try to involve people with mental handicaps in their work, and that seems right. But CMH is still the Campaign for (not 'of') People with Mental Handicap. The International League of Societies for Persons with Mental Handicap working party on participation wanted representation for self-advocates on boards and committees of existing associations; people with mental handicaps are involved in many of the ILSMH's own committees. But it also wanted to see the growth of independent associations of self-advocates, and more links between these and other organisations of (not 'for') people with different disabilities.

The issues are maybe getting harder not easier as the movement grows. But the strength to resolve them is growing too. The story of the Avro student council shows how complex a situation self-advocates may find themselves in, and how vulnerable they may be. But it also shows how the movement is finding its base in its constituency. The story of the MENCAP participation forum shows how the network of self-advocates is growing and spreading.

'The time has come', says the ILSMH position paper on participation, 'to remove the barriers to greater participation – those that lie within our own attitudes, in families and colleagues and in the community around us.

'If we accept that persons with mental handicap are our fellow citizens, with the same basic rights as anyone else, it follows that we must work to ensure that they are given the same kind of opportunities to participate in the life of their community as are available to any other person.'

That position statement was drawn up by a working group composed of parents, of friends – and of people who have a mental handicap.

Reaching a hand out in friendship
Helping someone along the way.
Saying you can do it,
give it a try.
By helping others,
I help myself.
It's a feeling, I just can't explain.
Seeing the person hidden way down beneath
reaching out for someone to hold.

Looking beyond the handicap to a person
who is willing to learn
and to understand.

I give my hand out in friendship and
help out wherever I can.
To help others stand up for their
rights and beliefs.

Shout out a big HURRAH!
WE ARE THE PEOPLE FIRST!

Terrie Erwin,
People First of Washington

BUILDING A BASE

The aim of the Council is to make sure we are all treated fairly and as people with our own likes and dislikes.

We have the right to be treated like any other human being without being labelled retarded or subnormal.

We have the same rights as other people and we will fight to make sure we get them. When we do stand up for what we believe, people should have the decency to listen to us.

We have the right to go into the community when we please and do the same things as other people do.

We have the right to vote in all elections if we are over 18 years of age.

We have the right to become independent and choose where we want to live and who we want to live with.

We have the right to love and be with the person we love.

We have the right to education and training that will help us to become more independent.

We have the right to work.

We have the right to say 'no' to something we don't want to do.

We have the right to stand up for ourselves, or to speak out for others, if we are abused or treated in a degrading way.

Constitution of the Avro Adult Training Centre council

The student council at the Avro Training Centre in Southend in Essex grew from the suggestion of one of the centre's users. It has been working since 1979 for the recognition that people labelled 'mentally handicapped' have the same right as any other to express their views and to have these heard with respect.

The council encourage the people they represent within the centre to become more aware of their own rights and needs. They are concerned not just with the centre's affairs, but with anything that affects the lives of its users – and of other people who have a mental handicap. Through personal contacts, attendance at meetings and speaking engagements, the Avro student council is part of the wider movement of self-advocacy, of the struggle of people with mental handicaps to have a greater say in the pattern of their own lives and the shape of the services they use.

When in 1982 the students at Avro became the first group from a training centre to join the National Union of Students, the council's then chairman, David Ward, made it plain why this was important: 'We need recognition by the public. We don't want to be treated like children. We want the right to speak for ourselves.'

How does the council work?

Each September, as laid down in the council's constitution, there is an election in which every member of the Avro student body has the chance to vote for 10 councillors, each representing one of the groups within the centre. The constitution spells out carefully how the election should be run. There is an election campaign two weeks before the poll, when people who want to be a councillor can make a poster and give a speech explaining how they feel they can represent others and help to improve the centre. The vote is private and secret; people who can't read the names on the ballot will have them read to them (but no opinion given about how they should vote) or pictures of the candidates shown to them.

'Councillors', says the constitution, 'will be expected to take their place on the council very seriously.' Their job is to gather the views and concerns of their group at its regular morning meeting, and to take these to the council's weekly meeting; they also report back from the council to their groups. They meet every week with the management, and monthly with the parents' association; until the end of 1984, they also met regularly with the staff group. They elect their own chairman, vice-chairman, secretary and treasurer among themselves.

The council has an adviser, who is appointed by the management from among the staff to work with the council as an official part of their job, and agreed by the council. Chris Young, the adviser since 1983, is very clear about her own role. She is there not to say what the council should be doing or thinking (she has no vote), but to help them be aware of the options and then how to go about their chosen course of action. She is also there to teach the essentials of running a meeting – like administration and how to come to a democratic decision – and to offer backup by taking minutes. Finally, she is there to help people learn the self-advocacy skills which are important not just in meetings but in every aspect of life: like how to present yourself to other people, how best to communicate your ideas and how to regard yourself as a valuable and worthy member of society.

The council has some practical support from the centre: it holds its meetings there and can draw on its resources for some administrative backup. Otherwise, it is quite self-supporting. It raises funds through events like sponsored discos and darts matches and wine and cheese parties – so successfully that it can reckon to have some £250 in the bank. This money goes on making it possible for members of the council and others to go to self-advocacy meetings and speak at conferences in different parts of the country.

What does the council do?

One of the council's main jobs is to gather the views of the people it represents, discuss these and take them on to management if necessary. It took about two years for the students to realise how valuable this could be to them. Now there is no shortage of issues at the council's weekly meetings – and the fact that there have been over 30 candidates for the 10 council seats shows how valued the council is.

The council may discuss practical issues – the level of heating in the art room, for instance, the availability of new records for the disco, the new equipment that students feel they need. Sometimes, these issues can be resolved. Sometimes, that's not so easy: as a past treasurer has put it, 'it always boils down to money'.

The council discusses issues of principle too, about the way students are treated in the centre. Should they, for instance, be offered pre-mixed tea, and a choice between cups which already have sugar in them and those that don't? Some people have felt strongly that they ought to be able to mix their own tea, to the strength they choose and with as little or as much sugar as they want. Others have felt that not everyone could cope with this. The idea of vending machines came up in discussion as one way out of the dilemma. The council spent quite a lot of time discussing how they could be sure that they really had canvassed the opinion of all the students before they made any recommendations.

The council has also taken up wider issues which are important not just to the people it represents, but by implication to anyone who has a mental handicap. In 1981, for instance, it met with the management of a holiday camp, which refused to accept a booking from a group of Avro students because they wanted to go at the height of the season and not during the off-peak period when the camp needed their custom. 'They are treating us like second-class citizens, and we're not', said David Ward of this incident; 'we are able-bodied and we have no problems. People ought to know better.'

The council has also made its views known on Essex's policies towards the people it represents. It has had some strong things to say about cuts in the 1981/2 social services budget and their effects on Avro. As one council member put it: 'We can work hard, so we should have work to do. When we are short of staff, we cannot go to so many groups. This should not happen. We should have good training to help us with our lives.'

The council sought out its allies: 'The cutbacks on staff and groups mean you get fed up in the workshop all day with nothing much to do. But the NUS are backing us up. It means we have the right to more education outside the centre, and to become real students and be more independent, and social services can't stop us.' It is at points like this, perhaps, that the real challenge of self-advocacy begins to be felt.

The challenge of self-advocacy

As Avro's membership of the National Union of Students shows, its council is clear about a fundamental point: the people who use the centre are students and the central aim of the place is to educate them to take their place in a wider world. 'We need the staff', as one council member once put it, 'for the education and the expertise to help us in the community.'

The implications for the centre's – and indeed the country's – policy are clear. But these have not always, it seems, been easy to accept. By 1981/2, the issue had crystallised around the use of the term 'student'. 'We don't', said the council then, 'like being called trainees, we like being called students.' But centre staff were told that the official title was 'trainee'. By 1985 – when the council's 'outside' activities had for some time concentrated on advisory work for different committees of people with handicaps and participating in the growing network of such committees – 'trainee', the official title, remained.

By the end of 1984, Avro centre itself was in some difficulty. A new manager had been appointed; staff remained in dispute with management, as they had been since the autumn, over proposed staffing changes. The manager suspended the student council. Its members were not allowed to meet with their groups, or to meet together within the centre. Their adviser was not allowed to work with them. No NUS representative was allowed into the centre; continued membership was felt 'inappropriate'.

For a period of some four months, the council met first on its own in a pub, and then with some advice and support in a friendly group home. But reaction to the suspension was widespread and shocked. Parents of Avro students supported the council; local MPs were involved; self-advocates from all over the country made known their support for the council.

In the spring of 1985, the council was reinstated. Its position was nearly what it had been before the dispute blew up – but not quite. It still has its weekly meeting with management, but the formal opportunity at least to report to (if never really to discuss with) the staff group has been discontinued as 'inappropriate'.

The lessons about the complexity of self-advocacy in a service setting were still, by mid-1985, being discussed. The self-confidence of the council was still shaky. But it was back in business.

FURTHER INFORMATION: Chris Young, Avro Student Council, Avro Training Centre, Avro Road, Southend-on-Sea, Essex

SPREADING THE NETWORK

We like to have valid and valued information as well as opinions on information, as well as opinions on many subjects to our own needs. You also need to know everyone's rights who work in the centre, patients in hospitals, residents in hostels and group homes, members of Youth Clubs, residents who live at home with parents and those who work outside and have got jobs, and not forgetting those who have nowhere to go and the unemployed who have not come back to the centre or can't get into one. We speak as individuals, as well as members of a group.

Your group has learned to take responsibility and to see our people become responsible adult citizens and to be able to act unselfishly for the benefit of those people and develop self-assertive skills to become a good officer.

Most important is that non-handicapped should see us do something worth-

while to offer. We also need to make ideas that we all agree, not just the group.

Gary Bourlet, Chairman, MENCAP metropolitan participation forum.

The participation forum set up by the MENCAP metropolitan regional office* first met in November 1981. When it held its first seminar some seven months later, about 80 people came, mostly from social education and training centres. The seminar was called Speaking for Ourselves, and it tackled issues like who makes the rules, keeping fit and how to raise funds; it looked at what 'handicap' really meant.

Sixteen months later, the forum held another seminar. This time, it was in London's County Hall and 280 people came, including professional workers as well as users of special services. The discussions and talks centred on how people could live more freely and get the training they needed for that. The seminar was called Have we a Future? By the end of the day, there can't have been much doubt that the answer was positive. But there wasn't much doubt, either, of the participants' determination to make it rather different from the past. For as Gary Bourlet, the forum's chairman, has said: 'We are human beings, not robots. We don't need people to control our lives. Self-advocacy enables us to make choices and make our decisions. When we need help, we ask for it – not to be told.'

The participation forum held its first meeting at the instigation of Doreen Flint, MENCAP's London divisional manager. It was the participants in that, however, who made the decision that the meetings should continue – and so they have.

The forum is not a formally-constituted self-advocacy body; it doesn't have an organised representative structure. Instead, it is the focus of an ever-growing network of people who themselves are working through self-advocacy groups and committees in day-centres and elsewhere. They come together to exchange views and learn from each others' experiences; to learn the skills that people need if they are to speak up with confidence for themselves and their less able friends; to decide how to respond to the actions of others that affect their lives; and to gain strength from knowing that they are not working alone. By 1985, the forum's quarterly meetings could circulate representatives of groups and committees in over 30 metropolitan boroughs.

The second 'tier' of this network is the forum group of nine people, who come together once a week to discuss whatever issues seem most important to them, and increasingly, as their own confidence and expertise grows, to act as a resource, not just to forum participants, but to a whole variety of others.

The issues of the day can range from a discussion of the complexities of human relationships to the need to write a letter of support for a trainee committee

*From 1985, the London divisional office.

which is fighting a social services department's proposed imposition of attendance charges at its day centres.

The giving of advice can be as varied. The group has been approached, for instance, by a financial journalist from a respected national newspaper who wanted some consumer accounts of the adequacy or otherwise of social security benefits for people with disabilities. It has been approached by staff people from London Transport's disabled passengers unit – and told them in no uncertain terms that the giant 'H' stamped on special passes is demeaning and should be abolished. It has met with MENCAP's own working party on self-advocacy (made up of parents and MENCAP staff).

Finally, the group responds to many requests for speakers – from professional groups (which have included medical students at a London hospital) and from existing or would-be self-advocates. These requests are by no means restricted to the London region: a recent visit to Ireland, for instance, has left behind it a determined new and formally-constituted network of centre committees.

So the message is spread. And so the self-advocacy movement grows.

How is the participation forum organised?

The backup for the forum has come from the start from MENCAP's London divisional office. This provides a meeting place. It also provides administrative help and circulates the different London boroughs and their facilities with news of the forum's meetings and activities. And it pays, on a sessional basis, the forum's adviser, John Herzov, who combines this role with a plethora of others which have to do with the promotion of self-advocacy.

He sees his work with the forum as an active one. He will guide discussions, for instance, in ways that help participants learn the skills of presentation and confidence in debate. He has been instrumental in ensuring that videos of the major seminars are available and in making sure that they are used as training and discussion material. He actively seeks out occasions to speak on the self-advocacy movement – usually in company with one or more self-advocates. But there are occasions, too, when he has not been able to attend the weekly forum group meetings. He knows well that after two or three years of working together, its members are more than able to conduct a worthwhile meeting without him.

Other people increasingly take their own initiatives, too. There was the group of people from a training centre who phoned up the MENCAP office and asked for an appointment, because they wanted to learn for themselves exactly what MENCAP was doing. Doreen Flint was delighted. There are the self-advocacy groups who in1985 were still coming for the first time to the participation forum meetings – and sharing with the group some very well worked-out and effective examples of how the job could be done.

What next? If the forum had the funds, it knows what it would concentrate on next because it has drawn up a fairly extensive plan and discussed it in its small group and full forum as well.

It would, for a start, try to extend its network to those centres and other places in the metropolitan area which don't yet seem to have self-advocacy groups. It would contact them and find out why not. It would invite them to send a representative to the forum to find out what its work is about. Forum members would go out, too, and visit special schools, hostels, hospitals, ATCs and parent groups, to form links where these don't exist and strengthen them where they do. They wouldn't take too much on themselves either: they would do all they could to help and encourage local meetings of centre committees, parents and professional people.

These are just some of the things that the Forum members have said they'd like to do if a full-time adviser to the group could be funded and adequate secretarial and administrative help for such an expanded programme ensured. The forum would, of course, want to be represented on the interviewing panel that appointed such a full-time adviser – and to serve on the management committee that oversaw his or her work.

We need to break down barriers, to get rid of unwanted labels and to educate other people from school onwards. We need to help those who have had their feelings hurt. As one adult would say: 'People call me nasty names or treat us like kids because they're frightened of us. They don't know what we're like and what we can do.

What have these people got to be frightened of? Don't they know what human beings are like? Or could they be frightened of being one themselves?'

FURTHER INFORMATION: Participation Forum, MENCAP Divisional Office, 115 Golden Lane, London EC1Y 0TJ

9 TOWARDS FURTHER OPPORTUNITIES

WHO ARE THE CHANGE-MAKERS?

The services, schemes and gatherings together of people described in this book are far from being the preserve of any particular agency or set of agencies. Between them, they have been initiated and sustained by health authorities, local social services and education departments and what's known as 'the voluntary sector' – and sometimes by more than one of these at once. As they have grown, they have drawn in housing departments and associations, industrial and commercial enterprises, municipal services, local DHSS offices and grant-making trusts.

The main concern of very many of these agencies and organisations is not with people with mental handicaps and their families at all. It may be with the provision of services in cash or kind to a whole series of groups, of whom they are only one. It may be with creating a profitable business.

So the first thing to say about making change for people with mental handicaps is that almost any body or organisation can be part of it. We are not talking about creating a whole lot of 'special' agencies – though we may be talking about some special arrangements within agencies that exist already.

The second thing to say about change-making is that it isn't with 'agencies' that it starts, but with people. Each of the schemes, services and gatherings together of people described here exists because someone, some day, had an idea. And there is nothing at all to say that having ideas is the preserve of a particular sort of a person in a particular sort of a place.

Sometimes, the idea will come to people who to an extent, you could say, are paid to have them and certainly have a measure of authority to do something about them. It was when an idea came to a medical officer of health in Southend, for example, or to a consultant paediatrician in Exeter, or to a consultant psychiatrist with university connections in Bristol or to the director of a voluntary organisation in Liverpool, or to the chairman of another in London, that the seeds were sown of the parent support groups, Honeylands, Wells Road, the Barnardo's professional fostering project and the Islington adult education Links scheme.

Sometimes, the people who have the idea are less easily pin-pointed. Social services departments live in a very different culture from that of the entrepreneurial individuality of the medical profession; they like to talk about sharing and teamwork and collective responsibility and tend still to refer all letters to the director. Yet the seeds of the living arrangements for one very handicapped woman in Greenwich, for example, or the house shared by students and people with mental handicaps in Cambridge, or the Leeds short-term fostering scheme were sown when someone in social services, some day, had an idea.

Sometimes, again, change starts with individuals who may have no formal authority as 'service-providers' at all. NIMROD grew from the determined lobbying of the South Glamorgan Community Health Council, to become one of the most determined attempts to provide comprehensive community residential services that we have. That handful of parents of young people with multiple handicaps in Birmingham only knew, at the start, that they needed something they weren't getting; today, the service that grew from their idea can offer that 'something' to around 100 others. The 'trainee' at Avro adult training centre knew only that it would be a good idea to have a student council; his idea is now part of a national movement and has helped inspire many others.

So the change-makers are all sorts of people in all sorts of places. And they may want change for all sorts of reasons. Sometimes, they have a firm philosophical commitment to a new pattern of opportunities, often fuelled by the example of other services in other places. The Wells Road project, for example grew from a commitment to the philosophy of *An Ordinary Life*, which in turn took a lot of its ideas from the Eastern Nebraska Community Office of Retardation's experience over years; the Barnardo's fostering scheme was first triggered by the example of a similar project in Michigan; Portage in Winchester was an adaptation of this work in many different parts of the USA.

But change can also be born out of a keen perception of needs and a sense of desperation that something should be done. The pioneering living arrangements of Maria in Greenwich were put into action because there were no alternatives; the Birmingham multi-handicap group was born because parents were at their wits' end. And change can come about simply because an idea sounds as if it might be valuable and turns out to be rewarding. The genesis of Path and the creative involvement of all the very many 'ordinary people' in the work and leisure of people with mental handicaps that runs throughout this book, are examples of that.

So there are all sorts of people in all sorts of places who have the ideas that make for change, and all sorts of people who help them to make it happen. The real challenge is to seek them out, provide the structures which encourage them – and weld their efforts into a whole which can truly be called a comprehensive local service, available to anyone with a mental handicap, whatever their needs.

THE STRUCTURES OF OPPORTUNITY

A comprehensive local service is one which provides opportunities in every aspect of individual lives; people may not need or choose to take advantage of all of them, but the service won't be truly comprehensive until they're there. That takes some planning between the multiplicity of agencies, organisations and individuals who will be involved. 'Comprehensive' has another meaning here, too: the aim must be to ensure that the service is available, in its local form, to anyone with a mental handicap, anywhere in the country. That also takes some planning, between county and regional authorities, and between them and central government departments as well. Yet one thing we can say for sure about planning is that the news could be a whole lot better.

The Department of Health and Social Security, which could fairly be said to have some duty in this, appears content to leave planning authorities with a dog-eared plan of a 15-year-old White Paper whose contents were dubious to begin with and are now almost totally irrelevant. It shows no public sign of working together with the Department of the Environment and the Department of Employment to produce coherent guidance and statement of principle to replace this. During the 1970s, it put its authority behind the stream of exhortation that came from the National Development Group; that Group is now dead. The National Development Team exists, but it was only in the mid-1980s that its reports were made public, and they continue to have to do with the minutiae of local services in the context of a dubious philosophy. At almost no point during the last 20 years has the DHSS taken any sustained initiative to seek out and publicise widely and attractively examples of the sorts of change this book is concerned with, either national or international. Its tentative moves towards finding a proper funding formula for community care have had, as we saw in the Introduction, far less than the boldness we need. As a change-maker, the DHSS has been hesitant.

With leadership like this, it's perhaps hardly surprising that the regional health authorities have some way to go in their own planning efforts; yet given the huge investment still tied up in the mental handicap hospitals, their performance is clearly crucial. There is some good news: at least the authorities *are* planning, and often grappling bravely with the complexities of finance and staffing. But much of this is being done without any clear philosophy or idea for why, and in woeful ignorance of the best new ideas, in this country or elsewhere. It is still bound up in the inflexibility of 'beds' and buildings, rather than working towards a strategy that can respond flexibly to changing individual needs. It is often done without even involving the agencies with a high stake in the future shape of services, like local authorities or even, amazingly, district health authorities.[1]

Joint planning is a headache not just at the regional level, but at pretty well every point where different agencies and services touch the lives of people with mental handicaps and their families. Over recent years, a bewildering number of new sets of initials have been strung together: DHT, CMHT, JCPT, JCC. Yet the district handicap teams and community mental handicap teams hardly seem on top of their job, as we saw in the section on family support. Even getting joint care planning teams together, the House of Commons Social Services Committee found, could seem an insurmountable problem – and that only involves health and social services, not housing, education or local employment agencies. When it takes one JCPT 84 formal meetings to plan a single community mental health centre, you can well see why some people might feel they're better off without them. Joint consultative committees don't come out of the Social Services Committee analysis much more cheerfully. Not much wonder, perhaps, that the Committee found 'a disturbing degree of ambiguity, confusion and doubt over which agency should be doing what for mentally handicapped adults'.

So we seem to have got ourselves into an extraordinary position. On the one hand, there is a plethora of bodies charged with planning services who don't seem to be able to work out what they are doing and why. And on the other hand, there are a whole lot of energetic services, like the ones in this book, which know fairly exactly what they want to do and why, and are moving towards the sort of future for people with mental handicaps and their families that the best new thinking would support.

What to do? There is no shortage of ideas. The DHSS, says CMH, should replace the 1971 White Paper with a document describing the future shape of community services and use the National Development Team to make sure that local initiatives are in tune. Regional health authorities should accept responsibility, in conjunction with local authorities, for establishing the strategic framework within which health districts, local authorities and voluntary organisations develop comprehensive local services, and this according to a firm commitment to the new philosophies.[1] RHAs, says the Social Services Committee, should give a clearer lead and the DHSS should make sure they do it. Joint care planning teams should perhaps be strengthened by permanent staff, in the context of planning for social care for people with mental handicaps and their families that is administered entirely by local authorities by the end of the century. Joint consultative committees should have greater financial and policy autonomy.[2] 'Local people' should be involved in planning from the start, says *An Ordinary Life* (in the context of residential services). Planning teams should be representative of all the people and agencies involved in any future service; the team – which may have a different set of initials altogether from any yet conceived – must involve present service agencies too, to give it the necessary authority.[3] And so on.

Laudable all these suggestions may be. But there is one major snag. They all involve, essentially, putting more faith in a system that has already more than amply demonstrated that it just doesn't work. This isn't to say that we don't need planning. But it is to say that maybe the time has come to look rather more creatively at who should be doing it and how.

The first question is whether all those people involved in planning at the moment want to be. The inescapable conclusion, from what they come up with, is that they don't, but are only there because their job description says they must be, or because they have been singled out as representatives of 'local people', whatever that particular nod towards grassroots democracy may mean. Yet on the other hand, this book is evidence of many and varied 'local people' and professional interests involved not in something called 'planning', but in real services which are in touch with real people and therefore could be supposed to know something of their needs.

Not everyone who is involved in a local service will want to be translated into a planner. That is as well, for we don't need so very many of them. But it is a fairly safe bet that among them there will be people who have good and creative and realistic ideas for the application of principle to services other than their own; that is why they are involved as they are. Among these involved with Honeylands, Barnardo's fostering scheme and the Northumberland housing for young people, for instance, will be people with some clear ideas about how the education service of the future to mentally handicapped children and young people should look. Among those involved with the Pathway and Newcastle employment schemes, for instance, there will be people who have a fairly shrewd idea about what sort of housing needs some people in the area will have; the Hasland housing service is set up, jointly funded by health and social services, to know precisely that. The Islington adult education Links scheme is a fine example of this expertise in action across agencies. It is not because some 'local people' and others sat on a planning committee that social services day provision is changing in the borough, but because the Links scheme is in close touch with what its consumers say they want and its coordinator is jointly funded by social services and education.

It is not just the authority to help make changes which is important here, but where that authority comes from. Partly, to be sure, it is the funding agencies. But partly, it is from the very heart of change, the very people that planning is supposed to be about. The Social Services Committee put its finger straight onto one of the greatest weaknesses of present planning mechanisms. 'We have had difficulty', it said, 'in hearing the authentic voice of the ultimate consumers of community care... Services are still mainly designed by providers, not users, whether families or clients, and in response to blueprints rather than in answer to demand. Matching the service to the consumer rather than vice versa should be one central aim of community care in the future.'

There are few who would not pay at least lip service to that ideal. But how is it to be done? Regional health authorities are impossibly remote from local 'consumers' of services. The favoured device for ensuring that planning is done 'for individual needs' is the sort of 'assessment' process which relies not on what people or their families or advocates *say* they need but on what they are 'measured' to need by often crude professional devices, necessarily static rather than dynamic in what they record.

The people who are actually involved in providing the sort of services we want to see in future, on the other hand, have a very much better way of assessing wants, wishes and needs than that. It comes from their intimate involvement with families and people with mental handicaps; indeed, some of those people are parents and people with mental handicaps themselves. It comes through such devices as individual programme plans, not assessments for registers; from a device that is dynamic, not static. If we are trying to create services that 'respond to individual need', it is from the good services already on the ground that we will get our lead.

The people involved with them are the people who know, too, what 'planning' is about. Sometimes they will start from a very clear perception of the services that should result. Honeylands, for instance, has evolved on the basis of a very thorough-going research survey of families, and has kept itself on track by commissioning an evaluation of what users say of it, and by involving their representatives in its long-term planning. It knows from its experience that 'planning' is a dynamic, not a static, process. NIMROD and the Northumberland housing project are two other examples of services that started from a clear idea of whom they were going to serve, and more or less definitely, how. They too are discovering that 'planning' is something that should change as do the needs of the people who use the service.

But many other services, schemes and gatherings together of people described in this book set out with a commitment and a hunch that what they offered was what some people might want and need. Their hunches played off; they have grown in response to need as it is expressed, within the general framework of their philosophy, rather than according to some preconceived plan of what that 'ought' to be. And what is noteworthy about many of them is that they are the ones which show the greatest integration with their local communities and draw most heavily on 'generic' rather than 'specialist' provision. L'Arche, Gillygate, the other employment opportunities and Wells Road are some examples of what could be called creative uncertainty in action in their communities.

This isn't to argue against knowing what you want to achieve: that in some circumstances has proved essential. Nor is it to argue against highly 'specialist' services at certain times and places: these may be particularly important at the start of the life of a child with a mental handicap, as we can learn from these pages. But it is to suggest that there may also be a value in being less than a hundred per cent sure of the detailed goals, preferring instead to let 'the community' assist in their building. It is to say that there is a place for organic growth as well as certain structure, and that any 'planning' worth the name needs to allow for this.

So what the experience of the schemes, projects and comings together of people in this book suggests, when set against the dismal record of so much formal 'planning', is that we start in future not from the top – which seems both ignorant and unwilling to find out more – but from the bottom, from where the people and the energy are. It is possible to sketch out a planning process that asks the people involved in good local initiatives and hopes to discuss their implications for other services with the people who provide these. Together they would construct a plan for development based on the experiences of real people as they live their daily and changing lives. These local plans, in all their creative uncertainty, would be sent up to 'regional' level. Its job would be to assemble them, see how they fitted its declared philosophy, discuss where necessary and note what it could do to put local people in touch with good ideas from elsewhere – for by now it would have assembled these and educated itself. It would make its financial allocations; it would tell the DHSS very precisely where progress was held up by central policies and why. The DHSS would take seriously its responsibilities to dissolve these blocks, for by now it too, drawing on a whole wealth of experience in this country and elsewhere, would know what it wanted and not be ashamed of saying so in public.

The notion may seem naive. But it is surely better than creating another set of unhappy initials, drawing together people who neither want to be there nor know what they are about. It is a way of centring planning where the energy for change is known to exist, and with the people – including parents and people with mental handicaps – who are already intimately involved in the process.

And lest anyone says that 'no one' in his area is involved in change, let him simply reflect on the huge number of initiatives among parents of people with mental handicaps with whom Contact a Family is in touch, and on the growing network of self-advocacy groups across the country. The energy for change is there. What 'planning' is about is finding creative ways to tap it and build on it.

QUESTIONS OF CASH

Someone, somewhere, is bound to say 'But we can't afford it...' The quick answer to that is that all the agencies involved in the schemes and projects described here have somehow managed to. Most of them, of course, would like more cash. But very few of them cite financial constraints as a truly major problem. If you can identify a real need and pursue it energetically enough, it seems, money will be found.

The rather longer answer is to look a little at what money is really needed for and from where it might come.

Regional health authorities, as we have seen, still often think that money is primarily for beds, buildings and places. Local authorities have, in the past, made similarly enormous investment. Yet one thing that the services, schemes and gatherings together of people described here show clearly enough is that 'special buildings' are very rarely needed. The Gillygate Wholefood Bakery certainly needs one, because, among its other activities, it mills flour; as we have seen, it was by hard work over many years that that old miller's yard was brought into working order. Other than that, the buildings and places used as the heart of services in this book include someone's front room, a community centre on a housing estate, a Portakabin, rooms in ordinary schools and further education colleges, existing adult training centres, an old mansion turned TB sanatorium, and a whole host of ordinary council and housing association houses and flats. It is not too hard, it seems, to find a building.

The major financial cost – as in any caring endeavour – is for people. Sometimes, there have been major injections of new cash for that. Parents for Children, for instance, would not have been able to start its pioneering work in finding adoptive families for children with often very severe handicaps without a grant from the DHSS. NIMROD would not have pioneered the elements of a truly comprehensive local residential service without money from the Welsh Office.

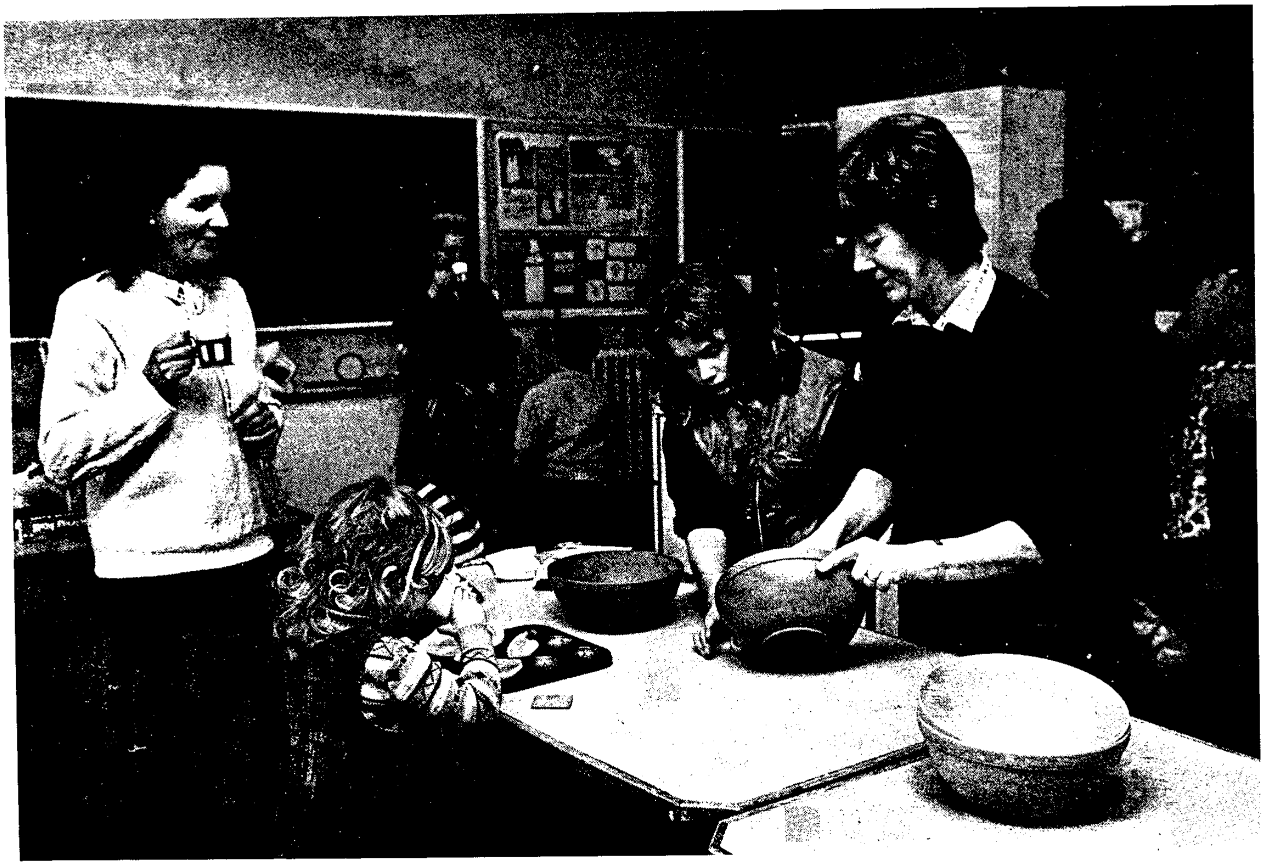
But sometimes, a new and highly effective service can be created by adding just *one* new staff person to a framework that already exists. The Newcastle employment scheme shows that, and so does the Islington adult education Links project, and the Mencap participation forum.

Sometimes, then, 'new' services may cost really nothing much at all. The network of parent support groups in Southend, meeting in people's own homes and coordinated by a volunteer, has certainly demanded energy and commitment over the years – and generated it, too. But it has cost not a penny piece in cash.

More often, from the experience in this book, 'new' services can be created out of what is there already, simply by using resources in a different way. The Camperdown adult training centre would have gone on existing and being paid for whether it had decided to work towards turning itself into an entirely new 'vocational service' or not; that is one reason why it is exciting, for it points a way for hundreds of similar places that already exist across the country. The young people in the Northumberland houses would still have been housed by their health authority in hospital wards had they not had the chance to move to new opportunities. The Portage home education project in Winchester is a prime example of how existing staff can be helped to work in new and exciting ways: its 10 home teachers are nearly all on part-time secondment from other jobs which they were doing already, and so brings additional resource to very many parents as well as helping to maintain other services.

Often, again, huge 'new' resources can be found simply by enabling people to tap into the variety of community provision that's already there. Derbyshire education authority would have had to create a 'new' school for those children and young people who go to Springfield Road and Pingle; they now have access to the considerable facilities of their ordinary local schools. If Islington had wanted to create further education opportunities for people with mental handicaps that were 'just like' the ones other people use, it would have had an expensive headache; instead, they are using the wealth of opportunities for creative and enjoyable leisure that already exist in the borough. The same can be said of all the housing arrangements described here; by rejecting 'domestic-style units' in favour of the real thing, time and money have been saved and opportunities enhanced. The same can be said, too, of all the local leisure facilities that the people who live in those houses use: they 'cost' the service providers not a penny, for they are already there for their communities.

Finally, the experiences of the schemes, projects and gatherings together of people in this book show that the money people need can come from all sorts of sources. As a rule of thumb, it seems that the further the service is from the regular 'special' provision of health or local authority, the more those sources can be multiplied. Inner City Partnership, Manpower Services Commission, a



variety of grant-giving trusts and personal fund-raising all figure in these pages. So, of course, do the financial contributions of the people who use the services themselves – through their earnings or the DHSS benefits to which they are entitled.

WHAT ABOUT STAFFING?

'The provision of a service depends ultimately on the people providing it, not on buildings or money or administration. There are community care services planned which cannot function because there are simply not people willing and able to do the job...There can be no community care unless all those responsible ensure that the staff are there, of the right sort, at the right time and in the right place.'

Few people would disagree with the Social Services Committee's assessment.

But it's worth looking more closely, perhaps, at what we mean when we talk about the 'right' sort of staff.

There has been no shortage of debate about that in recent years. This has centred particularly around the possibility of creating a new brand of 'care staff' for people with mental handicaps, with a new training programme, to cut across the present skills and job content of existing specialist nurses and non-specialist social services workers. The question was first raised as far back as 1972, in the report of the Briggs committee on nursing; it was elaborated by the Jay committee's emphasis on the need for social skills; it has floundered in the 1982 report of the General Nursing Councils and Central Council for Education and Training in Social Work, which recommended that nurse and social care training should, after all, remain separate.[4]

But concern about the 'right sort' of staff for the new patterns of community care continues. The Social Services Committee found it essential that existing hospital staffs should get the opportunity of preparation for moving to the new services and the encouragement to remain in the field. It wanted DHSS and CCETSW, too, to look carefully at how adequate existing training of social services staff was to the task of caring for people with more severe degrees of disability.

Yet much of the debate about the 'right sort' of staff remains academic. The huge majority of staff time given to people with mental handicaps remains 'untrained' in the formal sense. The time is given by parents, and it is given by largely unspecialist – though sometimes equally experienced – care workers. A memorandum from Sheffield warned the Social Services Committee that if career development for staff was neglected, 'residential services for people with mental handicaps may ultimately be staffed by a rapid succession of young people'. It's probably no exaggeration to say that there's not much 'ultimately' about it.

Even senior posts may be taken by people who don't necessarily have the experience that would be most helpful. Ideally, as one researcher has put it, we want senior residential staff who have already worked in a community setting, with a belief in a philosophy of comprehensive local services, and able to operate intense and relevant programmes; what we get are people with experience limited to an institutional setting, who have worked within a buck-passing system, and who know the programme terminology but don't operate by it.[5] His specifications may be particular to the very structured way in which his service works, but the general point is probably worth recording. And everything said about residential services may apply in different degrees to others.

Yet the questions remain: How much does any of this matter? And who are the 'right' staff anyway? Before we set up a cry for more trained staff, we might ask how much we need them and precisely for what. The schemes, projects and gatherings together of people described in this book are here because they offer to the people with mental handicaps and families who use them an unusually high degree of opportunity to live 'like other people' in their communities. Yet they don't seem to depend for that on an unusual ratio of highly trained staff. In fact, you could almost say of them that, taken as a whole, they rely more heavily than most on the energies and skills of 'ordinary people' who may not, in fact, have any training in 'mental handicap' at all. The adoptive and foster parents, the short-term foster families, the regular school teachers and further education tutors, the people who work and have their leisure alongside people who have mental handicaps, are all playing a vital part in helping them belong to their communities. These people clearly have very many human and humane skills, and sometimes working and professional ones as well. But they are not specialists in 'mental handicap'.

This is not to say that at certain times and in certain places, people with mental handicaps won't need sometimes highly expert help. Of course they may. This is particularly likely to be true at the start of their lives, especially if their handicaps are multiple and profound; it may be true at the end of their lives, and – as for any of us – at times of serious illness. But there are examples in this book of how that highly expert help can be provided by drawing on the resources available to us all, rather than on any 'specialist' mental handicap service. Honeylands is 'special' in that it is designed to cater for children who have all sorts of different disabilities and handicaps and their parents, rather than every child in Exeter. But the highly skilled help it offers has been welded from 'generic' health and social services resources, drawn together and refined by experience to create a whole that you could say is greater than the sum of its parts. On the other hand, the services that helped George Munnerley in Liverpool during his final illness were those on which any of us could hope to call: 'ordinary' skilled surgeons and nurses, a GP, a district nurse – and a large number of friends.

In more usual times, the people that those with mental handicaps may need around them are more likely to be those with no special 'training' but a range of *skills*. The two are not, of course, mutually exclusive. But to look more closely at the needed skills may help us clarify the issues of staffing.

The tasks of those who staff residential services, it's been persuasively argued, essentially boil down to four: protecting individual rights and interests, helping to develop skills and competencies, helping people present a positive image to the world and helping them form strong positive relationships with the community. And these are skills which very many 'ordinary citizens' practise already in their own everyday lives.[6] Leaders, as another analysis has it, need to be able to work with a high degree of autonomy and responsibility, to be able to coordinate the work of others, to have a commitment to the philosophy of community care, and to be able to develop individual programmes for the people they serve.[5] Again, these are skills which many 'ordinary people' have. The particular skill of developing individual programmes of learning may be rather less readily available than the others. But, as the experience of Portage in Winchester and elsewhere amply shows, it can, in one of its variants at least, be very readily acquired.

The examples in this book confirm that neither of these analyses is off-beam. People with often very severe degrees of mental handicap are able to enjoy a home-life with the help of others who could be said, for these purposes, to be quite 'ordinary people' – Community Service Volunteers, young assistants, care staff recruited from among the local population. One of the things that may be important to the 'helpers', however, is that they should get a thorough 'induction' before they start work; another may be a 'top-up' in different skills and understandings through regular attendance at different short courses. This is the pattern developed, for instance, by l'Arche, Wells Road, NIMROD and the Northumberland houses for young people. There is a growing and valuable pile of literature on what this pattern of 'training' may mean – and on the skills that those who select staff for residential services need to look for in the first place.[7]

What is true for residential services may be true for other services as well. As the examples in this book show, people with mental handicaps are being educated in working and social skills by 'ordinary workers' who bring no greater expertise than their own command of the job, goodwill and willingness to help; both the Pathway and Newcastle employment schemes show that very clearly, as does the Gillygate bakery. Outreach shows how the principle can be extended to ordinary leisure-time activities. Both Path and the Islington Links scheme show how much people with mental handicaps and others can gain from learning something new and creative *together*.

So is there to be no place at all in the new pattern of community services for staff who are 'trained'? Of course there is, and the examples in this book show what it might be. The adoptive parents and 'professional' foster parents would not have been able to meet some very demanding challenges from the children to whom they have given a new home without the highly expert social work support of Parents for Children and Barnardo's, backed often by the occasional input of psychologists. The home leaders in the Northumberland houses bring not just their home-making and managerial skills, but the valuable experiences of many years of working with people with mental handicaps as nurses. The young people

who live with Maria in Greenwich have the essential backing not just of skilled social work help but of the expertise of the local adult training centre. The Newcastle employment scheme can draw on the preparation offered to its workers by another adult training centre.

So what we are seeing is not the 'abolition' of staff who have been trained to work specifically with people with mental handicaps, but the emergence of a clearer role for them as coordinators, enablers and teachers of others who may themselves have 'skills' but no specific 'training'. If this is a pattern that has so far been emerging most clearly in residential services, it is also beginning to be envisaged in 'day services' as well. In its vision of the evolution of adult training centres into resource centres from which people with mental handicaps go out to share in a whole lot of 'ordinary' educational, employment and leisure opportunities, for instance, the Independent Development Council emphasises the new role of existing staff: they will become more highly specialised in a specific area, and work as coordinators of 'ordinary' opportunities in that area, to help the people they serve to participate in these.[8]

Two things are especially needed if these new patterns of staffing are to work and to be sustained. The first has not come up on these pages, because the people who work in these particular services are maybe not the sort to put it at the top of their list. But it has been raised elsewhere and it's realistic. It has to do with working out ways in which an expertise which is not necessarily dependent on lengthy formal training can be 'professionally' recognised for people who want a 'career ladder' in the new pattern of community services. As yet, there are no clear answers to that.[5]

The second thing comes up in these pages very frequently, and if there aren't always clear answers, then they need some working on. And that has to do with staff support.

There has sometimes been reluctance among pioneers of community services to discuss this. It can maybe seem an implied devaluing of the people with mental handicaps whose interests they are so determined to promote to talk about the very considerable demands that the new ways of working can bring. Yet to offer consistently high quality services and opportunities to people whose disabilities are often very severe is, quite simply, very hard work.

The people who work in the schemes, services and gatherings together of people described here know this. What keeps the service going, they most often say, is not money – though clearly that's essential – but the enthusiasm, determination and commitment of the staff. That that is there is evident to any visitor, in the very shape of the services and the extraordinary attention to the detail that the workers show. And what's needed to keep that going, as these schemes show too, is 'support'. Most usually, that comes through meetings, and 'supervision'; sometimes the opportunity for staff to go on short courses can be called 'support' as well.

There is maybe a way to go before the support to staff is as thorough-going as that which, for instance, Parents for Children and Barnardo's offer to the people who are caring long-term for severely handicapped children. But in logic, there's no reason why it shouldn't be as carefully thought out and many reasons why it should. 'Burnout' among social carers has become something of a fashionable topic recently. It would be better yet if the fashion led to some carefully thought-out patterns to prevent it.[9]

At one meeting, staff who work in a variety of the new community services for people with mental handicaps were asked what made them feel supported and unsupported. They came up with some fairly lengthy lists. They felt unsupported, they said, when people asked them to do something and then weren't interested in the result; when people didn't honour agreed commitments, or made decisions about their jobs without consultation, or forgot conversations, or didn't share, or left them uncertain about their function and future – and lots more besides. They felt supported when there was someone who listened, and shared, and noticed when something was wrong, and made them feel they'd done a good job, and was comprehensible, and who cared about what was happening to *them* – and a whole lot more.[5]

What is striking about these two lists is that they echo in great detail precisely what people with mental handicaps have said about the staff who work with them. Is anyone surprised at that?

QUESTIONS OF QUALITY

It is one thing to start a new community service. It is another, maybe, to ensure that the high quality and aspirations with which it started are not dulled over the years into routine and a gradual fading of energy and imagination for new and creative responses. It can be hard, perhaps, to keep on taking the knocks from people who say it can't and won't work, and who want to pick holes in the achievements. And community services can have, as sceptics are not slow to point out, particular dangers as well as particular advantages: the whole business of monitoring for quality can be made harder when we are talking about small, highly dispersed housing and a whole variety of places where individuals with mental handicaps may find themselves.

Not, it has to be said, that concern for quality of service has been a distinguishing characteristic of services to people with mental handicaps in the past. It would be hard to imagine a service of lower 'quality' than that routinely delivered in those grossly understaffed, under-resourced and appallingly squalid hospitals at the end of the 1960s, where not even the most elementary decencies were honoured.

The very fact of that starting point has itself skewed the answers to the question 'Monitoring for what?' The minimum standards laid down in the wake of revelations about hospital conditions were minimum indeed, addressing themselves, as they had to, to the most elementary conditions of physical environment. The work of the National Development Group on its 'checklist' for hospitals did introduce some further elements that touched on the daily lives of people living in these places. But it too was reacting to such a continuing deprivation that it found little space, perhaps, for forward-looking clarity of philosophy. The DHSS has hardly, despite the continuing evidence of neglect produced by the National Development Group, concerned itself with questions of quality at all. It is only through the recent and growing work based on the principle of normalisation that people working in community services have a tool, the programme analysis of service systems (PASS)*, by which to measure their performance within a coherent philosophical framework.[10]

For many of the services described here, the principle of normalisation has been a guiding one. For some, their own perception of the quality of what they offer is being tested against 'objective' research: NIMROD and Wells Road are being assessed currently, and Honeylands and Parents for Children have been in the past. Other 'outside eyes' include the consultants who have been valuable to Parents for Children and l'Arche's well worked-out system of visiting among the directors of its communities across the country.

But above all and most usually, quality control is exercised within agencies. The first way that this is done is through regular meetings and discussions among the staff – sometimes arranged fairly hierarchically, with an element of 'supervision', and sometimes with an emphasis on shared decision-making. The second way it's done, and very many of the schemes and projects emphasise this, is through listening to what the service users – both parents where relevant and people with mental handicaps themselves – have to say. Sometimes this is done more or less formally, in that a group of parents has been gathered together to act as message carriers and sounding-board. Most usually, though, it's done informally.

The fact that the main device for quality control is the one that's also used for staff support – meetings and discussions – is probably the surest guide to effectiveness. As one attempt to tease out the components of evaluation has emphasised: 'service evaluation is a process by which we learn about ourselves'.[11] 'External eyes' may be able to take an illuminating snapshot, but it's only the people who work in the service who are going to act on what it reveals.

Yet there are maybe some questions here, and some at least of the services are beginning to ask them. Should there be more 'formal' opportunities for service users to express their views? What you say about the people you depend on to their face may not be quite the same as what you'd say to someone else, or even to those people in the 'safe place' offered by a more formal meeting. Is there value in building a network of 'visitors' along the lines developed by l'Arche – but between different services united by a common philosophy?

Ironically, the new ways of working with people who have severe mental handicaps are beginning to bring a perplexity as well as a strength to this business of quality control. It is now not entirely unknown for some community services to bar the homes of the people they serve to the 'casual' visitor. That is perfectly

*CMHERA is the main agency offering courses in normalisation and PASS in Britain. See Appendix B for address understandable: it is in keeping with the best aspirations of the service that people should have the maximum degree of normal privacy and respect; to have perfect strangers tramping through their living-rooms just because they are 'interested' not in them but in 'service provision' is a violation of every tenet of 'ordinary' life. The perplexity is that if no one but the staff get into people's houses, then no one but the staff will know what goes on in them. The onus on the service to preserve the highest standards becomes greater not less; and the need to help people with mental handicaps to build their own network of friends whom *they* want to invite home has an additional dimension.

The strength that the new ways of working bring to the business of quality control is the other side of that coin. Just because they pay so much determined attention to individuals, these services have the surest guide to measuring their own performance that there is. The formal tool of the individual programme plan, through which many of them translate that attention, is in itself a built-in monitoring device: if the goals are not achieved, then something has gone wrong – not in the individual, but in what she or he is offered. Even where those plans are not formally used, the attention to the individual remains. These are not the sort of services that say someone is 'severely behaviourally disturbed because they are mentally handicapped'. They are the sort whose staff ask themselves at every point what it is that is making an individual angry or unhappy – and try very hard to find out and offer something else. That, in the end, is maybe the surest guide to quality that we have.

10 FROM SERVICES TO COMMUNITY

But the community isn't ready for them . . .

But what is this 'community' anyway? It just doesn't exist . . .

These arguments against offering people with severe mental handicaps their opportunities to share in the ordinary life of their own local neighbourhoods must be among the oldest in the business, and a powerful block they can seem to the development of new patterns of community services. They have a certain force, too. It isn't hard to find a story about outraged neighbours who object to people 'like that' coming to live on their street. It isn't hard to look around our inner cities, towns and villages and find evidence of loneliness, isolation and rejection among the people who have been singled out as 'odd' or 'different'. For a society said to be becoming more and more pluralist, we really are a pretty conformist lot.

Yet it isn't hard, either, to find stories of how the initial opposition, born of fear and ignorance, can turn to positive neighbourliness once people get to know the 'people like that' as individuals rather than relying on the mythologies. It isn't hard to find examples of how people who are 'odd' and 'different' can be not just tolerated but enjoyed for who they are. The trouble is, maybe, that it's a lot easier to believe the first sort of story than the second, for the first lets us go on talking about 'public education programmes' and so putting off action for another year or so, while the second demands hard work, commitment and a recognition that the best way to 'make the community ready' is to introduce it to some real people. The 'public education programmes' we need are based on the evidence of what's happening, not on what might one day be.

None of this is to deny the hard work, the knocks and the unkindnesses that people with mental handicaps are going to meet along the way to their place in their community. They don't need telling about that. They know it already and they can sometimes despair at the ignorance. They know what to do about it,

too: 'We should do more things with people who are not handicapped, so that they would get to know us.'

It is precisely this that the services, schemes, projects and gatherings together of people described in this book are finally about. If one thing that unites them all is that they are to do with enabling people with mental handicaps and their families to live more 'normally', more 'like other people', then another is that they know they can do it. A 'service' here is not structure which enables one set of people to be active around another set of people who are passive receivers of their kindness and concern. It is a dynamic process which depends on the *active* participation of the parents and people with mental handicaps involved, in their own homes and in the area of which they are a part. This new view of what makes up a 'service' is, in the end, about the building and the creation of community, for 'community' too is a dynamic and not a static concept, not a place you arrive at once you have learned the skills, but the places and the people that you meet along the way.

And what the 'services' gathered in this book show is that there's a lot of it about if only we put the energy into building on it. It is there in the streets and shops and Indian take-aways in the areas we know well – which is why it is so important that people with mental handicaps are helped to remain in their own home area unless they themselves choose to move on. It is there in the people who have known them for years and the people who get to know them as they go about their ordinary life at home, at work, at leisure. And it is something that grows from these bases as more and more 'ordinary' people are drawn into helping to create it. People with mental handicaps are members of 'communities of interest' in the variety of leisure activities that they are sharing with others. They are part of 'working communities' on the dustcarts of Newcastle, in factories in Bradford, in a bakery in York and in a whole lot of other places too. And they are not just somehow slotted into 'communities' that already exist. By their presence, they are helping to build them.

So community is places and community is people, and the challenge and excitement and hard work as well is to build with these. That is what all the people in this book are doing – whether they are parents, people with mental handicaps, direct care staff, managers, administrators, 'volunteers', friends, neighbours, shopkeepers, or any one of a whole host of others.

As one of them says: 'Your group has learned to take responsibility and to see our people become responsible adult citizens and to be able to act unselfishly for the benefit of those people . . . Most important is that non-handicapped should see us do something worthwhile . . .' He was talking about building self-advocacy. But what he says will serve here too. Most important is that people with mental handicaps are being helped to offer their presence and their contribution to the building of community. And that's not just worthwhile. It's something to celebrate – for them, for all those who help them and for anyone who has a care for the future of this society.

APPENDIX A

GOOD THINGS TO READ FIRST!

Each chapter of the book has its own references. This list draws together a few of those for anyone who wants to start finding out more about new approaches to services for people with mental handicaps. Many of them have the additional advantage of being quite short! A comprehensive reading list, covering all aspects of the lives of people with mental handicaps and their families, is also available from Campaign for People with Mental Handicaps (see Appendix B for address).

Philosophy into action

An ordinary life: comprehensive locally-based residential services for mentally handicapped people, project paper no 24. London, King's Fund, 1980. Outlines a philosophy of local residential services and how local people might work to achieve them.

An ordinary working life: vocational services for people with mental handicap, project paper no 50. London, King's Fund, 1984. Does the same for a vocational service.

Going to work, by Alison Wertheimer. London, Campaign for People with Mental Handicaps, 1985. Shows how people with severe handicaps can find satisfying and worthwhile jobs once those who help them believe it's possible; lessons from experience in the United States.

Hope for the future: CMH's evidence to the Social Services Committee on community care London, CMH, 1985. An examination of what's wrong with present policies on 'community care' – and what needs to be done to build on the aspect that *are* working.

Key concepts in community based services, by Nan Carle. London, CMH, 1984. What do we mean anyway when we talk of 'comprehensive community care' or 'core and cluster' housing? A guide to the real meaning and value of 10 key concepts behind developing services.

Leisure, by Alison Wertheimer, London, CMH, 1983. Examines the meaning of leisure in all our lives and how it can be made more fulfilling for people with mental handicaps.

Mainstreaming in Massachusetts, by Mark Vaughan and Ann Shearer. London, CSIE/CMH, 1985. How does special education develop when parents, educators and the general public really accept the principle of integration? Lessons from the United States.

People first: developing services in the community for people with mental handicap, project paper no 37, by Linda Ward. London, King's Fund Centre, 1982. A heartingly weighty compilation of new services initiatives, covering every aspect of the life of people with mental handicaps and their families, with assessments of strengths and weaknesses.

The principle of normalisation: a foundation for effective services, by John O'Brien and Alan Tyne. London, CMH, 1981. Outlines clearly the philosophical starting point for so many of the new services, and examines its implications in action.

The consumer view

Our life *and* Listen! London, CMH, 1972 *and* 1973. Reports of the first British conferences for people with mental handicaps; many of their comments on services are still echoed today.

We can speak for ourselves!, by Paul Williams and Bonnie Schoultz. London, Souvenir Press, 1982. A full and heartening account of the birth and beginnings of the self-advocacy movement – in the USA and in Britain – with much information on how self-advocacy groups can grow.

USEFUL ADDRESSES

This list draws together the addresses of the main organisations and services referred to in the text. The ones whose name is in bold type are the ones which are described in detail.

General

Campaign for People with Mental Handicaps (CMH)
Community and Mental Handicap Education and Research Association (CMHERA)
12a Maddox Street
London W1R 9PL

Independent Development Council for People with Mental Handicaps (IDC)
126 Albert Street
London NW1 7NF

International League of Societies for Persons with Mental Handicap (ILSMH)
248 avenue Louise
Box 17
B-1050 Brussels
Belgium

King's Fund Centre
126 Albert Street
London NW1 7NF

MENCAP (Royal Society for Mentally Handicapped Children and Adults)
117–123 Golden Lane
London EC1Y 0RT

National Children's Bureau
8 Wakely Street
London EC1V 7QE

The Spastics Society
12 Park Crescent
London W1N 4EQ

Family Support

Birmingham Multi-handicap Group
Cleveland Tower (Ground floor)
Holloway Road
Birmingham B1 1UB

Contact a Family
16 Strutton Ground
London SW1P 2HP

Crossroads Care Attendant Schemes
94a Coton Road
Rugby
Warwickshire CV21 4LN

Family Placement Scheme for Mentally Handicapped Children
Department of Social Services (Advisory Section)
Merrion House
110 Merrion Centre
Leeds 1

Honeylands
Pinhoe Road
Whipton
Exeter EX4 8AD

Southend Parents' Groups
19 Avenue Terrace
Westcliff on Sea
Essex SS0 7PC

Education

Centre for Studies in Integration in Education (CSIE)
16 Fitzroy Square
London W1P 5HQ

Tom and Bobby Hulley
8 Vallowsgate
Stevenage
Hertfordshire

Kingsway-Princeton College
(Social and Community Studies Department)
Sidmouth Street
London WC1

National Bureau for Handicapped Students
336 Brixton Road
London SW9

National Portage Association
4 Clifton Road
Winchester
Hampshire SO22 5BN

Pingle School
Coronation Street
Swadlincote
Burton-on-Trent
Staffordshire

Portage Home Visiting Service
Winchester Health Authority
Silverhill
Winchester
Hampshire SO23 8AF

Springfield Road Junior School
Swadlincote
Burton-on-Trent
Staffordshire

Work

Camperdown Day Centre
Mylord Crescent
Camperdown Industrial Estate
Killingworth
Tyne and Wear

Geoffrey Rhodes Centre
(Employment Liaison Officer)
Algernon Road
Newcastle-upon-Tyne NE6 2UZ

Gillygate Wholefood Bakery
Miller's Yard
Gillygate
York YO3 7EB

Pathway Employment Service
169a City Road
Cardiff CF2 3JB

The Wedge
11 Norwood High Street
London SE27

New Homes for Children and Young People

Barnardo's
7 Lineside Close
Liverpool L25 2UD

Exodus
(The campaign to bring children out of hospital)
16 Fitzroy Square
London W1P 5HQ

Northgate Hospital
(Unit Administrator)
Morpeth
Northumberland

Parents for Children
222 Camden High Street
London NW1

Housing

Cambridge Social Services Department
(Group Homes Officer)
County Hall
Hobson Street
Cambridge CB1 1NL

Hasland Community Living Assessment and Training Unit
55/57 Mansfield Road
Hasland
Chesterfield
Derbyshire

Greenwich Social Services Department
(Principal Care Officer)
Peggy Middleton House
50 Woolwich New Road
London SE18

l'Arche
127 Prescot Road
Newsham Park
Liverpool 6

l'Arche Secretariat (UK)
14 London Road
Beccles
Suffolk

Housing in Context

NIMROD
The White Houses
40/42 Cowbridge Road East
Canton
Cardiff CF1 9DU

Wells Road Service
Knowle Clinic
Broadfield Road
Knowle
Bristol BS4 2UM

Research

Mental Handicap in Wales Applied Research Unit
44/46 Cowbridge Road East
Canton
Cardiff CF1 9DU

Department of Mental Health
(Linda Ward/Oliver Russell)
University of Bristol
39/41 St Michael's Hill
Bristol BS2 8DZ

Leisure

Links Scheme
Islington Adult Education Institute
Shepperton Road
London N1 3DH

Outreach
393 Bury New Road
Salford M7 9BT

Path Productions
38a Duncan Terrace
London N1 8AL

Self-advocacy

Avro Student Council
Avro Training Centre
Avro Road
Southend-on-Sea
Essex

Participation Forum
MENCAP Divisional Office
115 Golden Lane
London EC1Y 0TJ

People First
126 Albert Street
London NW1 7NF

People First
P O Box 381
Tacoma
Washington 98401
USA

People First of California
Developmental Disabilities Council
Room 320
1507 21st Street
Sacramento
California 95816
USA

APPENDIX C

QUESTIONNAIRE TO AGENCIES*

1 *Title of service*
Address and phone number

When did the service start?

Who is responsible for the service?
Name of director/organiser/coordinator
Name of agency

Who funds the service?
Name of agency (or agencies)

---

2 *What are the aims of the service?*
Have these changed since it began? If so, how?
(Do use more paper if necessary!)

---

*This is the preliminary questionnaire sent to participating agencies.

3 *Who is the service for?* a) Geographical catchment area Total population of catchment area	
Number of mentally handicapped people in catchment area to whom service might be useful (please indicate whether number is actual or estimated)	
b) Number of people actually served – when the service started	
– currently	
Do the users have any particular characteristics? (specific degrees or types of handicap, for instance)	
4 *How is the service publicised?*	
5 *What does the service offer?* Programes offered – when it started	
– currently	
6 *How is the service staffed?* a) Professional groups involved Numbers in each professional group – when the service started	
– currently	
Involvement of volunteers – when the service started	
– currently	
b) Training offered to staff – before the service began	
– since then	
– currently	
to volunteers – before the service began	
– since then	
– currently	

7 *Financial details* Initial capital expenditure (amount, for what)	
Subsequent capital expenditure (amount, for what)	
Running costs per user per year – in service's first year	
– in 1983/4	
– in 1984/5	
8 *Setting up the service* a) Who had the idea? (Agency or agencies, group(s), individual(s))	
b) Who was involved in planning the service? (Agency or agencies, group(s), individual(s))	
9 *What were the key elements in getting the service started?*	
10 *What are the key elements in keeping the service going?*	
11 *How do you maintain the service's quality?* (Monitoring procedures, consumer feedback arrangements, etc)	
12 *Do you have any advice for others thinking of starting a similar service, arising from your own experience?* (Do use more paper if necessary!)	
13 *Do you give permission for photos by Raissa Page to be used in the book?*	(Please answer Yes or No)
Do you give permission for Raissa Page to use her photos of your project in other ways that benefit people with mental handicap?	(Please answer Yes or No)

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Note: The entries in **bold** are the schemes described in the book

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Building Community

WITH PEOPLE WITH MENTAL HANDICAPS, THEIR FAMILIES AND FRIENDS

What does it mean to build new community opportunities for people with mental handicaps? Who is involved? Who benefits? Are there key factors that make for success?

Building Community describes 30 different services that are finding some answers, and relates their experiences to the debate about 'community care'.

Between them, the services are offering family support, alternative homes for children and a variety of housing. They are working towards integration in ordinary local patterns of education, employment and leisure. They are united by a belief that everyone with a mental handicap has a right to a valued place in their community – and a contribution to make to its creation as well. And they are showing how statutory and voluntary agencies, families, fellow workers, friends and people with mental handicaps themselves are turning the belief into action.

For anyone who wants to do the same in their own area, *Building Community* offers ideas, encouragement and a starting point.

Ann Shearer is co-founder of Campaign for People with Mental Handicaps and is a freelance writer. Previous books include *Disability: Whose Handicap?* (Blackwell, 1981) and *Living Independently* (Centre on Environment for the Handicapped and King's Fund, 1982).

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