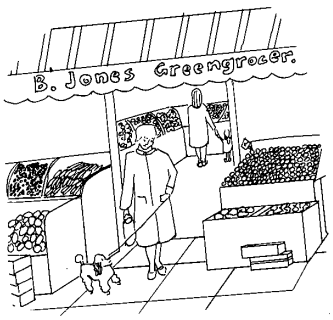
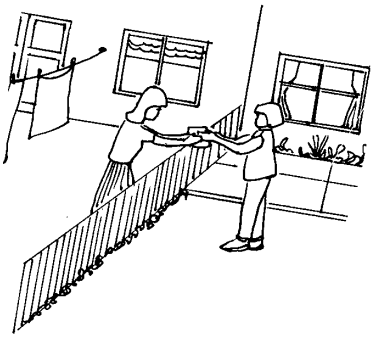
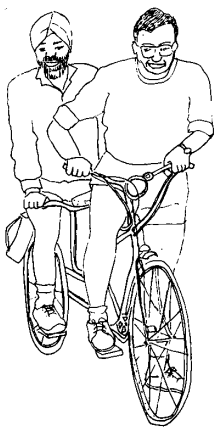


TIES AND CONNECTIONS

An ordinary community life for people with learning difficulties





KF CENTRE

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre for Health Services Development has a particular role in promoting advances in policy and practice in relation to problems of health and related social care. It offers a forum for informed debate, provides an information service and organises a range of activities designed to support local strategies for service development.

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TIES AND CONNECTIONS

An ordinary community life for people with learning difficulties

FOREWORD

It is now widely accepted that people with learning difficulties are entitled to live and receive support in the community. The King's Fund ordinary life initiative helped to point the way and has informed many service developments. Now the Griffiths Report opens up further possibilities for developing 'community care' schemes and ensuring that people with learning difficulties have opportunities to live and work with their fellow citizens.

So far, much of the emphasis has been on setting up housing schemes so that people have a chance to live in an ordinary house in an ordinary street. Whilst this is important, it is by no means enough. Most of us benefit from far more than simply being in the community. We enjoy leisure activities, have friends and make relationships. Many of us also hold down jobs which provide income and further opportunities to meet and interact with other people. If we think about our own quality of life, much of this stems from our relationships with other people - our ties and connections.

This book is about helping people with learning difficulties to develop their ties and connections with others in the community. It explores the many different ways in which people meet and develop relationships with others. Perhaps even more importantly, it makes practical suggestions for people with learning difficulties themselves, families, service workers and other interested citizens.

Like the other publications in this series 'Ties and Connections' is the product of a group of people who showed great commitment to their project over a long period of time.

Those most actively involved in the many meetings, and in writing first drafts of the book were:

Hugh Firth
Chris Gathercole
Keven Hall
Sue Hubbard
Kevin McGrath
Jan Porterfield
Mark Rapley
Joan Rush
Alan Tyne
Linda Ward
Andrea Whittaker.

Others who attended some of the early meetings, sent us ideas and commented on drafts included:

Peter Beresford
David Felce
Zenobia Nadirshaw
Paul Williams.

Various drafts of the chapters, and most of the editing were undertaken by Alan Tyne. Hugh Firth provided the Further Reading section.

As with other initiatives in this series, the King's Fund Centre will hold workshops and conferences focussed on the issues raised in the book, and will be looking for other ways of encouraging all who are interested in supporting people with learning difficulties to become actively involved in helping them make 'ties and connections.'

Roger Blunden
September 1988

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PREFACE

"...fellowship is heaven, and lack of fellowship is hell: fellowship is life, and lack of fellowship is death..."
William Morris - from The Dream of John Ball

In 1980 the King's Fund Centre published **An Ordinary Life** (1) describing ideas and strategies for securing for people with learning difficulties the same opportunities in life that other citizens expect and hope for themselves. It concentrated on ways of ensuring that people with learning difficulties had access to the same range of ordinary homes (houses, flats, bedsits) as other people.

At the time, this was a very important priority. The move to close the big institutions was not yet under way; many people still believed that hospitals were the best places for people with learning difficulties to live. **An Ordinary Life** explained why it was important for people to have ordinary housing options, and suggested some ways that these could be achieved. It also anticipated that this was not the whole story, and that as we began to open up new opportunities in people's lives, there would be more areas of life which needed careful thought and planning.

The working group that produced "An Ordinary Life" then looked at employment because this is what most people want for themselves. **An Ordinary Working Life** (2) has stimulated a lot of work aimed at helping people with learning difficulties to get real jobs.

Since the movement towards 'community services' started, many more people with learning difficulties are living in ordinary houses and an increasing number work in open employment. This does not necessarily lead to a 'community life' as other people experience it. We meet lots of people who receive all their services in the 'community' (in the sense of 'not in hospital'), and yet hardly participate and share at all in a community life.

This book is about taking that next step to supporting people's participation in the community.

NOTES:

(1) For ease of reading we have tended to use personal pronouns alternately, rather than "him/her" each time. Please read he for she and vice versa where appropriate.

(2) Throughout the book, the stories and quotes are true ones. However, we have changed all the names to give anonymity. We have tried to follow people's personal preferences for being called by first names or the more formal Mr/Mrs/Miss.

3) Throughout, we have used the term 'learning difficulties' or 'learning difficulty' instead of 'mental handicap'. In this we support the continuing search for more accurate and less stigmatising terminology, and the expressed preferences of many people with learning difficulties.

INTRODUCTION

What is 'ordinary'?

When we use the word 'ordinary', we do not mean dull, or exactly like everyone else, or standard, or even average. 'Ordinary' simply means having the opportunities and options which most people have. We live in a world where it is ordinary to have variety and opportunity and choice. It is ordinary to be special, at least to someone. It is ordinary to have opportunities for parts of our lives to be special and also to be different in ways which other people value very highly. Our book is about ways that people who have learning difficulties may share such opportunities.

What is 'community'?

Among people who organise and provide services for people with learning difficulties the word 'community' has come to mean almost anywhere that is not a large, long-stay hospital. But this book is not about 'community policy' or 'community care' it is about community life. By community we mean the ways that ordinary people live their lives. Community is the set of connections or ties a person has with others, whether or not it is based in a place on the map.

The notion of 'connections with others' is important in our understanding of what community life is about and it is worth looking briefly at some of the things which go to make up 'community' for the majority of people.

Community and place

In the past ties of family, work, religion and custom often not only overlapped significantly but were also strongly linked with the place where you were born and led your life. This created a distinct pattern of community life.

In twentieth century Britain people tend to travel much more and are familiar with many places. Some people travel long distances to work each day. Many people travel for education or holidays. Television, films, magazines and newspapers bring us pictures from all around the world. People leave their families and settle in quite distant places, yet with modern communications they can easily keep in touch. Many have important 'ties' in different parts of the country, or indeed in the world. People who own cars need not depend on their local area: for example, they may think nothing of driving some miles to do almost all their shopping at a huge late-night shopping centre.

But in spite of this increased mobility, for many people, some small local area remains important in their lives: perhaps because it offers useful resources which they need, such as shops, a place of worship, a bank, or garage. Having lived in a place for some time, people become 'attached' to it. They may think of themselves as 'belonging' to it, often with some pride. This sense of attachment comes from knowing their way around, knowing something about the history of a locality, its people and its customs, and being recognised by other people who live in or regularly use that local area.

'Place' then, is likely to be important in people's lives in varying degrees and for different reasons.

Community and interest

People describing 'my community' may be thinking of very different kinds of things. Yet people seem to have a pretty strong sense of what their community is and what makes it work or not work for them. Some people have ties and connections with others which not only stretch across the world, but are of many different kinds, including family, culture, and religion. There are 'communities of interest' of a thousand different kinds - of commitment to particular causes or groups, work, leisure and learning.

For some people, community may be a far-flung network of people, many of whom may never have met one another. Yet the connections are real and significant in their daily lives.

People who live in institutions have often lost all

connections with any kind of community. Often this was the reason why they went to live in an institution in the first place. Further, when people have lived a long time in an institution, any connections they might have had become weakened and broken. This can lead to difficulties when they return to community living.

Community and values

Values are a person's sense of what is important in life. In our society there are different sets of values existing side by side - some of which go well together and some which seem opposed to one another. For instance, many families, most religions, many social movements, and some political philosophies emphasise the importance of values such as cooperation, sharing, giving, and mutual aid. Other values emphasise independence and competition, self-interest and individualism.

Some people argue that in the modern world, values of independence, competition, self-interest and individualism have grown stronger at the expense of those of cooperation and sharing. They say that the ethics of personal success and gratification may have largely replaced older ideals of commitment to other people.

In a world that operates strongly on values of independence and self-interest, or where worth is judged by possessions and competitive achievement people who are vulnerable because they are handicapped are likely to be more at risk of rejection. In this book we are interested in exploring ways of supporting **interdependence**. We think that a society which is good at fostering interdependence will be less likely to push people out because they are seen as different and inconvenient. An interdependent society will be much more skilled at including **all** its citizens, regardless of race, sex, creed or disability.

Community as ties and connections

The best way we have found of thinking about community is to imagine it as the set of **ties and connections** which a person has with others. These arise and are sustained in many ways: through family, through locality, through work or interest. Some of these will be **strong** and some **weak** ties.

Four things seem to have an impact on the strength of people's ties and connections. (3).

Time. The amount of time people spend together and the length of time they have spent together in the past.

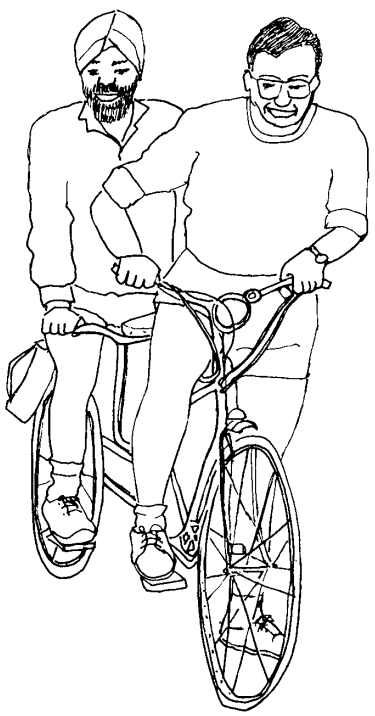
Intensity. Some ties and connections are invested with a lot of emotion. They mean a lot to us, perhaps more than anything or anyone else. Others are less important, and some not very important at all.

Intimacy. We share confidences with some people more than with others. Some of our ties and connections involve a lot of trust.

Reciprocity. The exchange of services between people. This may range from simply following the rules of politeness, to providing practical help, to sharing major parts of our life and work.

Typically, people have few strong ties in their lives but quite a number of weak ones, though both are important. Weak ties are the networks of acquaintance which provide familiar faces, people to get information from or just casual companionship. So people who have lots of fairly weak ties, may be well placed to gain important benefits from community membership. This is quite important when we consider the situation of people who, for whatever reason, have lost or have never had any substantial connections to others.

Having ties and connections to others is



important to the vast majority of people. It is not necessarily the same as achieving happiness or fulfilment, although it often seems to be. We recognise too that ties and connections involve constraints, restrictions, and tensions and look at some of the 'limits of community' in part four.

This book looks at a number of different important sources of ties and connections:-

Friendship: having friends, relationships, including a 'best friend'. Mostly these will be what we have described above as 'strong ties'.

Acquaintance: having a network of acquaintances.

Membership: being a member of associations and organisations.

Keeping in touch: with trends and movements of interest; subscribing to them; belonging to 'social worlds'.

Being part of a family: having an active connection with family life.

Having a partner: or someone to whom a long-term commitment has been made.

Being a neighbour: living next door to, or at least near to someone - down the street or across the road.

Knowing or being known in a neighbourhood: using the resources of a neighbourhood (usually the area within easy walking distance from where you live) and recognising and being recognised by others who use them too.

These different kinds of 'ties and connections' have a different importance for different people, they are not all essential. Each person combines some or all of them to make up their own community life.

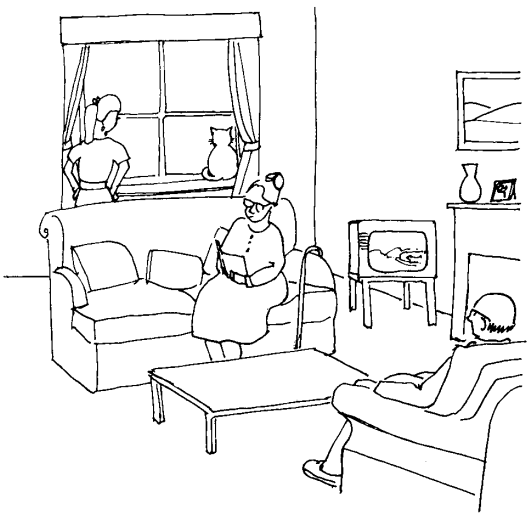
These are not the only ways of being connected with others. There are others too, such as being a patron, a customer or client; being an employer or employee; a candidate, representative, constituent or voter. Being a performer, a visitor, a patient or part of an audience, are all ways of being 'connected'. Many of these are to do with our position in the community, and the financial or political opportunities they give us for 'joining in'. We have chosen to explore the ties and connections which seem to us to be the most fundamental.

What's the situation for people with learning difficulties?

Many people with substantial handicaps find themselves needing a lot of help and support in securing a home and arranging a home life for themselves. This can lead to people becoming more and more dependent as a result of many separate decisions made on their behalf. Usually, each decision is taken by a well-meaning person who is trying to do their best with the resources available. Nevertheless, the effect often adds up to a distortion of the person's life and separation from the sort of community life lived by most of society. Some people remain with their parents until late in life. This can work well but often there are problems on both sides. Achieving some independence from parents seems to be important in the emergence of our adult identities. This is often accomplished by moving away, at least for a time, even if we continue to enjoy a close and loving relationship with parents.

In Asian and other ethnic communities, ideas about adulthood and independence are often less sharply defined: young people are encouraged to remain dependent until a much later age than in western cultures. Whilst this may mean that people get a great deal of family support, families from these groups may find it even more difficult to help their sons and daughters with learning difficulties make the transition from the dependent-child role to that of independent adult.

People with learning difficulties who miss the opportunity as young adults to move away from



home may find themselves trapped in the parental home in a kind of perpetual adolescent role from which there is no escape. The situation is well described by Alison Wertheimer in **'Living in the Present'** (4). The situation also impinges on the friendships and lifestyle of ageing parents who may themselves experience a narrowing social world and practical hardships too.

Other people are moved, often with reluctance, into some kind of institutional setting. This decision is usually recognised as an unhappy compromise, and often follows or accompanies a family crisis. The person finds herself living with strangers, in a place she did not select and where she has little or no control over any area of life. The institution and the people in it soon become the person's entire world.

In contrast to both of these, most non-handicapped adults have a variety of relationships, go to many places each day, and have many choices and opportunities. They have control over some, and often most of their lives.

An option that is increasingly available to people with learning difficulties is to move into a house, with support, in a community setting. Even here though, choices are often severely limited. People tend to be grouped in ways over which they have little control. There are very restricted daytime and leisure options. Even in relatively high quality community services, people can find themselves with very few relationships except with other people who have handicaps, or with paid staff; and very few opportunities to make new or long-lasting relationships. Even those a person does have, with family for instance, may fade away for lack of thoughtful support and attention.

Many people with learning difficulties have been discouraged from thinking about ordinary futures for themselves and have been denied opportunities for ordinary experiences, such as doing a job or learning a skill. Enforced poverty too creates a trap which further limits choices and restricts experience.

In short, many people with learning difficulties live in a world which is impoverished in its relationships. They may be seldom alone, yet often lonely; living with people not of their choosing; rejected by not being chosen by others. They may have no one to stand with them when things are difficult. They are likely to have many unequal relationships, few opportunities to be givers.

Many handicapped individuals find themselves quite literally abandoned and with no authentic relationship. That is not only sad for them and a failure for us but it is also immensely dangerous. People who have no one to stand by them, no one who has made a commitment to them are seriously at risk of being pushed to one side and forgotten in a busy and competitive world.

Yet we know, too, of stories of people who have built satisfying lives for themselves in ordinary communities. From them, and those who have supported them, much can be learned.

In Conclusion

- **In this introduction we have tried to summarise the project with which we would like to engage people's attention -** of building and sustaining connections with community in the lives of people with handicaps.

- **The second part of the book describes some of the main parts of community life -** friends, acquaintances, family and partner, membership, social worlds, neighbours and neighbourhood.

- **The third part explores what can be done about it -** by people with handicaps, families and friends, staff and service-providers, and community members.

- **The fourth part looks at some of the limits to ties and connections -** the pains as well as the pleasures of community life.

At some time in our lives, all of us are likely to need special help. With luck, we will grow old. Some of us will get to be handicapped before we do. A catalogue of complaints, diseases and accidents awaits us. Any of us may become the parent, relative or neighbour of someone who has a substantial handicap. In time age itself will be our handicap. If there are to be alternatives for each of us to living in an institution, then we all need to look to our investments in connections with other people - in our investments 'in community'.

People with learning difficulties are often at risk of losing their 'connections with others'. We need to work on ways of supporting people in maintaining old links and making new ones. In so doing, we may find ways of supporting greater quality in all our lives.

TIES AND CONNECTIONS

This chapter looks at what seems important for ordinary community lives for anyone. Key features are described as 'accomplishments' - worthy achievements that give meaning to life. It also looks at some of the important issues for people with learning difficulties in achieving each of these accomplishments. Each section looks at just one accomplishment and finishes off with some ideas about things that could help.

It's worth emphasising that this is not the complete list of every kind of 'tie and connection' - each person's 'community life' is unique, with its own peculiarities and strengths. There are however, some important 'building blocks' of a community life, and friendship seems to be the most fundamental of them all.

FRIENDSHIP

"It doesn't matter how bad we are, everyone needs friends. Friends are nice".

"Some people are nervous when speaking. Friends make you feel less nervous".

"If you are not going to do things together, there's no point in living".

"What makes a friend? Give and take. Being helpful".

"I met Mary at Sunset House. She's worse on her legs than I am. They're getting everybody out of there. London Road was converted to separate flats. It was suggested to us and we said we'd like to try it. And it's worked".

"You need to be introduced. My mother gets fussy about me talking to boys".
(From a conversation about 'friends').

Not everyone agrees what a friend is. The same relationship might be described by one person as friendship and by another as mere acquaintance. Whatever the definition, most people value friendship and those who feel they don't have friends would usually like to have them.

Relatives and lovers may sometimes be described as friends. Mahatma Ghandi said he and his wife were 'best friends'; and in discussing friendship with a group of people with learning difficulties for this book, one person said '... your mum is your best friend in all of your life...'. However this book separates friendship from having a partner and an active connection with family.

Friendship is a two way thing. As one person in the discussion about friendship said "a friend is someone you like who likes you". Friends get many things from each other - support, help, advice, someone to tell troubles to, to share happiness with, and many other things besides. Even when they can't spend time together, they often remain 'close' and write or phone when they are apart. But even without this contact the friendship may flourish ("I hadn't seen her for five years and we felt as close as we did when she lived next door").

There are many things that are said to make for strong friendship - shared experiences, the same sense of humour, helping each other in times of trouble, common background, shared interests, similar or complementary personalities. Some friendships have some or most of these, others have few or none, and yet both people in the relationship would describe it as a friendship. In Western societies, close friendships between women seem to be more common than close friendships between men. There are many theories about the reasons for all this and we've listed some references at the end, where you can read more. For now it is sufficient to note that friendship is something that is given by both people in a relationship, and is freely given.

Friendships change over time. Childhood and adolescence are often a time of very close friendship, but as lives move in different directions the ties are sometimes broken, or

sustained with only very occasional contact (like greeting cards every year). People may be very close for a short period, through common experiences (like the adversity of war, or being in hospital together). Once the experience is past they lose contact. Yet for some people such friendships have become important and enduring ones. One often noted change is of friendships which become deeper and stronger as people spend more time together - through work, leisure pursuit, or common commitment to a cause or belief.

Friendships change as people's lives change. Children and adolescents spend a lot of time with a 'best friend' or small group - but 'best friends' may change from week to week! Others have a best friendship that starts in childhood and continues throughout life - although there are times when the relationship is closer than at others. Young parents may focus so much of their energy and attention on the family that they feel lost when the last child leaves home. They may find it very hard to re-establish old friendships or make new ones. Divorce, moving to a new area, changing job, unemployment, retirement from work are also likely to be difficult times for people when old friendship patterns are broken and new ones must be established.

People who have especially stressful jobs - such as nurses or police officers - may find it difficult to make friends outside those who share their particular work experiences. Shift workers and those who travel a great deal may find their irregular hours make it difficult to form regular commitments. Older people may find themselves without any contemporaries - and this may make friendship difficult, for lack of a common history to share.

Friendship can bring people close together, and be a source of great enjoyment and comfort. But it can also expose people to the risk of disappointed expectations or conflicting feelings and loyalties. Friendships can create demands and may even end as friends argue, move away or die. Despite this, most people would rather have friends than go through life without them.

Friendships are often forged from shared difficulties or an alliance against common problems.

Jim and Eva spent many years on bleak wards with few possessions and little dignity. They banded together against staff(who they said were hurting weaker patients) and were punished for it. They had their 'parole' stopped for speaking out against staff. People in the institution tried to split them up because they were 'trouble-makers' but they'd kept in touch. They now live in the community and sometimes meet to reminisce about 'old times'.

David lived in a secure hospital for 39 years. On discharge he expressed a wish to have a house of his own which he wished to share with one other person.

Jenny had lived for many years in a hostel and was beginning to think that because of her physical handicap she would never be able to live in her own place.

David met Jenny when he first moved to the hostel and over a period of two years their friendship grew and their understanding of how each could help and complement each other - David carried Jenny's shopping and Jenny helped David to understand money matters.

When the chance came they moved into their own flat where they share the household chores - doing those jobs that each is particularly good at and sharing others. Both have made friends through each other's families and have introduced each other to friends made in clubs and churches.

Miss McMahon and Miss Brown live together in a council flat in North London. They are both in their late fifties.

Miss Brown has always been physically disabled and lived in institutions from childhood, being moved from ward to ward, and eventually out into a hostel. Miss McMahon had lived in a large mental hospital where she was admitted as an adult after her mother died.

They didn't know each other before the move to the flat, but fortunately they get on well and are now good friends. At first they carried on with their previous activities - the ATC in the daytime and the 'Gateway' club some evenings. Latterly though they've both decided to stay at home and share the cooking and shopping, visiting the Post Office for the pensions. The club was somewhat noisy, and they only met people there from the ATC and hostel - no new faces. Now they are acquainted with the neighbours, and visit one old lady for tea. Miss McMahon attends the Roman Catholic Church a bus ride away, and sometimes people from the church visit them both, and occasionally take them on car trips and outings. At Christmas another local church invites them to lunch with thirty or forty others in the church hall. They are never sure why they don't see the people again till the following Christmas, but they always enjoy the lunch and the trip out.

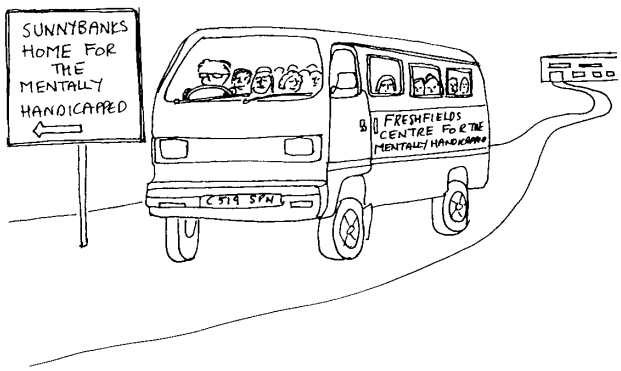
Miss Andrews, a friend from hospital days sometimes visits and stays overnight. But she used to cry when she had to return, and they found it hard to cope with. They often talk of the 'poor souls' in the hospitals they left, and occasionally Miss McMahon visits her hospital to see friends and staff.

They enjoy having people to tea, and pottering about the shops together. They've loved their holidays together at Butlins. Miss Brown's family have 'adopted' Miss McMahon too. Miss McMahon's church friends have befriended Miss Brown. Now they have each other and mutual friendships too.

What are the issues for people with learning difficulties

There are at least two kinds of important processes connected with friendship. One is to do with **making friends** and developing a friendship. Living at home with parents or in institutions, many people with learning difficulties find themselves with very limited opportunities to make friends. They may find themselves tied pretty closely to their parents' social lives, and surrounded mainly by people of an older generation, or by company only of their parents' choice. Or they may find that 'services' put limits around whom they meet and where.

People living in staffed accommodation are often off the beaten track. The size of the building or the way it looks may make it harder for people to mix naturally. When large numbers are grouped together, it is easy for segregated, group arrangements to prevail - a mini bus for outings, holidays and visits.



Attempts to provide volunteers or befrienders can be very helpful, particularly when they mean that one helpful citizen is matched up with one person with a learning difficulty. But often the one-to-one matching does not happen and volunteers work with whole groups. It is not clear what they are for, or how they are different from staff.

Some services are so arranged that almost every part of life happens under one roof or on one site - living arrangements, daytime activities, leisure

and recreation. This means that most people with learning difficulties meet relatively few people who are not either other people with disabilities or staff who are paid to be with them.

None of these things in themselves prevents friendship, and there are some good stories, for instance of Joseph Deacon (5) of how friendship has grown and remained strong in these surroundings. Nevertheless each of these things limits the opportunities for the kinds of relationships which are common for most non-handicapped people.

People from minority ethnic groups may have additional problems making friends. They are doubly handicapped - first by their learning difficulties and secondly by being perceived as 'odd' 'undesirable' or 'unfamiliar' just because of the colour of their skin. Low self-esteem and fear of prejudice may make it particularly difficult for them to make 'connections' in the community.

Meeting people and making friends leads to the second important process - **sustaining friendship** - doing all of those things which help keep friendship alive. Strong friendships can apparently survive many challenges - long separations, frequent disruptions, unequal relationships, few resources. But its likely that if all of the relationships you have are severely challenged in all of these ways all of the time, eventually some or **all** of them will succumb.

Because of limited opportunities for making friends, many people with learning difficulties find themselves with few friendships in the first place. Often those they have are continuously tested out. People may get moved from place to place a lot. Staff move in and out of people's lives too, and often as staff leave there is no-one who knows them well enough to be able to help sustain past friendships. Even where people live in 'community services' using ordinary housing, staff may not understand how important a part of their job it is to support relationships which are independent of the services. Even when they understand, they may not be sure how to go about it.

For many people with a learning difficulty, the staff who work with them are as close to a friend as they have. In one way that is a strength, and many staff come to see themselves as 'near-friends'. In another way, it shows how vulnerable people with a learning difficulty can be - even their closest friends are able to offer only a very limited friendship, bounded by a professional role and a job-description; they are always liable to move on and move away.

For people with learning difficulties it can be a kind of vicious circle in which restricted experiences and activity offer fewer possibilities of friendship; and fewer friendships further restrict the possibilities for experience and activity.

FRIENDSHIP - WHAT HELPS?

Of all the different ways of being connected with others, friendship is probably the most important to support. The essence of friendship seems to be that it is freely given and that makes it particularly difficult to arrange. The following ideas could help:-

- Paying particular attention to recognising friendships, especially when people themselves may not be able to tell us much about it directly.

- Not disrupting friendships by doing things such as: transferring people a long way away, or moving them from house to house, or to share a room with someone else, or shifting staff about to 'gain experience'.

- When someone does have to move and an important relationship is under threat, taking extra care to find ways of maintaining that relationship and seeing that other opportunities are created.

- Ensuring that people with learning difficulties have lots of positive encouragement and active support for developing connections with people thus increasing the chances that acquaintances may in time grow into friendship.

Remember - each suggestion is intended only as a starting point for practical exploration. The further reading at the end of the book may suggest others.

ACQUAINTANCES

Often people only have a few real friends, but many more acquaintances. Acquaintances are people to exchange greetings, chat and share information with. They give a sense of belonging and make an important contribution to many people's lives. Acquaintances may spend a lot of time together (for instance in the same workplace), or see each other only briefly if regularly (for example shopkeepers and customers).

have with others are these close-knit patterns of fairly small exchanges on a daily basis.

Acquaintances provide **company** when close friends are not around - parents watching children play in the park, shoppers waiting for a bus, office staff who regularly eat lunch at a particular local cafe. Acquaintances can also provide each other with useful **information** - contacts for self-employed decorators, or insurance salesmen, advice about the best doctor or dentist, greengrocer, supermarket, and so on. They may help each other in small ways too -

Acquaintanceship usually springs from circumstances or activities which bring people into contact - living on the same street, working together, going to the same place of worship. Going out to pubs, clubs, the cinema, theatre and leisure centres probably offers more opportunities for acquaintanceship than staying in to watch TV, read or listen to music. Using the local launderette offers more opportunities for meeting different people than doing the washing at home. Even doing outdoor chores, like hanging out the washing or sweeping the path, makes people more available for conversation and thus making acquaintances.

These small daily exchanges of pleasantries may be extremely important in the lives of people who would otherwise be very isolated. In some people's lives almost the only connections they

returning books to the library, giving a lift to a meeting, taking messages at work.

Many friendships begin as acquaintance, often merely by chance, and time and shared experience confirms them into friendship. Most acquaintances though, remain just that - casual contacts or 'weak ties'. People may have many separate acquaintances in different parts of their lives - home, work, leisure. When many acquaintances also know each other then we can think of them as forming a **network of acquaintance**. Though each individual tie may be a relatively weak one, there can be great strengths in these networks - they may pass information around very quickly, or act as gossip channels. In a crisis they can quickly mobilise help.

What are the issues for people with learning difficulties?

Many acquaintances simply grow out of the routines of everyday life - they are a fairly natural part of the business of living in a family and a neighbourhood, having a job, running a household and so on. When people with learning difficulties have these things, they can provide a basis for the growth of a circle of acquaintance. However what they often have instead is a wealth of organised leisure activities - visits to pubs and discos; music; pottery; keep-fit and beauty care classes at the further education college, and so on. Through these they are able to develop an expanding pattern of acquaintance - mainly though with other service-users, and the staff who come with them. It is as if a separate world is being created for them, a community within the community, and one which hardly touches the ordinary lives of ordinary people at any point.

Acquaintances seem to be sustained by some fairly simple social skills - chatting, taking turns in a conversation; saying hallo in the street or standing aside to let someone pass through a doorway. Simple acts of hospitality - buying a round of drinks, making a cup of tea, are all the stuff of acquaintanceship. With time, some people unused to these skills are able to learn them. Others will always need someone on hand to ensure these little customs are observed, and that the person with a learning difficulty gets to participate even if they may not be skilled in initiating them or carrying them through on their own.

The lack of a rich circle of acquaintances and sensitive help which could develop and sustain it, means that many people with learning difficulties simply lack company a lot of the time. They may spend their time with other people, and yet without any sense of being connected with their lives even by something so slight as acquaintance. Perhaps most importantly, they may lack some of the vital kinds of useful contacts which acquaintances bring into many of our lives.

A network of acquaintances can probably never stand instead of what we have described as real friendships. But for people who may have very few friends indeed, and may be in danger of losing those they do have, then a circle of acquaintance becomes very important.

ACQUAINTANCE - WHAT HELPS?

Since forming and sustaining an acquaintance does not demand too much of the people involved, it is relatively easy to foster. Some ways of helping are:-

- Using places where other people are, and at times when others are there. For instance it is better to use a pub or cafe that a reasonable number of local people go to, although maybe not at a frantically busy time which might make any kind of conversation (except with a crowd of friends) very difficult.

- Developing a regular pattern of using places such as the swimming pool or library, so that you are likely to meet the same people.

- Having someone (a staff person, citizen advocate, friend, relative or volunteer) accompany the person with a learning difficulty to help develop acquaintances. In time that person can gauge how far it is possible to withdraw.

- Always being careful to set an example of appropriate social behaviour. For example many people with learning difficulties have spent a lot of their lives in large groups in noisy surroundings where you have to speak loudly, or even yell, to be heard. It might be extremely important, then, for staff or others to set the right example by speaking at an appropriate level in small group or individual conversations.

Remember - each suggestion is intended only as a starting point for practical exploration. The 'further reading' at the end of the book may suggest others.

MEMBERSHIP

When people join voluntary organisations, clubs, groups and classes they may simply be interested in the activity or cause. They may feel they have something to offer, or want to meet people with whom they have something in common. Perhaps for business contacts, or to give something back to the community.

Some people are just 'joiners' and can't seem to resist anything they are invited to join, still others do not join any kind of group. People often join organisations, classes and groups when they move to a new place. Moving away from previous ties and connections creates gaps which they want to fill. Also clubs and organisations often seek out newcomers - the vicar calls to welcome new parishioners and at the same time asks you to join the church choir or Women's Institute.

Joining at times of change may be very helpful in adjusting to new circumstances, but membership isn't necessarily permanent. People may become less committed to an organisation or evening class as they build up other ties and connections. Or they may find that the organisation is something they want to give a lot of time and energy to. Being a member is a matter of choice about whom to associate with, what to do and belong to.

There are a vast number of organisations, groups and classes, though choice may be to some extent limited by what's available locally, or by membership requirements. Some are for men or women only, for people with particular religious beliefs, political affiliations, occupations, skill levels; or for people from a specific ethnic group. Some claim they are open to anyone but set very high membership fees. Others require a character reference or that new members be nominated by a number of existing members.

Most organisations have some specific focus of interest which unites members - it may be a particular hobby or sport, a concern with civic affairs such as CND, or Friends of the Earth; or age group (toddlers, over 60s); being in similar circumstances (single parent family, retired, widowed, being overweight).

In 1987 the Community Organisations Forum of Tower Hamlets, (a London borough of 150,000 population) counted some 700 separate organisations in the district, including:-

Advice and Information Centres	51
Arts and Media	52
Business	2
Children and Youth	145
Docklands	32
Education	47
Elderly	29
Employment	16
Environment	20
Ethnic Minorities	90
Health and Disabled	47
Housing	30
Housing Associations	8
Housing Cooperatives	11
Housing (Residents Associations)	13
Housing (Tenants Associations)	96
Legal Advice etc.	3
Planning	3
Pressure Groups	28
Recreation	72
Social and Welfare Organisations	71
Technical Services	4
Transport	5
Umbrella Organisations	11
Women's Organisations	33

Some people give a lifetime commitment. Others simply want to be associated by being on the membership list and taking the quarterly magazine. Organisations provide many different opportunities for involvement and sharing with others.

Belonging to organisations is one way that people become part of their communities. Membership gives people status, (for example, 'She's a member of the Women's Institute'), because the individual gains from the reputation of the organisation.

Membership of organisations, groups and classes also offers opportunities for shared activities and this is an important basis for all kinds of relationships - a network of acquaintances and friends. There are routine activities for which the organisation exists - for example, the programme of events, football matches, ramblers' walks, social evenings. Each of these offers many roles (participant, team member, organiser, helper) - some very public (the team, the cast or exhibitors), but also many smaller, behind-the-scenes roles such as those who take the programme to the printers, or iron the costumes.

Most organisations have different kinds of meetings - comittee meetings, planning meetings, meetings to listen to a talk, take part in a debate, swap collections, and so on. These meetings also offer many opportunities to participate, beyond the obvious ones of chairperson, committee member, speaker, audience. Name badges need to be prepared, chairs arranged, refreshments provided, people welcomed, minutes and agendas circulated and so on.

People may seek roles that are very different from those they have in other parts of their lives (such as a coal miner who sings in a choir) and thus find outlets for creative abilities or organisational skills. Others take on roles that are similar to those in other parts of their lives (such as an accountant who becomes club treasurer).

Whatever role members of groups and organisations have, membership gives individuals a sense of belonging and being part of something that is larger than themselves. This sense of belonging is in itself important, as are the ties and connections that membership brings.

Mary Jones became involved with CND when her parents set up a group about three years ago. She goes to meetings which are held in a local community centre, and has been on demonstrations. She helps with preparing a CND newsletter and leaflets and assists on occasions when CND works with other organisations, for example during One World Week when various organisations set up stalls in the local square.

Recent experience in Islington, Bristol and Manchester has shown that ordinary people who themselves have an interest in an evening class or club can be the best people to support a person with learning difficulties who has the same interest. As in all membership, the shared

interest is essential.

Alan Baxter had been a local Scouting official for some years. When his son David, who has Down's Syndrome, was old enough he joined the local Cubs, and moved up through the pack, then the troop and into the Venture Scouts. Now in his early thirties, David still helps with a Cub pack. Through scouting, his childhood was enriched with a host of activities and friendship, even international visits.

Now as a man David lives at home with his parents and attends the ATC everyday. Church life is very important to David for he attends services regularly, and undertakes many duties in connection with the church and its maintenance. Recently they celebrated their centenary, and ceremonially walked the bounds of the district. To draw attention to their 100-year mission, church goers dressed in Victorian finery, as the founders would have, a century ago. In the picture which appeared in the local paper, David appears among the group, who are all dressed in 19th century formal dress.

One of the nice things about the picture and accompanying article was that nothing drew any attention in particular to the fact that David has Down's Syndrome. His membership of organisations has given him such a firm place in his local community that it needs no explanation or further comment.

David's story is quite unusual. Many people with learning difficulties are not valued members of their communities in the way that he is. David is a member of, and contributor to, a number of organisations which are part of the mainstream of life in his community, and had nothing in particular to do with handicap. This is partly due to David's engaging personality and motivation and partly due to the help and support his parents gave him. From the time he was a young child they advocated strongly for his inclusion in things from which he might easily have been excluded. As he grew, he began to follow their example, and now speaks out strongly on his own and others' behalf when he needs to.

What are the issues for people with learning difficulties?

Many people with learning difficulties do not belong to any organisations, groups or classes, others belong only to those which are specifically for people with learning difficulties. Often from the time they are young children, they start spending time in 'special' organisations, with others who are labelled in the same way.

In segregated schools and youth clubs, their experience of life becomes more and more separate from others of the same age and their activities child-oriented and without any valued responsibility. As people with learning difficulties spend more and more time with each other they feel less comfortable with non-handicapped people and non-handicapped people feel less comfortable with them. In the end everyone, including those with learning difficulties, begins to feel that they just don't fit in and are 'better off with their own kind'. A vicious circle has been created.

For these reasons many people with learning difficulties need some special help or support to enable them to join and actively participate in ordinary groups and classes.

In some parts of the UK, Individual Planning (also called Individual Programme Planning) (6) is helping people with learning difficulties decide whether they want to join groups, classes or organisations, which to join and the kind and level of support they will need in order to participate. Members of staff and families or volunteers are supporting people with learning difficulties by accompanying them to classes and meetings, helping them join in, and discussing the meeting or activity afterwards.

Schemes such as *BLISS (Blackley Leisure Integration Support Scheme) in North Manchester began to show how this can be done. In general it seems that people with learning difficulties need people who are not staff and not paid to be with them to sponsor and support their participation - people with the same interests as themselves. Staff often work shifts and there is a lot of turnover - nor are they necessarily interested in the same things as the people they work with.

**BLISS - For further information contact: Caroline Kagan, Dept. of Psychology, Manchester Polytechnic, Hathersage Road, Manchester 14.*

MEMBERSHIP - WHAT HELPS?

- Making, and keeping up-to-date, a complete list of all the groups, organisations, clubs, classes you and anyone you know can think of. Finding out about those you are not familiar with - making an 'associational map' for the local area. (See Appendix I) A resource centre for people with learning difficulties in East Sussex, for example, co-operated with their local library to produce a comprehensive list of local resources.

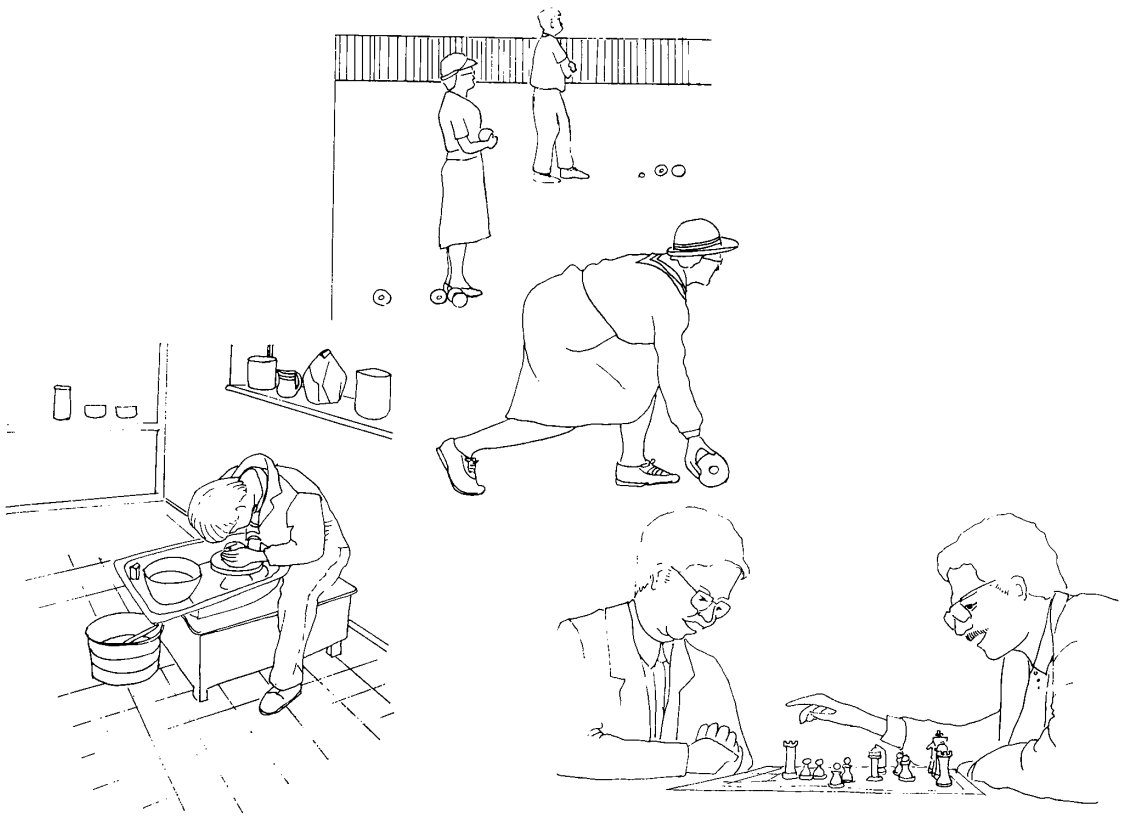
- Helping with skills the person may need to make joining in easier. Taking part may mean having a helper who can walk independently, hold things and so on, and can do so alongside the person with learning difficulties.

- Including discussion about possible membership in IP preparation. Exploring the associational memberships of people who know the person well, encouraging them to 'sponsor' his membership in their clubs and associations.

- Accompanying the person to several meetings, classes, groups that sound interesting so she can decide which, if any she wants to join. If the person can't speak, take photographs at the various places visited, so she can indicate which she would like to join or go to again.

- Finding someone who has a strong interest in the activity or cause who will accompany and support the person with learning difficulties. A skilled and interested potter will be the most effective sponsor into a pottery class, regardless of how much they know about 'handicap'.

Remember these suggestions are only starting points. The further reading at the end may suggest others.



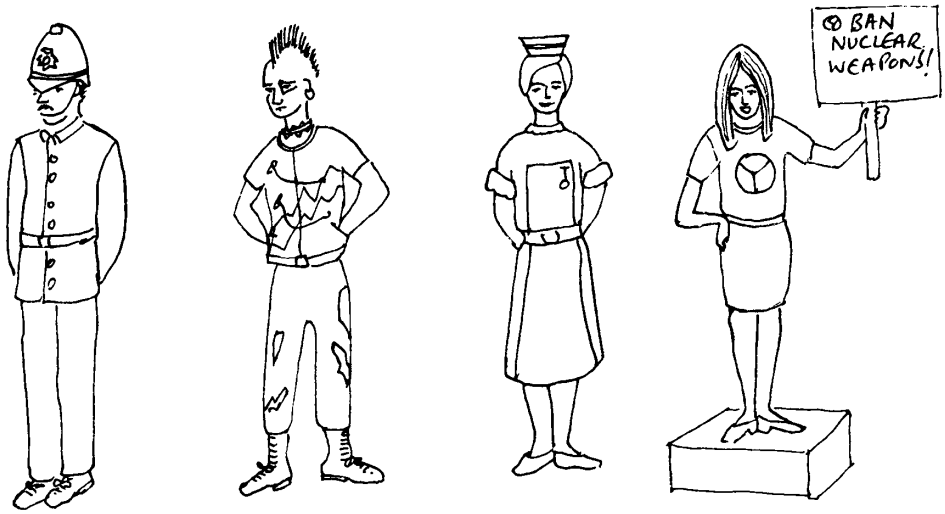
KEEPING IN TOUCH

Many people like to feel that they are part of something which is larger than themselves and the people they know. This sense of belonging does not always require joining an organisation or club It can come just from having a special interest or concern that makes people feel attached to many others with the same interest or concern. One sociologist has described this as belonging to a "social world" (7).

One way to keep up with a cause, concern or belief is by regularly reading a special interest magazine or newsletter, or a publication which supports a particular position such as on nuclear weapons or apartheid, or brings the news of current trends, heroes, champions such as pop idols and sports stars.

particular TV programme or listening to a particular local radio station. All these activities or interests provide the basis for a growing area of expertise, interest, and a sense of connection with those who share it.

Some ways of belonging to a social world involve an active declaration of some kind - wearing a badge or T-shirt with a symbol or slogan, or keeping a poster in the front window. This often involves attending events of various kinds - perhaps to help people share information, get up to date, or examine the latest products or equipment; or to demonstrate support for a cause. All have the effect of bringing together people with a shared interest and commitment and strengthening their sense of belonging to something larger than themselves - even if they do not know one person among all the others present.



Another way of belonging is to adopt a style of dress, appearance or possessions. These may be formal uniforms such as Scouts or Guides, or a similar style of clothes such as black leather jackets and distinctive hair styles, or badges such as the peace or feminist symbol. Young or old, mass-produced or unique, they all relate to the impersonal world of 'style' whose main advantage is that anyone can belong.

More active forms of keeping up include things such as submitting an article or photo to a special interest publication, going to a meeting, sporting event, concert or demonstration. Many of these interests might be called hobbies and involve collecting, sorting and recording in a systematic way (for example, train spotting, stamp or china collecting). Others involve regularly watching a

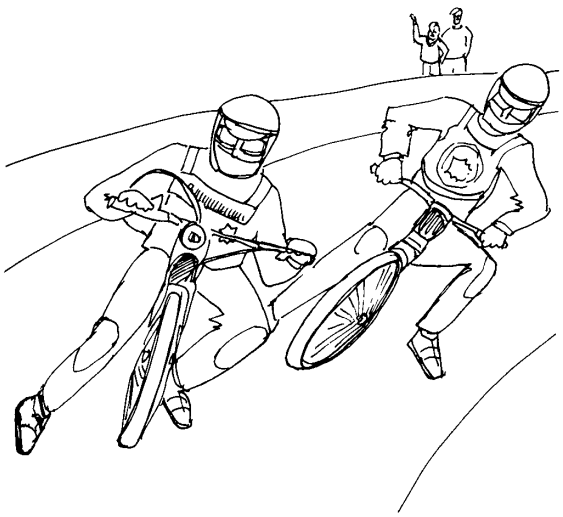
Another way of keeping in touch may be by making a voluntary contribution - gifts or donations, money, time or effort - as a way of supporting a cause, whether it be famine relief, or the local hospice appeal, supporting 'Band Aid' or by taking an active part in a fundraising event.

What all of these have in common is that they foster connnections between people, but not necessarily with any ties, or often only very weak ones. None of these ways of keeping in touch necessarily involves anyone in a relationship with others. Social worlds can be very active, involving a lot of getting-out-and-doing, or they can be relatively inactive - done from the comfort of an armchair. They can be solitary, or involve being with lots of people. They can lead to people being immensely busy, but still having few

relationships. They can be a useful way into a closer involvement with others - extended networks of acquaintances who share a common hobby, or close friends and partners who make a strong commitment to pursuing their interest together.

Terry Chandler is 34 and lives at home with his mother. He is passionate about motorbikes, an interest he shares with his married brother, Gordon. In the summer the two brothers regularly go to motorbike scrambles together. Terry's knowledge of the world of motorcycles is exceptional. At home his favourite occupation is looking through the motorcycle magazines he buys and swaps with Gordon each month, and watching motorcycle racing on TV. In his bedroom he has a collection of programmes, photos and other souvenirs of events he has attended. At scrambles Terry is an enthusiastic spectator. Over time Gordon and he have got to know a fair number of other "regulars", to say "hallo" to, or have a chat and a drink with.

Terry is quiet and retiring usually with strangers, and doesn't find it easy to join in conversation. At scrambles, or whenever the talk turns to motorcycles however, he is transformed from someone with a learning difficulty into an animated enthusiast about a subject dear to his heart.



What are the issues for people with learning difficulties?

Many have no basis for developing interests because they have been severely deprived - of resources, relationships and experiences. Many do not know what to be interested in, because they have not been introduced to interests. Others may have clear interests but have had few opportunities to develop them. There are also people who have had interests selected for them by staff or parents, or have become locked into interests which they once had - such as children's games or adolescent records - which they have had no opportunity to replace with more appropriate adult ones.

Other people's expectations can be a problem. One parent said, "My daughter basically isn't interested in doing anything - no-one wants to spend time with a person like that. She's happy enough with other people like herself. Trying to draw her out into the kind of social life we lead wouldn't work, in fact it would be really unkind". The problem is not only to get beyond these very negative assumptions, but also to get beyond the very real power that parents and staff and others may exercise over the choices people with learning difficulties can make.

Social worlds provide easily accessible ways of gaining a place in community life. The potential choices are almost unlimited. What stands in the way for most people with learning difficulties is the lack of someone who can provide the 'way in', and give long-term support for participation and involvement - keeping up the subscriptions, organising the collection, attending events. For most people, the way in is to share someone else's social world, as it is for Terry and Gordon.

As we have seen, there is no shortage of social worlds. We need to find more ways of supporting people in sharing them.

KEEPING IN TOUCH - WHAT HELPS?

- Talk with the person herself about what she is interested in, or show pictures of activities, and invite her to choose. You may want to try and find other interests which complement existing ones, or you may need to try an entirely new line of interests.

- Introduce the person to a wide range of activities with the purpose of trying things out. Treat each 'try' as a 'one-off' in the first instance, so it doesn't matter too much if the person decides not to become involved. It will be important to try things out properly though; for example, if the activity is swimming, going to a nice pool with one friend who is comfortable in the water is much better than going as a group to the local mental handicap hospital pool.

- Find the activity or concern first and then find a compatible person who is also interested in this to support the person with learning difficulties.

- Someone who is going to try and introduce others to a range of 'social worlds' is going to need to know an awful lot about the range and variety of what's available. Go to a big newsagents and review the magazine sections for ideas about the sheer variety of interests. Many social worlds are very age-specific so get some people of the relevant age to help you list all the kinds of things someone of that age might choose to be interested in. Keep looking for new things to add to your lists.

BEING PART OF A FAMILY

There are all sorts of families - single parent families, extended families, families with a mum, dad and a child or children, families which include half and step-brothers and sisters, a couple of the same sex with or without children, a man and a woman living together or married without children and so on. Some adults live on their own although they probably have a family of origin that they relate to. And of course some people have no family at all - at least not that they know about.

This section is concerned with the 'family of origin' - the family people are born, adopted or fostered into as children. Starting a new family - marrying, living together or having children is discussed in the section **Having a Partner.**

Just as families are very different from each other, being part of a family means different things to different people. For some people, particularly people from Asian and Far Eastern groups, 'family' is the source of all major decisions, and a focus of important social duties and obligations throughout life.

For others, family arrangements are seen as more open to choice. Some people feel very close to their families and get a lot of support and help from them. Others have little contact with their families and others still are hurt both physically and emotionally by them. Even though people may not come from happy families themselves, it seems they like to think of the idea of family as a positive force in our society.

Families also change - new members are added through birth, adoption, fostering and marriage; members are lost through separation, divorce and death. As family patterns change, individual members may get shaken loose from their connections with others. A family argument may mean that someone leaves and is not heard from for many years. Financial or health problems may mean that children are taken into care.

When people lose touch with their families, it is often difficult to re-establish contact. Sad evidence of this can be heard on radio SOS messages - "Will Anne Bloggs last heard of five years ago somewhere in Scotland please contact the Royal Westshire Hospital where her mother Mary Bloggs is dangerously ill.....". It is not uncommon, it seems, for people to drift away or get shaken loose from family ties.

Being part of a family helps give people a sense of who they are, and where they come from - 'eldest child', 'my big sister', 'our new baby'. Families can provide a unique source of relationships with people from different generations. The experience of living with a family has a major impact on the way that people relate to others outside the family. People who are separated from their families when they are children or who come from families with lots of problems sometimes find it difficult to make good relationships in later life.

What are the issues for people with learning difficulties?

Many people with learning difficulties, both children and adults live with their parents and these families are just as varied and complex and changing as other families. Sometimes families which include a person with learning difficulties may get labelled as 'problem families'. Many such families would not consider themselves a problem at all - although they may not be too happy with the services they receive - and greatly value their family member who has learning difficulties.

Barbara Findlay can't wait for her family's next holiday so that she can have a go at waterskiing. Back home, she spends her spare time learning synchronised swimming, horse riding, ballet, gymnastics and trampolining.

Her mornings are taken up either with cooking - she eventually wants to run her own catering business with her mother - or continuing her studies on the family's word processor.

In the evenings she goes out with friends, or takes part in charity work with the local junior branch of the Rotary Club. A full and active life for any normal 20-year old'.

Barbara's story featured in a national woman's magazine. The article goes on to give some information about Down's Syndrome, and describes more of Barbara's achievements, - passing her driving test - and her aspirations to be married to a 'good tempered' person, and to run a catering business.

Barbara's parents are very encouraging, but they worry too about the future. They hope she'll be totally independent within the next ten years, and ideally married to someone 'thoughtful, kind and protective'. They've also put her name down with a special trust which will guarantee financial security and a home for life with people with learning difficulties.

Richard Adams is twelve years old and lives with his Mum and Dad and younger brother John. He uses a wheelchair to get around, and although he can do a lot for himself, also needs help with some of the ordinary everyday things.

Richard goes to a special school for children with severe learning difficulties, travelling there by coach. He doesn't have any particular friend there, but knows all eight children in the class. He particularly liked Fiona, one of the Welfare Assistants, but she left. Richard goes to quite a lot of leisure activities organised by the school.

He sees a lot of his grandparents, aunts and uncles. Every Tuesday evening the school coach drops him off at his grandparents' house for dinner, and they bring him home later. Sometimes he goes with his Dad and brother John to spend the weekend at his uncle's holiday caravan. His Dad takes him and John to the local park, and places like museums and the riding school. When friends of John's come to play they talk to Richard but he's not able to join in their games. The neighbours all know Richard. When he was smaller they used to look after him for short periods, but not now. Recently he's been away for a week in 'respite care' at a hostel 17 miles away. His parents regret there is nowhere closer, and that he has to miss school while he's there.

There are many people with learning difficulties who were separated from their families as children or growing adults. They have lived in large, remote, poorly resourced and inadequately staffed mental handicap hospitals for all or most of their lives. Some have families who have been able to maintain contact but others have not - often because distance, expense and other family difficulties have made it impossible. This has created many problems both for the individual and the family. The problems may be greater for people with learning difficulties than for non-handicapped children who are removed from their families because they may not be able to understand what is happening - indeed, sometimes no-one has tried to explain.

Some people now are moving out of large hospitals back into their communities and are being helped to reconstruct their histories and to understand their former ties and connections. Many have no family left - but just knowing more about themselves and perhaps visiting the places where their families used to live can help them come to terms with what happened to them - sometimes a very long time ago.

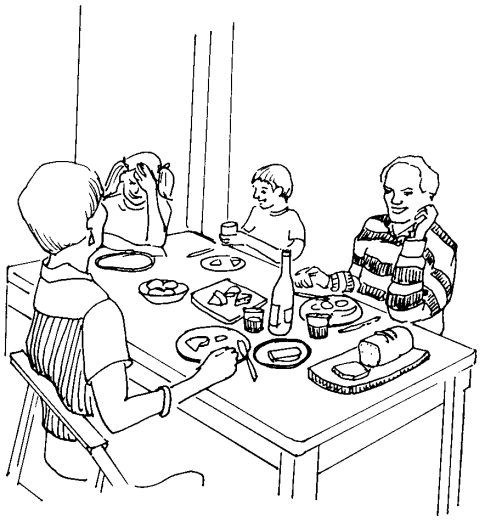
Maureen Gates is in her fifties. For the last five years she has lived with fifteen other women in a hostel run by the local health authority. Before that Maureen lived in a large mental handicap hospital on the outskirts of town. She had entered the hospital when she was in her teens. She was an only child and to her knowledge she has no family beyond an aunt in her nineties who lives in an old people's home in a city a hundred and fifty miles away. Maureen cannot remember having met her aunt (not since childhood anyway) but appreciates the birthday and Christmas cards she receives from her each year. She knows her mother is dead but does not know what happened to her father or even if he might still be alive.

Until recently at the hostel Maureen was a rather solitary figure with no special friends or individual interests of her own. Recently, however, things have begun to change. Through a local Citizen Advocacy Office Maureen got to know Jane and her family who live close by. As a result, Maureen's life has begun to open up. She is getting to know some of Jane's friends and enjoys visiting and going out with them. She has been to a lot of new places and enjoyed a lot of new experiences. Back at the hostel she has become more outgoing. She is more respected and talked to by others, staff and residents alike, and now she regularly has visitors to call.

At Jane's home Maureen sometimes talks a bit about early memories of family life; folding washing with her mother, helping peel potatoes and, later on, being collected by her father from the hospital for a week's holiday at home in the summer.

With Jane's help Maureen is keen to build up a better picture of her family and her past. Together they hope to find out from hospital records where Maureen lived as a child and go to visit. They want to meet Maureen's aunt if that is possible. They also want to find out more about Maureen's mother and where she is buried, and her father and whether he is still alive. In the meantime, as the search for more information about Maureen's family of origin continues, she is clearly relishing her new involvement in the ordinary life and activities of her recently acquired family of adoption. She enjoys days out, birthday celebrations, mundane shopping trips, and quiet times at home with Jane, Peter and Clare, Sarah and Ben, their three children.

There are of course, many other individuals, particularly children, like Richard and young adults like Barbara Findlay whose ties with their family are strong and secure. For them the family gives a sense of permanence and belonging - a place to move out from into the wider community, where new interests can be sampled, new relationships made.



BEING PART OF A FAMILY - WHAT HELPS?

The point is not just to have a family but rather to have an **active connection** with family. This can be helped and supported by -

- Ensuring each person knows who and where their remaining family are and where they originally come from.
- Arranging for people to have photos and mementos of family members, and 'Life Story Books' (see **Further Reading**) organised in a way that they can look through them and show them to others.
- Where contacts have ceased, exploring opportunities for renewing them; re-opening these opportunities from time to time. Never 'giving up' on any possibility of a relationship.
- In particular, supporting people in celebrating the traditional times when families express their connection - Christmas and New Year, Divali, Chanukkah, birthdays and anniversaries, bahmitzvahs, christenings, weddings and funerals.
- Ensuring that administrative arrangements do not become obstacles to an active connection with family, for instance by moving people a great distance away, or having inflexible visiting times. Making sure that visits are not being discouraged in often unintended ways: 'He was so upset after your last visit!' - so making the visitors feel they are doing more harm than good; or treating visits home as privileges to be earned, rather than rights - 'Do that again and you won't go home this weekend!'
- Supporting people in having a growing and developing relationship with their family, with a degree of independence appropriate to their age and the family's cultural norm. This may mean supporting the family too, in accepting the growing independence.

Remember each suggestion is intended only as a starting point for practical exploration. The further reading at the end of the book may suggest others.

HAVING A PARTNER

> *"In ten years time, I will be 42. I hope things will have changed . I would like to live in a flat with my boyfriend. We would be sharing the housework".*
> *From "Life, Boyfriends and other Things" - the William Brunsen Centre, Tower Hamlets, Jan.1988.*

In most cultures people pair up at some stage in their life and have one particularly close relationship. One story that most children learn is that a man and a woman meet, fall in love, marry and have children and stay together forever. But we know even in the old days it didn't work out like that for everyone, or even for very many people.

In today's society, people might or might not marry but may live together and have children; gay men and lesbians are becoming more open about their relationships and some of these as couples or even as individuals may have children or adopt them. There is a wide range of ways to form families.

Some people will have a partner chosen for them and will experience a lot of family pressure and support to learn how to make that relationship work. Others are freer to do whatever seems right for them at the time. They may go through conventional patterns of courting and choosing a partner, or may even advertise or go to an agency to find a partner. Others may visit a family or neighbourhood 'matchmaker' or consult 'fakirs'.

It seems likely that a lot of people will select a partner, but that a fairly large proportion of these partnerships will not last. Some people (though probably relatively few) will have several different partners during a lifetime. Partnership and family is such a strong ideal in most cultures, that even when faced with disappointment people will continue to seek it anew.

Most partners have very tightly interwoven lives. They usually share a home and household chores. They also share affection for each other and most also have a sexual relationship. Partnership, like family, gives people an identity and status. Marriage is a public commitment to one person and is an important social goal for many people.

Partnership is viewed in various ways in different cultures. In some it is simply a relationship between two people and a new arrangement of their life together. In others it is a major event bringing together two families, even major sections of a religious or cultural community. The new partnership may bring with it a great weight of community sanction and critical observation, and be the occasion for communal celebrations that reinforce the two people's inclusion in a larger community life.

Partnership also brings together people's resources - financial, emotional, intellectual and physical. Partnership gives people an immediate source of companionship - someone with whom to talk, share chores, discuss worries and celebrate happiness. Partnership provides for some people a safe place in which to retreat from the rest of life. For others it brings access to another set of relationships and connections - another potential gateway to new people and experiences.

As with other forms of friendship there are risks in partnership. In bad partnerships people may feel more lonely or oppressed than they did when on their own. One partner may dominate the other.

Partnerships also break up and then people are often very upset and are faced with coping on their own again. But even with the difficulties that partnerships can bring most people want a partner and would rather take the risk than go through life without one.

Stan and Irene had known each other more than three years, meeting on Tuesdays and Thursdays at the Ballroom Club, run by social services to keep people occupied, who live in group homes, lodgings and private homes in the town.

"STAN: For the sheer fun of it I asked Irene to marry me, walking down the sands at 11.3O p.m. on a cold February night.

IRENE: Well, at this point I got the giggles. I thought he was joking! Then he said he was serious and I said coolly 'I'll think about it and let you know'. Inside I was happy and knew I would say yes but I thought I'd make him wait a few days. When we met next day I asked if he remembered what he'd asked and he did, I asked him to repeat it to be sure, and I said yes.

STAN: I thought she might change her mind, I couldn't believe me luck.

IRENE: At this point we had a think about the practical side of things, like telling the right people first. We made an appointment to see Mike Collins the social worker, and he told us we should wait a year. Then we saw Jane Weston the Community Nurse, and she suggested we thought about where to live, and saved up some money. She arranged to see me the next week for our usual chat".

Irene's brother was a little surprised at first, but then he asked what they'd want for a wedding present. He told the rest of the family about their plans. Stan told his mum and dad who were pleased. There was a big party at the Ballroom, and they got a fair number of presents.

Jane asked Irene if she and Stan would like some counselling from an expert on relationships and the sex side of marriage. Irene was very definite she didn't - later she said she was too embarrassed.

Stan and Irene have a detailed story which they often tell, of the preparations for their wedding. Sometimes it was hilarious, and at other times it was obviously a big worry whether everything would go right, and particularly if they could even afford the various expenses. They give credit to a lot of different people who rallied round to help at important moments. These included Irene's landlord, who when it seemed they might be homeless, said Stan could move in to Irene's bedsitter until they got fixed up with a flat, and he'd provide the double bed. The staff at the rehabilitation project, and the people at the Ballroom, had all collected to pay for a honeymoon - one night away in a hotel.

Some months after the wedding had gone off successfully, Stan and Irene reflected on married life:

"It just feels like fun. Things are going well. We're more down to earth about it all now. Sometimes it's a little boring. Life is definitely less lonely".

When Stan goes to the Tech., Irene visits friends, but otherwise they do things together. They feel like (and are hoping) they will be together for years.

What are the issues for people with learning difficulties?

Many people with learning difficulties - whether they have lived with their family, in institutions, or in the community - are now also forming partnerships and marrying. This idea sometimes creates considerable unease among parents, staff, and people who plan and manage services. They are not always as helpful as they might be, and may even seek to prevent relationships, or to put difficulties in the way. Sometimes too, people 'turn a blind eye', or simply deny what is happening and by doing so expose people to unreasonable risks - of unnecessary failure or disappointment or consequences they find it difficult to cope with.

Glen is 4O, lives with his mother in a two bedroom council flat. He and Hazel have been engaged nearly a year. Hazel lives in a local authority hostel for people with learning difficulties. She works at the ATC, stapling boxes in the mornings, knitting in the afternoons. Glen has graduated to the SEC where he's preparing to move into a semi-independent hostel scheme.

Glen and Hazel have some difficulties in seeing each other. On Mondays when Glen visits the hostel, it depends on which shift of staff are on duty, whether Hazel is allowed to have Glen visit her in her room. Four evenings a week they meet at the Gateway club, Volunteers who run the club say it is 'inappropriate and ridiculous' for them to talk of marriage. They wonder who was allowed

to 'put such an idea into their heads'. The couple are often prevented from dancing together at the disco, and are put in separate groups for games. The staff say they do not think Glen could cope if Hazel had a fit. A psychologist has undertaken 'epilepsy management training' with them both. He has also negotiated with staff on Glen and Hazel's behalf. Even so, Glen is not allowed to escort Hazel the one and a half miles from the hostel to the club on his own.

Hazel's parents are happy with the thought of Glen as a son-in-law. Glen has made a concerted effort to forge links with them. He also enlisted the help of several sympathetic professionals and a MENCAP volunteer to be advocates for him and Hazel. They are both going to 'relationship counselling' sessions.

They both talk of a desire to have children. Hazel does not yet know that an operation she had some years ago was a sterilisation.

They both feel that many people they come in contact with are "trying to split us up" - some actively, and others by simply not recognising the genuineness of their relationship. Though they have no doubts, they both think it could be quite a long while yet.

One reason why it seems so challenging when people with learning difficulties form a partnership is that it shatters some powerful myths - for instance that they are 'eternal children' who never grow up and therefore 'have no sexual urges'. It also calls on parents and service providers to help people in a delicate and sensitive area of life. Many people find it hard enough to talk about or manage these very personal areas in their own lives, without also taking on the task of helping other people with these relationships.

Whatever the reasons, many people with learning difficulties may find that when they very much need help they are met instead with a wall of silence, cheerful breezy denials, over-simple answers, or 'rules' that deny opportunity.

Well-meaning attempts to help may go wrong too. For example many people with learning difficulties are directed into sex education classes. More of these are concerned with how to avoid pregnancies than with the content and quality of important relationships. It may also not be responding to people's most fundamental needs when what they experience is a lack of any relationships at all, or only very impoverished ones. As one man attending an ATC said: "Oh hell! I had sex education six times already, it's just that I never get to meet a girl".

In January 1988 a Birmingham couple were told they could pay one last visit to see their three month old baby, before he was placed with long term foster parents. This will be the last time they will ever be allowed to see him. The couple, both of whom are people with learning difficulties, were informed they would not be allowed to keep their child, only weeks before it was born. The social services department felt, and the High Court upheld, they were not capable of looking after the baby.

From "The Guardian".

People with learning difficulties seeking to start a family may set themselves and those who provide services a substantial challenge. Denial of people's rights can never be the right response, yet it will almost certainly continue to happen while we remain relatively inexperienced and unskilled in meeting the challenge. We will never learn to meet it if our responses are guided by administrative fear of failure and avoidance of inconvenience. In the long run, we have to defend vigorously the rights of people with learning difficulties who start into family life together, and seek actively for ways of supporting them through the challenges they may face.

Many people with learning difficulties live in a relationship vacuum. There are many spaces to be filled. They may have a real yearning for partners and friends and for parenthood too. So far we do not have too many effective ways of helping people with these needs (8).

HAVING A PARTNER - WHAT HELPS?

The need for a partner has to be understood in the context of a wider need for a range of satisfying friendships. When people have very few friends at all they may find it very hard to choose a partner.

- People who have many close friends with many different kinds of interests and resources are more likely to be able to make some longer term commitments to one person.

- When people find it very hard to communicate, it's important to try to understand what kind of a partnership they may be seeking. They may not be making conventional choices. It may need a lot of careful thought to help someone decide what kind of a relationship would be most likely to work out for them, and to anticipate some of the possible risks and gains.

- Some special skills may be helpful (counselling, therapy etc.) in supporting people making decisions about important relationships. Probably the most helpful resource though is a wide range of other close friends.

Remember each suggestion is intended only as a starting point for practical exploration. The further reading at the end of the book may suggest others.

BEING A NEIGHBOUR

A researcher (9) who talked with a great many people in England about neighbours says there seemed to be three 'rules' about what makes a good neighbour. Neighbours should be friendly, they should be helpful, but they should respect one another's privacy. **Friendliness** meant offering warm, polite greetings, and generally being interested and encouraging. **Helpfulness** meant an exchange of small services like keeping an eye on someone's house if they were away, or taking in a parcel left by the postman. It also meant being helpful in emergencies (such as being locked out, or having an accident). **Privacy** was about not intruding unduly into the other person's life; it meant not making unreasonable amounts of noise, it meant not being 'nosey'; it meant respecting confidences.

Neighbours are people who live near each other - usually next door, across the road, or perhaps further along in the same road. Having neighbours can be a good or bad experience. Bad neighbours can be a source of aggravation, ill feeling and distress. Bad feeling can be created when people play loud music late at night, have many noisy visitors, have dogs that bark or intrude, let weeds grow or rubbish accumulate, park cars thoughtlessly, have public rows. Some neighbours become so upset or angry that they stop speaking, or argue, fight, take each other to court, or move.

Sometimes the relationship of casual acquaintance and polite friendliness of good neighbours may move towards real friendship - as people get to know each other better and discover common interests and concerns. Nevertheless, when individuals need fairly substantial and constant amounts of help in their daily lives (for instance, someone with a substantial long term handicap) it's not usually to neighbours that they can turn for help. Even 'good neighbours' won't replace the need for sufficient resources to employ skilled helping services and sensitive practices.

Dorothy Atkinson in her study of fifty people with learning difficulties living in ordinary houses, (10) states: "Often good 'neighbourliness' extends beyond saying 'hello' and chatting together. Neighbours alter clocks, write letters, change light bulbs, provide emergency candles, lend money, mend fuses, repair televisions, tend the sick, unblock drains, stop floods and put out fires".

Eric Jones had always lived wih his mother until she died suddenly, leaving him alone at home and very determined to say in his own place. Despite other family members' misgivings, Eric had shown himself very capable in such tasks as house cleaning and cooking. Staff of the centre he attends have helped to remind him to change his clothes regularly and have particularly helped with his shopping and use of money. He has followed his mother's example of putting money in tins to help him budget but has been able to do what his mother would not allow - invite friends home and offer hospitality, spend the odd evening in the pub, and so extend his circle of acquaintances.

Eric and his neighbours had never got on too well. Eric is quite deaf and his speech is not too easy to understand - so his neighbours had left him alone. Since he has been on his own, however, they have had the opportunity of getting to know Eric as a person with many abilities, instead of the severely handicapped person they had been led to believe he was. He now goes in to them for coffee and a chat, and also helps out by doing shopping for those who are elderly.

Eric is enjoying living alone at present but is talking about having a friend sharing with him.

What are the issues for people with learning difficulties?

In the past, services for people with learning difficulties were often purposely sited in places where there would be no neighbours, or simply in self-contained institutions where the normal rules of good neighbourliness didn't seem to apply. This means that for a large part of their lives many people have not had good opportunities to learn about being a good neighbour. Likewise ordinary citizens have not had a chance to learn about those who have learning difficulties. Nowadays, services are increasingly being planned in very ordinary settings, and many people are getting a chance to know their new neighbours.

It's important that neighbours share reasonable expectations of one another. Sometimes the expectations are unreal. Residents of a neighbourhood may have heard some bad stories about the people coming to live in the house next

door to them. Often well-intentioned efforts to consult with neighbours give rise to much greater anxieties. People may even be asked to 'consent' to people with a learning difficulty living next door to them, and if they don't have accurate information or good past experiences to draw on, they may well say 'No'.

Very often such fear and prejudice dies down once people have actually moved in. Most people with learning difficulties can be helped to at least meet the 'three rules' of neighbourliness and be helpful and friendly but not intrude. The example set by staff, relatives and friends who live in or visit the house is usually very reassuring to anxious neighbours. Some staff who work in 'ordinary housing' services say they know the neighbours of the house where they work much better than the neighbours where they live. Many neighbours have found having people with learning difficulties living next door to be a very positive experience.

Such happy endings though are seldom achieved without conscious thought and effort. Many people with learning difficulties will be unusually dependent on local resources and relationships. They may also have unreasonably high expectations of neighbours. It can take time and attention to get to know and build a good relationship with neighbours for anyone moving into a new area. Time is probably one of the most important resources to invest. Becoming a good neighbour can sometimes mean serving a long and patient apprenticeship.

BEING A NEIGHBOUR - WHAT HELPS?

- Having helpful and considerate staff and other visitors, who themselves behave as good neighbours.
- Not 'asking permission' when people with learning difficulties move in to the neighbourhood, but rather making sure that some ground work is laid for good relationships to form.
- Asking neighbours to help in small ways - to lend their garden shears, or give advice on pruning the hedge. for instance; offering to help them - watering their garden while they're away on holidays, or putting out the dustbin on the right morning.
- Inviting neighbours in for an occasional cup of tea, or to a special party.
- Being sure to exchange seasonal greetings.
- Joining 'Neighbourhood Watch'.
- Taking care of the garden and the house so they aren't seen as letting down the neighbourhood. Paying attention to areas of shared concern (walls and fences, overhanging trees and shrubs, gutters, household pets that may not be welcome, cars parked outside).
- Seeking out elderly or handicapped neighbours - to bring messages, doing shopping, going to the laundrette for them.

Remember each suggestion is intended only as a starting point for practical exploration. The further reading at the end of the book may suggest others.

KNOWING AND BEING KNOWN IN A NEIGHBOURHOOD

A neighbourhood is the area around the place where you live or work. The area within walking distance is an easy rule of thumb. There can be a lot of advantages to knowing and being known in the neighbourhood where you live. One is knowing where to find important local resources such as the post office, park, mosque, swimming pool, library, shops; where important activities take place, such as clubs, playgroups. classes, community meetings; where to find jobs in industrial estates, offices, farms. Another is the sense of belonging that many people get from being in a familiar place, and having people around them whom they know at least a little, and who probably know them a little too.

It can also bring some restrictions.The traditional village is sometimes described as a very harmonious kind of place, yet village life can also be very restrictive and there can be severe social penalties for anyone who is very different or who lives in an unconventional way. Many people like to live in big cities simply because they can be anonymous, and can have privacy and participate in neighbourhood life as much or as little as they want. Big cities can be very lonely places, but they can also be places with a lot of energy and excitement, and many opportunities for a rich and varied community life.

When moving into a new neighbourhood people often find out about it by reading local newspapers, looking at noticeboards, talking to shop-keepers, asking neighbours, or getting a street map or town directory from the council offices or perhaps from an estate agent.

Some neighbourhoods are very rich in resources. Some have very extensive 'networks' of friends and acquaintances from whom they develop a sense of safety and security whereas in others people keep themselves to themselves and have little to do with one another. Some people depend very heavily on their neighbourhood for important resources and relationships, and others hardly at all - most of the things they need they get somewhere else, and most of their relationships are located elsewhere.

Neighbourhoods can be so complicated and so varied, that even two people coming from the same neighbourhood can have quite different experiences of what sort of a place it is, and what sort of people live there. Whatever they think when they first arrive, many people seem to develop a sense of attachment to a neighbourhood the longer they've lived there.

Just as people gradually get to know the neighbourhood, so they become known by people living there. Local people may become acquaintances - they may not know each other's names but may smile in recognition, or exchange a greeting, or pass the time of day.

Becoming an active participant in the neighbourhood is a step beyond simply being recognised. It may involve becoming a member of local organisations or clubs, taking part in charity or social activities, or simply being a good neighbour. Some neighbourhoods offer extensive opportunities for local participation - attending a gurdivar, singing in a choir, attending the Guy Fawkes bonfire, attending party-political meetings, helping with a stall, door-to-door canvassing. Some people participate by choosing to use the local shop or garage even though prices are higher, because it helps maintain a local resource.

To quote Dorothy Atkinson again:

"Some people have moved on from simple acceptance in the neighbourhood to becoming party of the web of neighbourhood relationships. Such participation in local events and involvement with local people, brings with it a special reward, a sense of belonging. Only a few people have succeeded in making these inroads and they have done so in two ways; through making a contribution to the welfare and well-being of others, and through developing relationships which are reciprocal .... (Those) people who have

moved beyond community acceptance to the next stage of community participation are exceptions. Most people have settled for far less."

What are the issues for people with learning difficulties?

Past experiences have denied many people with learning difficulties the opportunities to know a neighbourhood. Sometimes this is because they've lived in institutions, or because although they've lived with their family, services have dislocated them from local neighbourhood life. Fears and prejudices have often played a part too. So many people who are now living in community services are only just starting out on the business of getting to know a neighbourhood, and getting to be known by others who live there. Many will need a lot of thoughtful help and support if they are to make a success of exploring their neighbourhood and the resources and relationships it may have to offer.

The neighbourhood may be a lot more important in the lives of people with learning difficulties than it is for some other people. Many do not have a job, or extensive networks of more dispersed relationships. They are likely to be poor and are unlikely to have personal transport. More than most they will rely on those places they can reach easily on foot or by public transport. Many will also rely on someone else being with them, who knows them quite well and can help when they experience difficulties. Being in a place where you are familiar to people who know where you live if you tend to get a bit confused, or if you perhaps have seizures occasionally while you are out can be very helpful. The more you are able to use local resources and to develop local relationships, the less you need to depend on special arrangements such as special classes or special transport,and the more you can manage your own life rather than have it managed for you by staff.

KNOWING AND BEING KNOWN IN A NEIGHBOURHOOD - WHAT HELPS?

- Taking as many opportunities as possible to use neighbourhood facilities (shops, leisure facilities, workplaces, places people go to for help and advice). Find out about as many as you can and make a list.
- Wherever possible, locating homes and services in neighbourhoods that have extensive and varied local resources. In places that have fewer resources (such as some country areas) it is necessary to set up ways of supplementing them with extra transport, travelling services and so on.
- Joining local organisations.
- Contributing to neighbourhood events (such as a Royal Wedding street-party, a sponsored clean-up, or a fun-run on Bank Holiday Monday, 'town-twinning' visits, Neighbourhood Watch Schemes).
- Volunteering for neighbourhood activities (help with a fete, deliver meals-on-wheels and so on).
- Being friendly and speaking to people in local shops.

Remember each suggestion is intended only as a starting-point for practical exploration. The further reading at the end of the book may suggest others.

In Conclusion

This chapter has reviewed some of the important accomplishments of 'an ordinary community life' for many people, including having friends and acquaintances, belonging to organisations and groups, keeping in touch with interests, having an active connection with family, having a partner, being a neighbour, knowing and being known in the neighbourhood. People combine these different kinds of 'ties and connections' in unique ways to form their own versions of a community life, and many variations are possible and desirable.

For each accomplishment some of the special issues for people with learning difficulties have been reviewed - some of the reasons why these accomplishments which are so taken for granted in many people's lives, may need some extra thought and attention when we are trying to support them in the lives of others. Each section too starts to make a list of some of the practical things that help support friendship, membership, neighbourliness and so on, but it is only a start. Readers are encouraged to enlarge on the lists, and to let others know when they find successful ways of supporting these 'connections in community'.

WHAT CAN BE DONE -

by families, people with learning difficulties, service workers, other interested citizens

INTRODUCTION

There are many changes taking place in the way services are provided to people who have a learning difficulty. Some of them will provide opportunities for people to become neighbours, to gain acquaintances and develop friendships, so that people become more in touch with the worlds of those about them.

But much of the change needed won't just happen as a result of better community services and policy changes. It is going to take more than that to reverse the processes by which people who need some extra help in their daily lives tend to get pushed out to the edge of things, and excluded from a lot of the ordinary, 'taken for granted' experiences of community living.

As well as policy changes (which are important, because they set an example, and may make resources available in new ways), we are going to need changes in the ways the individuals and communities behave towards people who have learning difficulties. We don't pretend this is easy and we don't have all the answers to how it may be done.

But some things will help. One is for many more people to see that their interests and those of people with learning difficulties are very much the same. Another is to help people see that there are fairly straightforward things that they can do - things that they know how to do already, because they do them every day. With a bit of thought and care, these can be extended to include many more people with learning difficulties in ordinary community life. It's these which we will consider in this chapter.

- **Things to LOOK FOR** (such as the ties and connections described in chapter two in our own lives and those of others)
- **Things to BE CAREFUL ABOUT** (such as the assumptions we make and the language we use)
- **Things to DO** (such as including people with learning difficulties in our own lives, and the organisations in which we are involved)

Some of these are things which individuals can tackle themselves. But many people may need help to think about them in a new way. For instance, for most of us friendships just arise naturally in the course of life - we generally don't even notice they've happened till they are there and well established, or until something happens to draw them to our attention. Mostly we don't set out purposefully to make friendships, or to consider the situation of someone who may be friendless, and how they may be helped to have friends.

WHAT CAN BE DONE - BY FAMILIES?

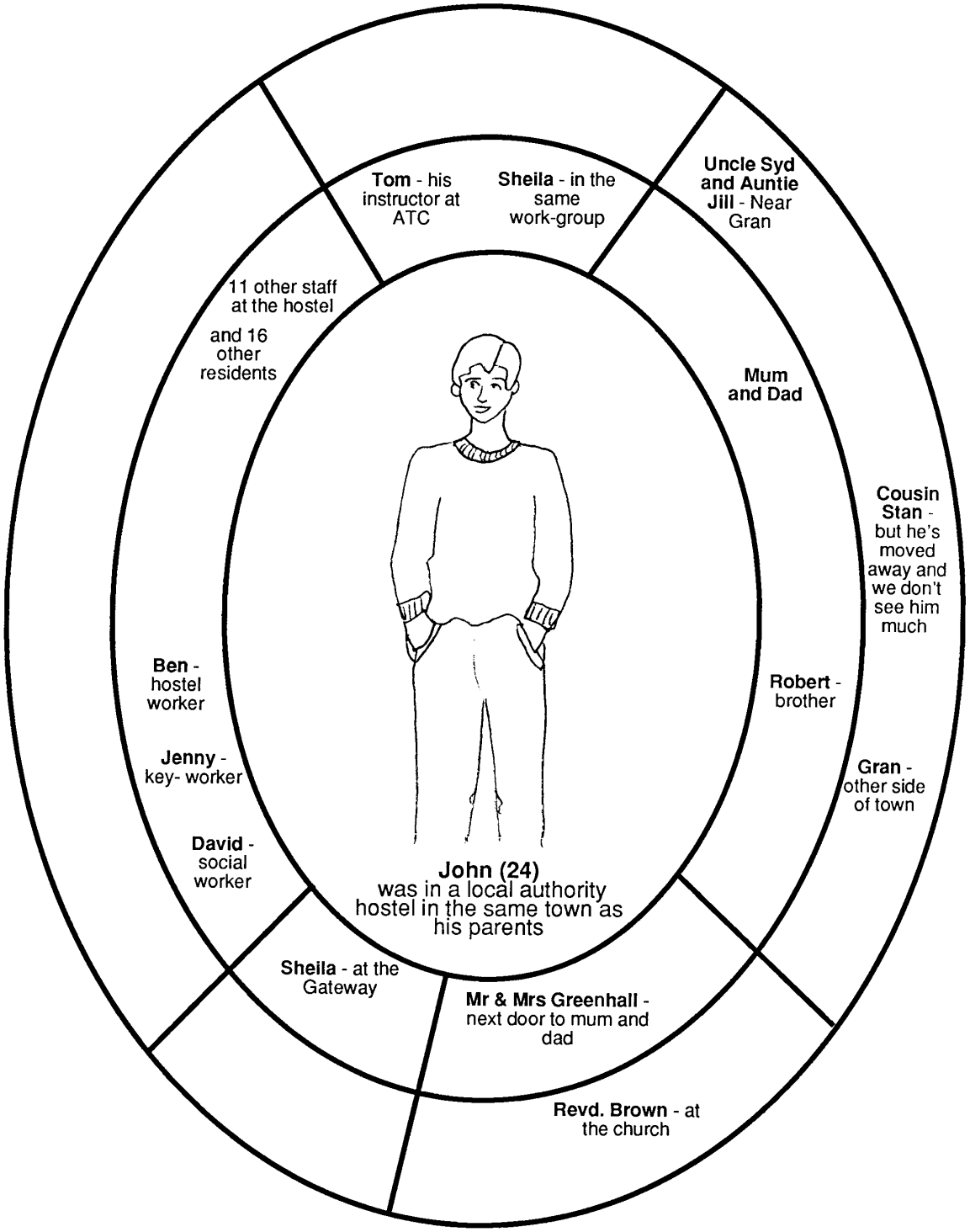
Things to look for

The family is particularly well placed to make very accurate descriptions of the ties and connections of the person who has a learning difficulty - to measure and count their 'relationship map'.

Such a map can be a very helpful starting place, both for the family themselves in understanding fully their son or daughter's need for separateness, and for professionals whose job it is to help them. New connections and relationships will rarely just emerge. Most often they will be built on to existing networks. The family can support this process by making very accurate descriptions which show some of the

A Relationship Map

94 other people attend the same ATC - no *particular* friends



strengths of existing relationships, and some of the areas in which new relationships need to be supported and developed. Making a 'relationship map' may need a bit of practice at first, and it is worth trying it with several different people - not just the person who has a learning difficulty, but other family members too, and maybe friends and others. Then when comparing the maps, some of the differences stand out more clearly, and some of the common themes too.

One kind of map which is particularly useful is a 'family map' - one that shows all of a person's ties of kinship. Extended family networks can provide an important source of relationships. These may be particularly important for a person with learning difficulties - family relationships you may be able to call on when needed.

Things to be careful about

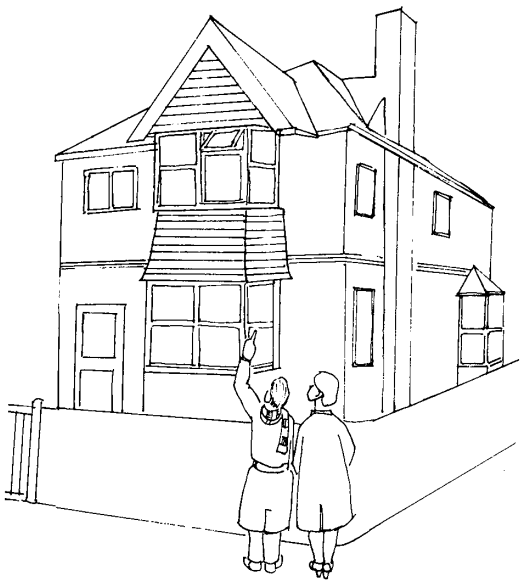
Family members are just as likely as anyone else to carry damaging limiting assumptions about a person's abilities or potential for relationships with others. But a family's assumptions may be more powerful, more limiting than those of others, simply because of the extent of the day-to-day control they may exert in the person's life. So it may be particularly important for families to review their assumptions, beliefs and attitudes towards disability, the language they use about their relatives with learning difficulties, and to test the limits of what they believe is possible in that person's life. It is important too, to have a clear sense of the limits of family life. Whilst it may be of immense importance it is not everything, nor should it be. But it can provide the springboard for developing friendships and other connections beyond.

These kinds of ideas can be hard for a family to accept - particularly when they may feel they have been left to cope alone. They may find they have little enough time, energy and skills to cope with life as it is, without all the effort of reviewing old assumptions, testing new limits, learning and making discoveries.

Things to do

An important accomplishment of a community life we described earlier as an active connection with family. The family is uniquely placed to foster this itself. Much in modern life leads to the fragmentation of family life. Links between the generations, or even members of the same generation just slip away and it may take concentrated work to sustain them.

To a person with learning difficulties however, it can be very important to have as clear a sense as possible of who they are and where they come from. A detailed knowledge of the family tree can support this - with photo albums and scrap books, as well as visits to where the family once lived in the past, or to look up some long-lost relative; exchanges of greetings cards and letters, collecting family curios with bits of history attached to them, attending important family ceremonials and celebrations.



As well as developing links and connections between people which may be rewarding in themselves, such activities can be the basis of a developing hobby, or even to the handicapped person having the valued role of family historian. Developing a strong sense of family can be of immense importance in ensuring that the person with a learning difficulty is located in a past, a present, and a future.

In all of this of course, family members may need to put aside a natural enough inclination to have little to do with an aunt with whom they do not see eye to eye, or a brother who behaved badly some years ago, or simply a family that has quietly split and gone its separate ways. Creating a strong sense of family may be more possible in some families than in others. At the very least a family may be able to furnish information which will enable someone else - a staff member, social worker, advocate or friend, to help discover more about the person's family life.

In supporting family membership in this wider sense, connections with other families may be very important too. Often families form networks, through local MENCAP, Contact-a-Family and similar groups. These can be very supportive of parents, and non-handicapped siblings who share their experiences and understanding. It is of great importance though to build links and connections with other families who **do not** have a member with a learning difficulty - **developing a stronger sense of their common experience of family, rather than of handicap**.

WHAT CAN BE DONE - BY PEOPLE WITH LEARNING DIFFICULTIES?

What people can do themselves depends a lot on their individual talents, experience and skills; their present situation and the possibilities it offers; and their personal interests and wishes. What follows indicates directions in which progress may be made, rather than the distance which may be travelled. This will be different for each person and situation.

Things to look for

For each of us who wants to get more pleasure and satisfaction from our community lives,it is important to have accurate descriptions of the way things are now, and of our place in the scheme of things. Anyone can learn from making inventories or maps of ties and connections. As people get better at it, so it may be possible to start collecting other people's views of their community, and of how it works.

A community study would begin to show people's expectations of, for instance their neighbourhood and of neighbourliness. It could be done through interviews or a survey, or through recording with a camera. It might start out with people who are already familiar - staff and friends, a neighbour, the priest or local policeman - and move out to people who are less well known - perhaps their friends or neighbours, or people who use the local newsagents, or people stopped in the street. Opportunities could be found to feedback information on the community to ordinary citizens through church meetings or local civic groups. We need to look for and understand the patterns of ties and connections in community life, in order to be clearer about our own place within those patterns.

Things to be careful about

It is important to be careful about the assumptions other people may make, and the limitations these may impose on us all. It may be necessary to review these carefully - is it really true for instance that 'it is a big cruel world out there, and no-one will give time to help someone who needs a little extra consideration'? And if it is, is it always so, or are some places and situations easier or worse than others? It is worth working with others to compare experiences of those places and situations that seem to work well for most people with a learning difficulty, and those that work less well, or hurt badly. (11).

It is important to recognise some of the risks and problems that go with relationships of different kinds. It is good for instance, to have a lot of friends at the place where you work or where you live. But for anyone who lives in a hostel or ward and attends a day centre, that may mean having mainly friends who also have a handicap, and who may have similarly missed out on many ordinary experiences of work and living.

One of the exciting things about friendship is often the way it brings whole new areas of experience into life, enabling them to be shared. Even a very few friendships with people who've had very different life experiences can bring great interest and stimulus, encourage aspirations and ambitions. But simply because their lives are very different, it may not be so easy to see those friends often or to share so many things with them - they have different routines, work in a different place, have different (and often quite complicated) demands on their time. Each kind of friendship has its particular unique qualities, and problems and challenges too.

Things to do

To get the best from our ties and connections with others, probably the most important thing is to work hard on improving our own personal skills and resources. That's not enough by itself, of course: every relationship has at least two sides and relies on the readiness of at least two people. But what we can do something about is our own contribution, and in time that may encourage others to do the same.

Joining a self-advocacy group can be one very helpful support for people who are working to improve their own skills and resources. Organisations such as People First* and the National Association of Handicapped Students

can put people in touch with local groups, and a few towns have a Citizen Advocacy Office which could probably do the same. Many people find strong friendships and mutual interests within self-advocacy groups, as well as help in learning new skills. More importantly, self-advocacy encourages people with learning difficulties to tackle issues which affect their lives. This often leads to new connections being made with decision-makers and planners, employers and executives, community leaders and representatives.

Some of the ties and connections we described are easier to attain than others. Certainly it is possible, for example, to achieve friendship or to find a partner, through a dating agency. But it should be much easier for each of us to do something about being a good neighbour, knowing and using our neighbourhood, maintaining acquaintances, joining organisations, and keeping in touch with affairs and events that are interesting to ourselves and others. There are no rules about how to do each of these things, yet there are some simple things that many people can do - like greeting people you often meet, joining in a conversation about everyday things, listening carefully, using local shops and facilities regularly, and keeping up to date with what is going on locally. These are all things to help with involvement in a local community. Sustaining some of the more dispersed connections may need some other skills - making telephone calls, sending letters and cards and reading them, making trips to visit people or entertaining guests. Getting each or any of these things done may involve help from staff or family or friends.

Other people don't always just know when their help or attention is needed, or when we think they should be doing more to assist us. One of the most important things about self advocacy is that it helps people develop the skills and the confidence to say clearly what they want, and how best others may help them. Working and learning with others to develop effective self advocacy is probably the most important thing people who have learning difficulties can do, to support all the other accomplishments.

** People First - 126 Albert Street, London, NW1 7NF.*

WHAT CAN BE DONE - BY SERVICE WORKERS?

In this section, service workers includes a lot of different people - planners, managers, professionals and practitioners who may only meet the person with a learning difficulty once in a while; teachers, social workers and others who may see the person quite often; and residential workers, centre staff or community care workers who may spend a good part of each day with the person, on a regular basis.

Things to look for

It is sometimes quite hard to recognise how the system may make it difficult for people to have any close friends, or may locate people in places where there are no neighbours, or may pull people away from their families, and make it difficult for those links to be sustained. Service workers who are a part of the system may find it very hard even to recognise these effects, let alone to make criticisms of them. It may also be difficult to work out what can be done to change things.

There are several ways in which service workers can learn to take a more consumer-oriented view of things, and probably learning to use the evaluation instruments PASS and PASSING are the most useful of these (12). There are informal ways too in which service workers can encourage one another to take off their 'professional hats' and ask themselves simply 'is this what I would want for myself or my family? And if it isn't, what would it take for me and others to make things better?'.

Service workers also need to make careful descriptions of what makes up community life. They cannot assume that the way they live their own lives will be the way that is right for others. It is important to be as aware as possible of the diversity of patterns of ties and connections that different people find satisfying and useful. Many service workers will have had a fair bit of further education, will be reasonably well paid and in a secure job, will be mobile, and find it fairly easy to get around, to travel at will, and to have many choices in life. Their community lives will be shaped by all these things, and are likely to be very different from those of many service users and their families.

In particular, many service workers will be working in a locality that they don't live in, and may not be very familiar with. This can be a real handicap particularly when one very important part of their work should be to help service users discover their neighbourhood and make connections with local networks. Service workers will often need to make special efforts to discover neighbourhoods themselves, as a way of helping others to do so. They may need to think about both living and working in one area, about joining local organisations in the area where they work, and taking an active part in their development. They should work too, to appoint local, well-connected people in jobs where that matters - for instance as support-workers in community living services.

Things to be careful about

Service workers are as likely as anyone else to make limiting assumptions about people with handicaps and their possibilities. Some of the most important limiting assumptions for service workers though, may be about their job itself. Consider priorities for time and attention for example. There are so many tasks to be done each day, and not enough time for them all, it is easy for some things to be left aside, to receive little attention. Things to do with relationships often get left aside in this way. More important, if managers don't see relationships as significant, staff are not employed or expected to facilitate relationship-building. Sometimes, the whole area of relationships seems risky and full of problems, and service workers may choose not to put much energy into it because it may expose them to risks and challenges they do not want to face, or which they believe are unlikely to be overcome.

Also service workers have often learned not to get their own personal lives mixed up with their work. When your work is about supporting someone who may have very few relationships to develop some new ones, then that may be very hard to do. Many service workers find themselves in the position of being virtually the only person who expressed an interest in a particular person who has a handicap. In that situation it is very hard indeed to remain detached. Indeed, service workers may be the only important relationship in someone's life, the only possibly bridge to a wider world of social contacts and connections. It is important for service workers to see that being involved and giving of oneself is a part of their work, and that only in that way can they themselves really understand what is involved when they ask others to do the same. Making space in their own lives for individual people with a learning difficulty is an important piece of 'modelling' of behaviour for others. That may not

be the conventional way of thinking about boundaries between job and home life in big organisations, and it may create some unanticipated problems and dilemmas. So it is important that managers are supportive of service workers who blur the boundaries in these ways, and are prepared to encourage, enable, and give 'back up' as needed.

Service workers will find it difficult or impossible to be independent advocates for people in the area where they work. They may do this in another area, where they have less conflict of interest, but in the area where they work they must encourage others to take up the role.

It's important too, to recognise that there are limits to what service workers themselves can achieve. Most of us would not want the future of relationships with people who have learning difficulties to lie mainly with paid workers. Their main contribution is introducing people to one another - maybe being helpful with practical arrangements, even some support and counselling, but essentially leaving them alone to work out what the relationship will become. That may be very difficult. Service workers may feel that they are responsible and that they need to supervise the relationship. To a degree this may be true, but it is also important for service workers to learn when to step back and to leave the natural processes of forming relationships to take care of themselves.

Likewise it is important that service workers do not see their role solely or primarily as preparing people for future relationships. Many of the things a person needs to know to create and sustain relationships they will ony learn in relationships, rather than in artificial teaching situations. Many of the best teachers will be ordinary people and much of the most effective learning will be done when people need to know what to do in real situations. For many professionals this kind of thinking may seem risky and uncertain.

Things to do

Most of the systems in which we work have severe unintended consequences for people with learning difficulties. Service workers need to discover how the system works, and how they can work towards making it more responsive to the real needs of the people whom they serve. However no one should be surprised if this process of change is frustrating and difficult. Sometimes workers may have to make the choice whether they want to go on working in a system with which they have come to fundamentally disagree. Many people however find that change happens at many levels. Even if people make only very slow progress in the business of system change, there is often quite a lot which can be done by individuals in their own life, and in the bit of the organisation over which they do have some control. Although this kind of personal change may have a very small impact overall, it is nevertheless fundamental. None of the bigger changes can happen without it. It is possible too, that as more and more individuals begin to make small changes in the way they do their particular job, in the priorities they set and in the ways they decide to use their time and energies, small changes begin to roll into bigger ones.

What matters is for service workers to see it as part of their work to make space and time for individual people with learning difficulties, to foster friendships between themselves and the people whom they serve, and to build ties for them with their own personal networks, even when there are many other demands on their time. These may be informal connections, mainly organised around leisure, or more formal arrangements. Each will give rise to problems, especially of conflicting roles and interests, but these are good reasons for facing and taking on the challenge.

If a person with learning difficulties has no particularly noticeable problems very often life will just potter along, and nobody will be thinking or planning ahead. Here the service worker has a very special contribution to make, in seeking out appropriate resources and setting forward-looking agendas. Thinking about a person's ties and connections may involve a lot of planning for future relationships, laying the groundwork for these by making introductions, and working to develop many of the skills and resources that help to sustain them. Important among these are skills of independence and mobility. People who can use a telephone themselves, and move about the neighbourhood or travel on public transport unaccompanied will have many important resources for sustaining relationships with others. Many people with learning difficulties will need a great deal of help to do these things. The most important enabling resource will be other people. The more these other people are non-service people, the greater will be the independence gained.

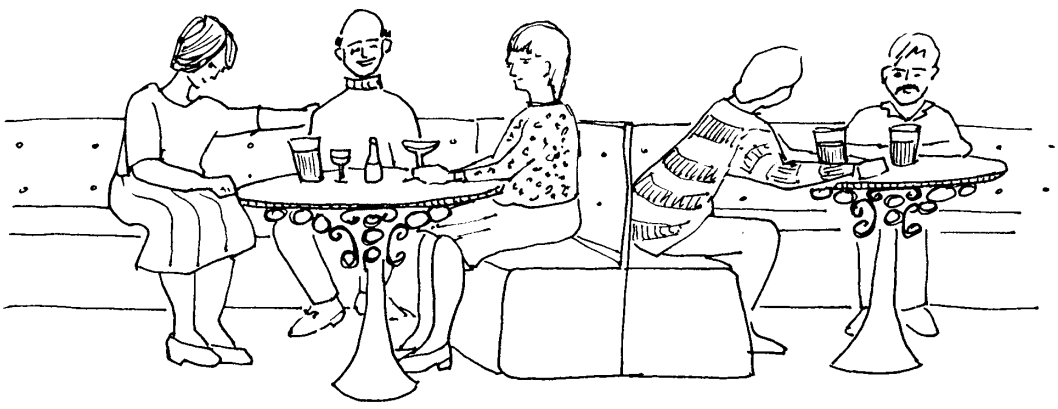
Much of this thinking and planning can focus on the more obvious and maybe mundane accomplishments - of neighbourhood and acquaintance and of keeping in touch. But service workers have the advantages of long term and sustained contact with individuals, and professional skills and resources too. So they are

also well placed to take on the challenge of some of the more complex and difficult accomplishments - of helping people who seek close friendships or a partner, or who want to re-establish lost family connections.

Many service workers need to learn a lot more about enabling people with learning difficulties to forge new links with community. Many managers need to get a lot better at supporting their staff in this kind of work.

A support worker in South London described how she took Lennie (a young man who doesn't speak) to the pub near his new home regularly at about the same time each day. They didn't go out of their way to meet people, but gradually regulars began to take an interest in them. At first they wanted to question her about Lennie but carefully and patiently she encouraged them to talk directly with him, to spend time with him, to find out for themselves what kind of a person he is, what he likes, what interests him, what activities he can share with them. Gradually she was able to fade out. Now her role is limited to simply helping him to get there and back, though she hopes in time one of the regulars will begin to do this. She's waiting to see if anyone will suggest it. It's taken commitment and patience and imagination to get this far.

The more that service workers engage others (non-service people) in the task of supporting ties and connections, the more likely they are to succeed. Their greatest resource in doing this will be their own set of ties and connections in the community, and their ability to use networks. Whatever the limits on their roles imposed as government policies change, there is much that service workers can do. In particular, there are many helpful ways they can create a supportive context for others - direct care staff, families, advocates - to be directly effective. Inevitably they will encounter limits and real frustrations. It is important to keep these in proportion by developing other areas of action outside work, where they will be less subject to these particular limits. They can join for instance the wider movements towards normalisation, community living and advocacy, by being involved in courses, workshops and service-evaluations that take them to other people's 'patches'. They can become an advocate for someone in an area other than where they work, and can provide direct support (as committee members or advocate-associates) for citizen advocacy schemes, or indirectly (as ardent and vocal supporters) for self-advocacy. They can join national organisations to maintain pressure for policy change, or they can form small 'core groups' close to home who will support one another and provide cover to work behind the scenes with community health councils, community groups, local councillors and MPs.



WHAT CAN BE DONE - BY ANY INTERESTED CITIZEN?

Interested citizens of course potentially includes us all - whether we are service workers or users or families, or the ordinary person in the street who has no particular knowledge of the world of services for people with learning difficulties. Whatever our daily occupation, we all have another role as citizen, with an interest in communities that work well for all of us.

Things to look for

People need to find out for themselves whether the picture we have given is accurate. What is life like for people with learning difficulties? And how does that compare with the lives of other citizens? What additional opportunities would add to people's ties and connections? What are the things that currently get in the way?

People who have not spent much time thinking about this before might want to think a bit about their own ties and connections - and perhaps meet with others to do it. The mapping process we have already described (p. 37) could be useful here. It is important that people make as accurate a description as possible of the way they would really like community life to be.

The next step is to begin to think about what ordinary citizens could do in their own lives that would make that picture of a more desirable future a little nearer to reality, if not for everyone, then at least for one person they know.

Things to be careful about

There are no experts in being an ordinary citizen. Many ordinary people are a bit reluctant to give an opinion or to take action if they think there is an expert (such as a doctor, teacher, or social worker) who can catch them out with the right answer. While all these people have an important contribution to make, many of them will readily admit that they are no nearer to the 'right' answers than anyone else. They are very constrained in what they can do - they have to make the best of limited resources. Often they disagree with one another about what is best, and have to compromise to get any agreement. Also, although they may have a lot of useful knowledge about many things to do with learning difficulties, they probably know no more than what everyone knows about being a neighbour, having friends, connections with family and so on.

Ordinary citizens should take courage from the fact that they probably know about as much from their own experience as anyone does, about achieving these things in the lives of people with learning difficulties. Professionals should support and encourage them in this.

Things to do

Many ordinary citizens (who are not service workers) are well placed to make a whole variety of ordinary settings 'open' to people with learning difficulties. People who work in public services for instance (on the buses or trains, or in the police, or local government offices) are able to set an example to others, encouraging an accepting and welcoming attitude to people with a learning difficulty. Similarly, people in shops and restaurants can foster a friendly and welcoming relationship with regular customers. Other ordinary citizens will be more interested to meet people with learning difficulties when they see them in public and observable positions being friendly and courteous, and enjoying their friendships.

When people see that it is often quite simple to help someone who may need a bit of extra assistance and consideration in negotiating their way through life, they will see it is something which they can do too.

You do not have to be an expert to be a good and helpful citizen, and far from costing you something, it will probably make life a lot more enjoyable.

People who work in the media can encourage other citizens to see people with learning difficulties as the sort of people they would like to have among their friends. Positive news stories about people and their achievements help to do this, particularly those which show people with learning difficulties making their way successfully in community life in partnership with other ordinary citizens - as givers and contributors. News stories can show the very wide variety of settings and activities in which people with learning difficulties participate, encouraging ordinary citizens to see this participation as nothing out of the ordinary, but something to be welcomed because it may enrich their own experience of life.

People who have a public office - councillors, magistrates, religious leaders - all have an important part to play. They can influence the ways in which the institutions they represent

respond directly to people with a learning difficulty. Are people who come to the public gallery of the council meetings or the courts or to the church congregation helped to see and understand what is going on? Is sufficient time taken, and are there enough people on hand to ensure they are able to join in appropriately? If each of these settings works well for people with a learning difficulty or a physical disability, they are likely to be more welcoming and enjoyable places for all of us - encouraging all of us to participate more in the public aspects of citizenship.

Some people who have learning difficulties are good at introducing themselves into new places and meeting new people. Matthew, for instance, makes a definite effort to get to know people - "...I say 'Hello' to familiar people in the street and in the shops" and Rose says she "tries to get on with everybody, although it doesn't always work out like that". Others may need some encouragement and practical help.

On page 42 we described how a good support worker used her very ordinary skills to introduce Lennie into one part of his local community. It was a good example, and it took time. If ordinary citizens wait for people with learning difficulties, and for 'the authorities' to bring about the changes needed, then we may wait for ever. Everyone of us who thinks the accomplishments we've described here are important has to do something about it to make these accomplishments real. This is not because we are particularly good people, or even because we are particularly qualified, but rather because we all have an interest in being in a society which is good at supporting people who need a bit of extra help and consideration in their lives.

People may be reluctant to take the initiative if they can see no immediate need to do so in their own life or those of people immediately around them. Yet many people will be willing to follow a lead where one is given and they see good clear examples around them.

Most people are likely to be personally influenced by the example of someone else whom they know well already, and whom they respect. Probably the most helpful thing that each person can do, who reads this book and is interested in what it describes, is to act on it in their own personal lives. Also they could search around among their own ties and connections with other ordinary citizens, to see whom they might personally encourage to develop a relationship with a person who has a learning difficulty. Who in turn could that person influence by their example and by encouragement and support?

Some people, even when they are keen, may be unsure about how to start. Quite a lot of people in their ordinary life just never meet a person who has a substantial learning difficulty, or if they do, they are unsure about how far they can go beyond smiling encouragingly and being generally pleasant. For most people it will help if they can be introduced by someone who already knows the person well - just as in any other relationship. It is worth pondering beforehand how best to make the introductions. What needs to be said to make each feel comfortable, and what are the things best left for each to discover about the other as time passes?

For some people it may be best to seek an introduction through a formally organised scheme, which may provide some measure of support and backup when people feel unsure about what they are doing, and what to do next. Some areas for instance have a friendship scheme which sets out to try and link people with learning difficulties with potential friends. This may provide a good starting point. Some schemes have a strong focus on leisure - using people's leisure interests to support and encourage a person with a learning difficulty to take part too. That can be valuable, and may often be the beginning of a path toward a wider set of connections.

In some places there are schemes that may be called adult fostering or something similar. They set out to recruit people who may eventually help to find or provide a home for someone who has a learning difficulty, either on a short or a longer term basis. Although that may be more than someone wants to contemplate at the outset, these schemes are sometimes willing to start with a very much smaller, but nevertheless significant commitment to friendship.

Some areas now have a Citizen Advocacy office, which seeks to match individual people with learning difficulties with someone who will represent their interests in an independent way. This may include becoming their friend and introducing them into wider social networks and relationships. A citizen advocate who really is an independent person can be of immense importance in the life of someone who has hardly anyone to stand by them.

In each of these examples it is important to keep in mind the objective - of making a personal link between an interested citizen and a specific person who has a learning difficulty. This is quite different from simply introducing our interested citizen as helper in some volunteering scheme where big groups of non-handicapped people give help to big groups of people who have

learning difficulties - such as many specialist clubs, and some sports organisations for disabled people. This may be fun, but it is not what we are talking about here. Making individual links between one person and another takes a different sort of time, commitment and understanding, and has a unique and very special part to play in the lives of people with learning difficulties and those involved in relationships with them.

In conclusion

In this section we have described a framework for thinking about what different people can do to create and sustain ties and connections in the lives of individual people with a learning difficulty. We have suggested some things to **Look For** - to study, read, learn about, to examine in their own lives, and those of people near to them. We have also drawn attention to some things to **Be Careful About** - attitudes and perceptions that need to be tested, the ways that our particular role - as a parent, or as a 'service professional' may make us blind to some very important things. Lastly we have proposed some things **To Do**. Because we are thinking about individual ties and connections these mostly revolve around ways of using our own sets of relationships with others as a starting point.

The sections overlap somewhat, because each of us in addition to any special role we may have, is also simply an 'interested citizen', who has an interest in finding ways of engaging other citizens in what concerns us. The more ways we find to do that, the better community life seems likely to be for us all.

SOME LIMITS TO COMMUNITY

'Another fine mess you've got me into, Stanley'
(Oliver Hardy)

People writing about the positive possibilities of 'community' are at risk of accusations of naive romanticism. We have tried to show there are some real challenges in supporting ordinary community lives for people with substantial learning difficulties. This book has set out to describe small strategies which ordinary people can tackle in everyday ways, but we recognise that there are limits to these processes. Some of these limits are about places where other, larger-scale strategies need to be working too, to make them successful. Some of them are notes of caution about our expectations in an age when many of us (not just those who have handicaps) may not have experienced a richness and diversity in 'community life' and may be unclear what it is reasonable to expect from community.

Social Processes

Three kinds of major social processes have had, and will continue to have a big impact on the opportunities for community life experienced by people in our society. First there are some long-term, well established patterns of inequality between people, in health and wealth, in culture, in employment and other opportunities in life. Social class, race and ethnic origins, North and South, country and town, age, sex and gender, all have an impact on the kinds of lives people have, the opportunities they experience, and how they see themselves and the world around them. These are big and far reaching patterns in our society, which change only very slowly if at all, and they make very important differences in people's lives. The kinds of strategies we have described in this book will not make much difference to these, especially in the short term. For instance, it would be hard to claim that the world would be a fairer, less unequal place, and that the ideas and practices that lead to discrimination and separation between people will get weaker as a result of what we suggest. But there is no reason why the lives of individual people should not be very much better and in ways which are well worth achieving.

Second, there are opportunities for many people to develop a more personal private way of life. The scope for personal mobility and travel, the very complexity of modern life, and the enormous extent of day-to-day choices available to many people, makes it possible to opt out of a wide range of traditional ties and connections with others. Some people find it reasonably easy to have little to do with family or neighbourhood, to avoid associational ties except strictly useful ones. This goes particularly for those who enjoy wealth, health, good housing, and educational opportunities. Equally, others may lose these ties and connections not by choice, but by chance and accident. Relationships that break up, jobs that end, families and friends who move away or lose touch, accident, sickness handicap or death that strikes unexpectedly. Others again are born into or find themselves in situations where they have few of the rich range of choices outlined above, and few of the chances to 'opt in' which they offer. Whatever the individual reasons, there seem to be strong forces that push some people into individualistic lifestyles that have advantages for some but strong disadvantages for others.

Third, there are strong pressures towards more and more ways of professional and organ-isational interventions in all of our lives. Things which used to be seen as personal or family responsibilities have increasingly become defined as areas for 'professionals'. The business of having and rearing a child, for instance, has become increasingly surrounded by practices and procedures in which professional management and control is a major feature. Many aspects of personal and family behaviour now come within the remit of powerful professions; doctors, social workers,counsellors and therapists are seen as having an increasingly important say in how we manage our lives.

In particular there are a multitude of professions which surround anyone who has somewhat special needs,with segregation and specialisation working to reinforce the sense of being different. Professional progress has given us many more

accurate and powerful ways of helping people with special needs, but may have also discouraged ordinary citizens from seeing they have an important role too. Increasingly, ordinary people may lose the confidence of knowing 'intuitively' the right things to do, the right decisions to take, the right ways to behave. One paradox is that, at a time when ordinary people have been encouraged to see themselves as 'less competent', the professionals who usurped them are increasingly starved of resources. We end up with a situation in which no-one is competent.

Some limits to this book's approach to community

Of race and culture. Many readers will have guessed that the book was written by people who come from a narrow range of mostly English, white, middle-class backgrounds. Even though we have tried hard, many perspectives of others who come from significantly different backgrounds are not represented here. To some people for instance it may seem curious that in the list of important sources of 'ties and connections' more attention was not given to ethnicity and religion.

Some people will find the sense of place and locality, or the description of family or partnership, simply does not square with their own experience. The crucial issues of race and culture cannot be ignored though, when people are working to support changes in someone else's life. Often the person with learning difficulties and those around them will be among the best 'teachers' of these issues.

Of men's and women's issues. There is a huge literature on the different ways women and men experience relationships and community membership. This book has been written with some awareness of these issues, but without any attempt to review them all systematically. Again, when working to support real changes in someone else's life, many of these issues will be critical. It is important to study the practical effects of these differences for the particular person with whom you are working.

Limits to neighbourhood

Some neighbourhoods, especially in cities, seem to have been laid out by the planners as if they were trying to ensure there is nothing of value or interest within reach of them - they literally have very few resources of any kind. Everything depends on what people who live and work there can organise. Many people may have purposely chosen not to live in such an area. It may have become 'blighted' by bad planning so that businesses and jobs leave. Facilities such as the school and the public baths, get closed down and the buses withdrawn. People may be very poor - families who don't have the income to sustain a rich variety of local facilities. It may also be an area where fears of being burgled, mugged or raped mean that people avoid contact with other people and are afraid of walking around especially after dark. Businesses and leisure facilities tend to pull out and go elsewhere, except for the odd pub and betting shop.

Other areas have been 'chosen' by people who have a lot of resources, and seek the seclusion from others this can buy. They are not interested in local facilities because they either provide all they need within their own homes, or they travel by car (or boat or plane!) to such resources as they need. Local neighbourhood relationships may not interest them because they have many other sources of contact with people, and the resources to easily get to meet them.

Both kinds of neighbourhood can be pretty inhospitable to those who in order to meet people need some useful resources near to where they live or work. For people with few resources and many needs, these kinds of neighbourhoods may be a real problem. Service providers and planners need to be careful about placing people with learning difficulties where there will be some real supports, and may need to work extraordinarily hard to support people who already live in, or have some reason for choosing, areas where these are not present.

Government policy in recent years has encouraged people to think of neighbours and neighbourhoods as a natural source of caring, possibly reducing dependence on paid services. There are signs that some neighbourhoods have a greater capacity for caring for dependent members than others and some useful ways of fostering this capacity have been devised. But none of even the most successful schemes suggest that voluntary care can completely replace all paid services, particularly when people have very substantial and long-term needs, or can only be helped by very specialised supports.

Probably the most significant investment which can be made by the person who seeks to belong in a neighbourhood which offers real supports is time. It takes time to gain acceptance and learn local ways, though being new it may also be an important opportunity to leave behind an unhelpful identity or reputation and to make a

fresh start. Moves sometimes seem necessary, particularly when services are poorly-developed and have few options to offer people in the neighbourhood where they have links. The gains and losses of moving must be weighed up very carefully by all the people concerned.

The limits to staff and service roles

In many traditional institutional services, staff were very aware of the limits on what they could achieve - as a result they often did not aim too high. Staff were trained not to get involved, and expected to move on regularly so as not to restrict their experience to one set of clients.

New 'community living' services have mostly been developed on a strong foundation of positive values and beliefs based on the right of every person however severely handicapped to live with appropriate support, in an ordinary community. Staff enter the services with high expectations of themselves and of service users, and of the new kinds of relationships possible between them. To some extent these are often achieved, with greater closeness, more informality. Staff though often find repetitive routines and 'making do' with limited resources, boring and stressful. Much of the day is taken up with routine supervision, and by 'teaching' others to be more independent. Service users often speak of staff as the nearest to friends they have. For staff though, their 'friendship' may not be genuinely two way - they receive much but feel able to give only in a limited way.

The higher the expectations with which staff came into this work, the more likely they are to experience the tensions and conflicts in their role, for these are the people who are pushing the 'staff' role to its very limits. One way in which this happens is that particular individuals identify strongly with a great deal of the pain and hurt sustained regularly by people with handicaps trying to make their ways in ordinary communities. If this is something they had not expected, or if managers show themselves unhelpful and unsympathetic, even staff who were initially very enthusiastic can quickly become disillusioned, instead of patiently learning from people with handicaps how they sustain themselves for the long-haul through life. Many highly motivated and effective staff move on. Others stay, but experience a fierce clash of loyalties between their attachment to the people with learning difficulties with whom they live and work and the constraints imposed by their professional roles and employing authorities.

This dilemma suggests that some of the most developed community living services, are beginning to run up against the limits of what a paid service can reasonably provide. While such a service may support people's inclusion in neighbourhoods, their family membership and friendships in a variety of ways it cannot provide people with friends. That must always be the responsibility of other community members.

Another limit to what services can achieve lies in the implicit contract between them and the wider communities they serve. Community members may understand this as 'we pay our taxes so that you will keep inconvenient people out of our way'. Where this is so, it needs challenging. When service providers seek to support people in ordinary communities without taking this aspect into account and carefully reviewing its implications, there are sure to be problems.

We have already discussed the process by which professional expertise increasingly encroaches on areas of ordinary people's lives. One risk, as service workers become more acutely aware of the need for relationships in people's lives, is of a new 'technology of relationships' developing. 'Relationship Assessments' and 'Friendship Goal-plans' and 'Acquaintanceship Reviews' could burgeon. There will be many commercial inducements to produce handy information-packs and training for 'Relationship-Providers'.

There is nothing wrong with trying to understand another's situation in a careful and systematic way, but there is a danger of these 'technical' activities becoming a substitute for activities which might actively enhance opportunities for relationships, and may even be a barrier to them. Services need to focus energy on encouraging more people who actively share that person's interests to take them on as their own. Only in that way will dependence on paid services for relationships be reduced.

The limits to family

Families who have a member with learning difficulties are not 'super-special' - they are ordinary families. They have some of the special knowledge that comes from learning-by-doing - about being with a person who needs some extra help in their daily life. They may have had more opportunities than most to attend courses and conferences about issues to do with handicap, and to meet with various professionals to discuss developmental problems or service-planning issues. Some may have made a special study of handicaps as part of their way of helping their son or daughter to the best of their ability.

Many will be just ordinary people with no special knowledge other than what they have picked up as they've gone along. Like most families, they probably believe that they know and understand their particular relative better than most, since they have spent more time with them and watched them grow up. And like most families, they will be only partly right in this belief. As the person with a learning difficulty begins to approach adulthood, his parents are likely to experience even more difficulties than most in achieving some separation between them and their child. This can cause problems for all concerned.

'Learning as you go along' means that families may have gathered their quota of the folk-lore of handicap simply from being around in our culture - 'they like to be with their own kind' - 'they do not feel things as we would'...and many others beside. However, unlike other citizens, they have someone with a handicap in their own family and they have a commitment. Often people arrive at their views on the basis of very limited knowledge and experience, perhaps in the context of professional advice which is obscure or conflicting or downright unhelpful. Many parents study carefully the pattern of available services and make some sensible and practical decisions on the basis of what they see. If what they see is institutions and hostels, and hastily-conceived 'community care', as yet untested, it is not surprising if they find other options more attractive.

Some simply hope to go on caring for their own son or daughter for the time being, without thinking too hard about what will happen as they grow older, or if disaster strikes. A surprising number of older parents in this situation come to the sad conclusion: 'We just hope she goes before we do'. Some parents pass on the responsibility to other perhaps younger members of the family. Others seek some kind of 'acceptable institution' - a contained 'village community for people with learning difficulties', in which they see safety and security for them and their son and daughter as the main advantage, even if it means sacrificing opportunities for development and participation in a wider community.

Other families seek the new opportunities offered by services that are seeking to support people in ordinary settings. They work both politically and practically to secure new kinds of provision. Whatever point of view families come to hold, and whatever decisions they personally make, the fact remains that these families' opinions and decisions are crucial in the lives of people with learning difficulties, long beyond the time when they would expect to be so for non-handicapped sons and daughters. Without strong independent advocacy, people with a learning difficulty are likely to remain confined in a world chosen for them by others.

These limits of people's 'family of origin' need to be explored with great care. Often by the time services are approached for help and support, the patterns of belief and decision-taking have already become firmly fixed. For the person with a learning difficulty, the failure to achieve any real separation from parents during adolescence may have created a pattern of extreme dependence in every aspect of life. Advocates and services need to understand the major implications this may have, and the kinds of long-term commitments they need to undertake with consistency if they are to see changes through to a satisfactory conclusion. Service organisations are often lacking in both the kind of consistency and continuity needed, and also the capacity for long -term commitments.

Other limits to 'family' concern having and bringing up children. Opportunities to form a new family have been denied in institutional services, which often sought to deny even the possibilities. Smaller, more person-centred service arrangements make it more likely that people with learning difficulties will want, and be able to start a family of their own, and that some staff will want to support them. We have very few good stories about how this may be done well, and how people may be supported in the long-term. There are a few accounts in which it has been a painful experience for all. Again, the demand is for services capable of a kind of consistency and continuity not often found. It seems likely that only outside service systems can we look to families, individuals and communities for the kinds of commitment which are demanded.

Limits to public awareness

If as we have said earlier, the hidden 'deal' between health and social service authorities and the community is about removing inconvenient people, saving the public from embarrassment or the need to care, then change requires a substantial job of raising public awareness. It may not be immediately apparent to many people that **the kind of community that works well for people with handicaps or learning difficulties is likely to be also a good place for them to live**.

It is tempting to think that publicity can help here - when once a good example of friendship or neighbourliness is spotted, then it can be 'turned

into a news story'. On page 43 we talked about ways in which the media, and the press in particular can be very helpful. But often this kind of story can turn out to be quite unthinkingly harmful to the person who has a learning difficulty - the press is often very patronising, using demeaning or disrespectful language, or making it seem as if some perfectly ordinary thing - two people in a pub together - is a Very Remarkable Human Achievement. Worse, it can often encourage very inappropriate charity appeals with readers being urged to send their unwanted toys or take part in bizarre fundraising events.

If there are problems of public awareness (and that assumption needs to be tested in each separate context), then the things that have most impact are likely to be the way in which services for people with learning difficulty are seen to work. When organised services clearly treat people as independent, adult, helpful, valued and respected citizens then there is a chance others will see them as so. Short term 'publicity tricks' are likely to be much less effective than the consistent multitude of small-scale and everyday acts that teach ordinary people directly by experience.

The costs of friendship and communality

Living in friendship and communality with others is not joy unalloyed. Friendship and communality make demands on people's time and attention, their concern and resources. The demands they make are sometimes very unequal ones. A friend may need you to stand by them, even when they have done something bad or wrong, or may need you to share with them when all they have to share is pain. Friendship demands the truth, even when it hurts. Making a commitment to another person involves envisaging their likely future, and having an expectation of being willingly involved in that future.

There is a great risk in entering communality with others, because to enter is to make a commitment, and you can never truly know what depth of commitment, nor exactly to whom it has been made. Communality may call on those commitments in unexpected ways and at inconvenient times.

Even people living in formally designated communities, such as L'Arche, say there are many compromises and many disappointments. Nevertheless, most people feel those costs are more than outweighed by the knowledge there are others who in friendship and communality will do the same for them when they have need, even if at present it seems somewhat far-off.

People who have virtually no ties and connections with others

For each of the people who wrote this book, probably the most difficult of all experiences has been meeting with individuals who had virtually no ties with anybody else at all. People who were almost abandoned, who seemed to matter to nobody, except perhaps that they had a place in some administrative records - their existence had been officially noted. It is impossible to say how many such people there may be. That there are any at all though, seems shameful. In a world with so many resources, so many opportunities, it should be possible to arrange life better than this.

One thing is sure: when people reach this point, the business of reconstructing their community lives is not a simple technical or administrative task. But the task is vitally important. There is **urgency** - a sense that this is something which cannot be left, it has to be tackled **now**. There is also a sense that each small step in supporting relationships has to be done properly and well, to ensure there is something in place on which the **next** small step may grow. On the positive side, each small advance which is made may thus be disproportionately important - one extra acquaintance for a person who has thousands may mean very little, but one extra for the person who has none at all, or only one, is an enormous step. Each additional step to secure new ties and connections or to safeguard existing ones may make other steps more possible.

People who seem to choose not to have any involvement with other people

Usually when people have very few or no connections at all with others, it does not seem to be from choice. It is often possible to trace a chain of incidents and circumstances in their life that has probably led to this. 'Probably' because we can never really know, only make more-or-less informed guesses. Mostly too, it is something people only notice after it has happened. The people who are withdrawing from

the person's life, or who are not getting involved, perhaps do not know that others are doing the same. It is the kind of circumstance that people who work in organised services may be better placed to see than others, since there may be many administrative reasons for seeking out contact with individuals who will not necessarily seek anyone out themselves - reviews, case conferences, 'client follow-up' research, and so on.

Some people though, seem to have chosen not to be connected with others. The process by which this happens is often much the same, but people may have taken steps to sever connections, or to remain alone. This presents us all, not just service-workers, with a dilemma. In one way it seems an affront - a rejection of us, our society, everything we stand for, and raises questions for all of us about whether our response is guided by this sense of hurt, or by a genuine concern for the person herself. There is the problem too of knowing and understanding what it means to 'choose' to avoid the company of others. Has the person really the knowledge and experience on which to make a real decision? Is what seems to be choice really so, or could the person in the right circumstances learn to behave otherwise, and if so is it right to try to intervene and help the person to learn these other ways? There may be no answers to such questions and the very questions may seem like delicate niceties not worth worrying about. However, the urgent need of people who have literally no ties and connections, impresses at least some people with the necessity to 'do something'.

For any of us, whether service workers, families, friends or just concerned citizens, there is a need to recognise people's rights, but also their vulnerabilities. Diffidence about 'intruding' should not prevent us from being around to see when people are reaching the end of their own resources and needing support from others. Many people who know someone who has become cut off from contacts still continue to offer them opportunities but without pestering and badgering them. We may need to just go on 'being there' because to turn away would be to remove even those few options which remain in a life which may have lost almost everything else. If we pull out, then there may be no way back.

SOME THREADS AND PATTERNS IN THIS BOOK

Being part of 'community life' means having ties and connections - relationships - with others. Along with these **may** come other things - a job, money, information, valued roles, status, responsibilities. Most of us would agree that for all the worries these sometimes bring, on balance we would rather not be without them.

It's clear that 'community life' is what most people work at in their every day lives, in a commonsense kind of way and without thinking about it too much. Through friendship and acquaintance, through making a home and keeping up interests, through an active connection with family and neighbourhood, people maintain their ties and connections with others. The patterns that result are very different - there seems to be a lot of variety and choice about how people go about these things, and certainly no one 'right way'. The skills of making and sustaining community require no special professional training or dramatic 'scientific breakthroughs'. It is something most people are good at anyway.

Nevertheless some people who have learning difficulties (and others too - elderly people, people with disabilities or mental health problems) have often been excluded from communities. This has come about in many ways - well intentioned efforts to help, misunderstandings of what 'the problem' was, or simple unwillingness to face the challenges their inclusion in our lives presents us. Whatever the reasons, not having ties and connections can mean being lonely and isolated, being excluded and rejected. Life itself can come to seem worthless, or more dangerously it may be seen by others as having little worth.

This book is based around the idea that communities which are good at including all citizens will be better for us all. The kinds of communities which are good at actively including people with learning difficulties will be better able to use all of the different gifts which each of us brings to life. They will have a greater richness and diversity, and offer more opportunities for learning and growth for everyone. Ties and connections will not always make us happy and content, but they will offer us more opportunities for happiness, for meaning in life, and some safeguards for when life plays tricks on us.

The book explores ways to support the inclusion of people with learning difficulties in having friends, acquaintances, a partner, in active connections with family, neighbours and neighbourhood, and in following interests. In doing so it draws on the ordinary experience of ordinary people. It shows that this is just what many people are already doing anyway.

People we have called service workers - such as nurses, social workers, teachers and others - will need to think about this book in a somewhat special way. Service workers have a community life too - they have friends and partners, interests, acquaintances and families, neighbours and neighbourhoods. The book encourages them to think of these as a resource. It is in their own role as ordinary community members that they may be able to do most. However, making the connections between their community life and their work will often be complicated.

Service workers are specially well-placed to be helpful, supportive and enabling of the community-lives of others. Particularly when they work in newly-developing 'community living' services, ties and connections should be well up on their list of priorities for attention. They have a key role in seeking connections and helping to make them, of giving supports that enable people to use opportunities. Mostly, their professional role will be limited to enabling and not interfering unduly.

There are many things 'services' cannot do - including providing friendship. Clever professionalism that turned relationships into simply a 'technique' to be taught in courses, measured in checklists and administered by specialist workers would be doing no service to anyone. Service workers need to be especially aware of the limits of their service-roles, but also of the possibilities and resources of their service positions as supporters of what others can do.

Service workers and other community members alike can also explore the relevance of the ideas in this book to other people who are at risk of becoming separated from community life. A lot can be learned on both sides from the ways in which some elderly people sustain their connections with others as they grow older and more dependent, or people with mental health problems maintain their family and their jobs.

There are also other areas - community development, parish work, voluntary organisations, intentional communities, citizen advocacy - which have much to teach us, and where experience of working on people's ties and connections in community life may be very helpful.

Ties and Connections is a challenge, an active invitation, an open encouragement to all of us individually and in groups to enrich our own connections with community, to explore ways in our own lives and our work of including people with learning difficulties, and to meet together from time to time to review and celebrate accomplishments and identify future directions for this endeavour.

APPENDIX I

An Associational 'map'

In one small town, John McKnight found voluntary organisations around the following names:*

Artistic organisations	choral, theatrical, writing
Business organisations	Chamber of Commerce, neighbourhood business associations, trade groups
Charitable groups and drives	Red Cross, Cancer Society, United Way
Church groups	service, prayer, maintenance, stewardship, acolytes, mens, womens, youth, seniors
Civic events	July 4th, art fair, Halloween
Collectors groups	stamp collectors, flower dryers, antiques
Community support groups	"friends" of the library, nursing home, hospital
Elderly groups	Senior Citizens
Ethnic associations	Sons of Norway, Black Heritage Club, Hibernians
Health & fitness groups	bicycling, jogging, exercise
Interest clubs	poodle owners, old car owners
Local government	town, township, electoral units, fire department, emergency units
Local media	radio, newspaper, local access cable TV
Men's groups	cultural, political, social, educational, vocational
Mutual support (self-help groups)	Alcoholics Anonymous, Epilepsy self-help, La Leche League
Neighbourhood and block clubs	crime watch, beautification, Christmas decorations
Outdoor groups	garden clubs, Audubon Society, conservation clubs
Political organisation	Democrats, Republicans, caucuses
School groups	printing club, PTA, child care
Service clubs	Zonta, Kivanis, Rotary, American Association of University Women
Social cause groups	peace, rights, advocacy, service
Sports leagues	bowling, swimming, baseball, fishing, volleyball
Study groups	literary clubs, bible study groups
Veterans groups	American Legion, Amvets, Veterans of Foreign Wars, their auxillaries
Women's groups	cultural, political, social, educational, vocational
Youth groups	4H, Future Farmers, Scouts, YMCA

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APPENDIX II

Further Reading

Atkinson, D. (1987). How easy is it to form friendships after leaving long stay hospitals? Social Work today, June 15.

Atkinson, D. & Ward, L. (1986). A part of the community: social integration and neighbourhood networks. Campaign for people with Mental Handicap, 12A Maddox Street, London W1R 9PL.

Bishop,J & Hoggett, E.P. (1986). Organising around enthusiasms: mutual aid in leisure. Commedia Publishing Group, 9 Poland Street, London W1V 3DG.

Bulmer, M. (1986). Neighbours: the work of Philip Abrams. Cambridge University Press, Cambridge.

Craft, A & Craft, M. (1979). Handicapped married couples. Routledge, London

Craft, A. & Craft, M. (1983). Sex education and counselling for mentally handicapped people. Costello, Tunbridge Wells, Kent.

Firth, H and Rapley M. (1987), Making acquaintance. Northumberland Health Authority District Psychology Service, Morpeth.

Gathercole, C.E. (1984), Residential alternatives for adults who are mentally handicapped. Composite edition, with Leisure Volunteers Guide. British Institute of Mental Handicap, Kidderminster.

Harris, J. (1983). Citizen Advocacy. Mental Handicap Vol. 11 pp145-146

Independent Development Council for People with Mental Handicap (1986). Pursuing Quality. How good are your local services for people with mental handicap? IDC, London.

Mansell, J., Felce, D., Jenkins, J., de Kock, U., & Toogood, S. (1987). Developing staffed housing for people with mental handicaps. Costello, Tunbridge Wells.

McConkey, R. & McCormack, R. (1983). Breaking barriers - educating people about disability. Souvenir Press, London.

National Bureau for Handicapped Students (1986). "We can change the future" Self-advocacy for people with learning difficulties: a staff training resource. Compiled by Cooper D and Hersov J. National Bureau for Handicapped Students, 336 Brixton Road, London SW9 7AA.

Open University. (1986). Mental handicap: patterns for living (Course P555) Department of Health and Social Welfare, The Open University, Walton Hall, Milton Keynes, MK7 6AA. Student pack.

Richardson, A. & Ritchie, J. (1986). Making the break: parent's views about adults with a mental handicap leaving the parental home. King's Fund Centre, London.

Ryan, T. & Walker, R. (1985). Making life story books: British Agencies for Adoption and Fostering, 11 Suffolk Street, Southwark, London SE1 1RQ.

Shearer, A. (1986). Building community - people with mental handicaps, their families and friends. Campaign for People with Mental Handicap and King Edward's Hospital Fund for London, London.

Walsh, J. (1985). Let's make friends. Souvenir Press. London

Weiss, R.S. (1975). Loneliness: the experience of emotional and social isolation. MIT Press, Cambridge, Massachusetts and London.

Williams, P. & Shoultz, B. (1982). We can speak for ourselves: self advocacy by mentally handicapped people. Souvenir Press, London.

Wertheimer A. (1985). Living in the Present. Campaign for People with Mental Handicap, London.

APPENDIX III

References

1. King's Fund Centre (1982). *An ordinary life.* King's Fund Project Paper No. 24, London, King's Fund Centre.

2. King's Fund Centre (1984). *An ordinary working life.* King's Fund Project Paper No. 50, London, King's Fund Centre.

3. Granovetter, M.S. (1973). *The strength of weak ties.* American Journal of Sociology 78: 1360-1380.

4. Wertheimer, A. (1985). *Living in the present.* London, Campaign for Mentally Handicapped People.

5. Deacon, J.J. (1974) *Tongue tied.* London, National Society for Mentally Handicapped Children.

6. Blunden, R. et al (1987). *Planning with individuals: an outline guide.* Cardiff, The Mental Handicap in Wales Applied Research Unit.

7. Unruh, David R. (1983). *Invisible Lives.* Sage Publications.

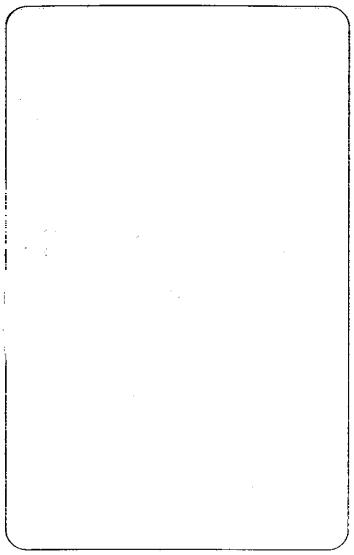
8. Attard, Marie T. *Point of view - mentally handicapped parents.* British Journal of Mental Subnormality, No. 66, January 1988

9. Bulmer, Martin. (1986). *Neighbours - the work of Philip Abrams.* University of Cambridge.

10. Atkinson, D. and Ward L. (1987). *Friends and neighbours: relationships and opportunities in the community for people with a mental handicap.* In N. Malin (ed) Reassessing Community Care. London, Croom Helm.

11. Flynn, Margaret (1987). *The neighbours aren't nice with me.* London, Community Living, Vol 1 No. 3, September/October.

12. Wolfensberger and Glen. (1975). PASS - Program Analysis of Service Systems. Toronto.
PASSING - Program Analysis of a Service System's Implementation of Normalisation Goals, Toronto, 1980.



Long Term and Community Care Team

The overall objective of the team is to enable ***all*** *people with long term disabilities to live as ordinary citizens by promoting the development of a comprehensive range of community services.*

In meeting this objective, our work is influenced by the day-to-day experience of the people who use services.

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- *developing strategies for change in local services*
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