



# "IF YOU DON'T ASK YOU DON'T GET"

## Review of Services for People with Learning Disabilities: The Views of People who use Services and their Carers

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## **EXECUTIVE SUMMARY**

### **AIMS AND METHODS**

The purpose of this three-month study was to explore the views of people with learning disabilities and their carers about social work and health services. The Scottish Executive set out seven topics for enquiry.

Twenty-five focus groups and six supported interviews with people with communication disabilities were held across Scotland. One further interview took place with an older person. In all, 124 people took part - 74 people with learning disabilities, 41 family carers and nine parents accompanying children to focus groups.

### **COMMUNITY PARTICIPATION**

The overall picture to emerge was one of social isolation with many people, in rural and urban settings, having few friends outside family or the service system. Everyone made some use of community facilities but this was often as part of a group or with a staff member.

There were exceptions, however, with some individuals leading more independent lives, 'doing their own thing' or going out with a friend. A few individuals who had lived in small towns for many years appeared to have more community connections and an accepted niche in the neighbourhood.

Due to a widespread lack of social and recreational opportunities for all age groups, people often relied on their parents for company and entertainment. Many were very close to their families. However, many parents thought this was an inappropriate and sometimes unwelcome responsibility.

Overall, younger people tended to have higher expectations than older participants. They often wanted greater freedom and independence from their parents.

Friends were very important to people. Many participants wanted to meet more people or have someone to go out with. A few had befrienders or personal assistants employed through Independent Living Fund monies who acted as important bridges, enabling individuals to pursue age-appropriate activities of their own choosing on a one-to-one basis.

Parents were very concerned about their children being socially isolated. It was very important to parents that young children should be able to play like any others.

Bullying by non-disabled children and unhelpful or hostile attitudes from some adults were a powerful barrier to participation for many.

A number of issues were identified around transport which acted as barriers to participation for some people. These included poor services in rural areas, inaccessible buses, signs that were difficult to read, the attitudes of some bus-drivers and inflexible policies operated by one or two schools.

Only two people in the study had full-time open employment. Some had experience of supported employment. The benefits associated with 'real jobs' were highly valued - having interesting occupation, meeting more people, earning a reasonable wage, having spending power and status, and, in at least one case, new friends and a better social life.

Many people wanted to work, or to work longer hours than they did at present. Social security regulations, for example disallowing people from earning more than £15 per week without loss of benefit, prevented them from doing so.

## **AVAILABILITY AND ACCESSIBILITY OF A RANGE OF MAINSTREAM SERVICES**

One of carers' major complaints was the lack of information available about services. This applied to both health and social work services, and sometimes to their son or daughter's condition. In addition, what information was available was seldom translated into minority languages.

The issue that had caused most anger and frustration to carers over the years was constantly having to fight for support. There was a widespread perception that help was not available until a carer was on the point of collapse. Other parents were often seen as the best source of both information and support.

Professionals were often very hard to get hold of. This was particularly true of social workers although other social care and some health care staff were also described as elusive. In addition, there were reports of professionals promising to do things which never materialised.

Respite care and recreational activities for children were the types of support most often identified by parents as missing. Many carers perceived services existing on a random basis with no rational planning, the allocation of support to individuals being largely a matter of luck or accident.

People with learning disabilities seldom identified gaps in services. They were far more likely to identify gaps in ordinary opportunities. Many individuals articulated 'ordinary' aspirations - to exercise choice over their lives, to have friends, to get a job, to go out and about and, in some cases, to have their own home.

Many people still spend much of their time in segregated services, travelling to and from them in 'special' transport.

Mainstream services which were experienced as welcoming were those which accommodated difference in a positive way by providing the right kind of support tailored to individual need. Simply placing a child or adult with learning disabilities in a mainstream facility and hoping they will 'fit in' had proved problematic, sometimes resulting in exclusion.

## **RECOGNITION AND ASSESSMENT OF SOCIAL NEEDS**

Few people were aware of their rights to an assessment under either the NHS and Community Care Act 1990 or the Carers' (Recognition and Services) Act 1995. Several users and carers were unclear whether they had undergone such an assessment or not.

Families' experience of assessment was often that people were expected to fit into professionals' pre-conceived categories and stereotypes, rather than being seen as an individual.

Families often felt that their knowledge of their relative and understanding of her needs was ignored and occasionally denigrated by professionals.

Sometimes people felt that assessment did not lead to any tangible outcome.

Parents felt that better inter-agency collaboration and planning was required. Their experience was of agencies working in isolation from each other, with families sometimes caught in the middle.

Overall there was a low level of regular social work support, with people tending to see social workers at times of change or crisis. Some people saw their social worker regularly but infrequently, for example, at an annual review.

A good social worker was seen as one who arranged practical help, provided information, acted as a link to other supports, had time to listen and allowed users to remain in control.

Resource and day centres were widely experienced as boring by those attending them. However, most people enjoyed the various part-time work opportunities and college attendance arranged through centres. Parents were more likely than users to value resource centres, perhaps because they provided respite care by another name.

Short-term (respite) services were an important support for many parents and all the people with learning disabilities having short breaks said they enjoyed them, whatever their form. They provided people with opportunities to meet new faces and sometimes to pursue social activities which they did not have at home. However, some respite services were very heavily subscribed, with one family having to book a break 18 months in advance.

Most carers were recruited to the study through the voluntary organisations supporting them. Three carers contrasted the support they had received from voluntary organisations with that offered by the statutory sector. The former was said to be more flexible, responsive and useful. Several local agencies were described as a 'lifeline' to families, providing a gateway to supports which they had not previously had, nor been aware of. A few individuals with learning disabilities who enjoyed control over their lives and a good degree of community participation were supported by voluntary organisations.

Dealings with the Benefits Agency were generally difficult for both users and carers, particularly its long, complex application forms. Parents sometimes felt these forms were trying to 'catch them out'.

Lack of planning for people's long-term futures was a worry for some parents. They wanted to know that their son or daughter would be well supported when they were no longer around.

Families felt that the needs of brothers and sisters were often overlooked both by themselves and by service providers and that more support should be available to siblings.

## **RECOGNITION AND ASSESSMENT OF HEALTH CARE NEEDS**

There was a fairly high rate of consultation with GPs by people with learning disabilities. Overall GPs were seen as approachable and helpful. The fact that most GPs talked directly to the individual was appreciated.

After GPs, the health professionals most often seen were speech and language therapists and community nurses. Little use was made of community psychiatric nurses, physiotherapists or dieticians.

Both users and carers reported a lack of continuity of health professionals, particularly those seen in hospital but sometimes GPs.

As with social care assessments, some carers felt that professionals conducting health assessments tended to overlook families' expertise, to rush through the procedure without taking time to get to know the person, to label or stereotype individuals and fail to produce concrete outcomes. In addition, the knowledge base on which professionals assessed people's conditions was sometimes seen as wanting.

Mixed reports were given about experiences of staying in hospital. Some units were inflexible, treating children with learning disabilities in ways which non-disabled children would not be treated. However, other hospitals were praised for their helpfulness.

Overall, the service people received was said to depend a good deal on individual health care practitioners.

## **CONSULTATION AND INVOLVEMENT IN DECISIONS ABOUT MEETING NEEDS**

People with learning disabilities want to be consulted more and have greater involvement in decisions about their lives.

A continuum was found of the ways people with learning disabilities are involved in decisions about their lives, as follows:

- people were simply informed about a decision taken by someone else, without apparent consultation;
- people clearly had a view or preference about the way a need was met but had not communicated this to staff;
- people had shared their views, sometimes spontaneously, sometimes in response to being asked, but nothing had happened as a result;
- people had been consulted and their views acted upon.

People varied in how far they felt able to speak up for themselves. A few seemed 'resigned' to others making decisions for them. Others had used recognised mechanisms such as a complaints procedure with no positive outcome. This resulted in feelings of injustice and disempowerment. Some individuals were 'fighters' who had struggled over the years to exercise choice and control over their lives.

Only a couple of people were known to have citizen advocates. A few people attended self-advocacy organisations or were studying the Open University *Equal People* course at college. Participants involved in either form of advocacy were enthusiastic about it.

Family carers were often very frustrated and angry that they were not more consulted and involved in decisions being made about meeting their relatives' needs.

As sons and daughters become young adults, tension can arise between professionals encouraging them to make choices about their lives and parents feeling their views are being marginalised.

## **AVAILABILITY AND QUALITY OF HELP WITH COMMUNICATION**

Carers felt that some professionals do not take enough time and trouble to communicate with their relatives, especially children.

Speech and language therapy was valued. However many carers complained that their relative saw a therapist rarely and briefly (despite being the health care professional seen second most often).

Those with communication problems who took part in supported interviews were generally satisfied with the help they received to communicate.

Some people wanted more help with reading and writing. These skills are important to inclusion.

## **THE EXTENT TO WHICH SERVICES ARE AGE-APPROPRIATE AND NON-DISCRIMINATORY**

From four focus groups and one supported interview came reports of 'bossy' staff in day centres, residential homes or FE College who told people what to do, shouted at them or treated them like children.

Some carers felt services were targeted at particular groups, such as families in crisis, people leaving long-stay hospital, disadvantaged families or parents who were demanding or manipulative. As these categories imply, there was a feeling that some of these groups were less than deserving and that such allocation of resources was unfair. There was little 'objective' evidence to support these perceptions although the study was not designed to examine resource allocation.

However it was clear that availability of certain services varied widely in different parts of the country. This applied both between and within authorities, in relation to certain aspects of social work, education, health and voluntary sector provision.

Education authorities were seen as responsive to the linguistic and cultural needs of families from minority ethnic backgrounds. Their experiences of health services were given a more mixed report while social work input to these families was low. Interpreters need to be made more available and information published in community languages.

There were no reports of discrimination on the grounds of gender or sexuality.

## **IMPLICATIONS FOR FUTURE SERVICE DEVELOPMENT**

People's views about current service provision, and about how they would like to be supported in the future, indicate that the following options for future development should be considered:

- More befriending schemes and 'community connectors'.
- Increased social and recreational opportunities for children and young people.
- Greater choice and availability of short term breaks.
- A national information and advice agency.
- A range of work initiatives, such as co-operatives, social firms and supported employment.
- More person-centred services and diversified housing and support options.
- Ensuring that all those eligible for Community Care or Carers' assessments are offered one.
- Ensuring that all those who may be eligible for ILF monies be supported in applying for it.
- Exploring the potential for a wider use of the Community Care (Direct Payments) Act by people with learning disabilities.
- Greater development of citizen advocacy schemes.
- Publishing more information in community languages.
- More support for the siblings of disabled children.
- Long term planning to address adults' future support needs.

## CHAPTER ONE INTRODUCTION - AIMS AND METHODS

As part of its review of services to people with learning disabilities, The Scottish Office (now the Scottish Executive) commissioned SHS (Scottish Human Services) to carry out a survey of user and carer views about social and health care services. The research commenced on 1 March 1999 with a completion date of 28 May 1999. Two methods of data collection have been used:

- Twenty-five focus groups with people representing a wide constituency of user and carer interests and circumstances.
- Six one-to-one supported interviews with people who have communication difficulties.

An additional focus group was arranged with older people but only one person attended. However, this allowed us to collect very rich data which appears in one of the vignettes in Chapter 2. As another focus group was attended by four older participants, this perspective is still included in the research.

In all, **124 users and carers were involved in the research.** This figure comprises:

- Seventy-four people with learning disabilities.
- Forty-one family carers.
- Nine parents who attended focus groups for children, primarily to facilitate the latter's involvement but also making some contribution to the discussion.

### STUDY AIMS

The aims of the research were as follows:

- To explore the perceptions and experiences of people with learning disabilities in relation to current service delivery and future service development.
- To explore and report on the views of family carers about the above topics and the kind of support they have found most useful and would like in the future.
- To include people from a range of age groups, with varying levels of support needs, using a variety of services and supports, living in different domestic circumstances and in contrasting geographic settings.

The Scottish Executive identified seven topics as issues for investigation in the research. These were:

- participation in community life;
- recognition and assessment of social and health care needs;
- recognition and assessment of needs;
- consultation and involvement in decisions about how these needs are met;
- the availability and quality of help with communication;

- the availability and accessibility of a full range of mainstream services;
- the extent to which mainstream and specialist services are age appropriate, non-discriminatory and non-segregated.

## **METHODS**

### **Focus groups**

Three main considerations guided the way groups were set up.

First, people with learning disabilities are not a homogeneous group: along with the rest of the population, they vary on many dimensions. It was therefore critical to include a wide range of people representing different age groups, living across Scotland. Secondly, it is well established that the views of people with learning disabilities and those of their carers can vary significantly: both can hold equally 'valid' but nonetheless conflicting opinions (Manthorpe et al, 1997). Relatives are not always reliable proxies and they may dominate discussion (Booth and Booth, 1994). For these reasons, separate groups were held for people with learning disabilities and their carers. Thirdly, in order to avoid the 'storming and forming' processes which can take up time and energy within new groups, as far as possible members of pre-existing groups, already meeting on a regular basis, were invited to hold focus group discussions. With these points in mind, and because of the short timescale of the research, convenience sampling was used. This involved recruiting focus groups through organisations already known to us, thus expediting the process considerably.

The focus groups held were as follows:

#### **Children (4 groups)**

- School age children: 4 groups.

#### **Adults with learning disabilities (14 groups)**

- Teenagers/young adults: 2 groups.
- People living with family.
- People living in a local authority group home.
- People with supported living arrangements.
- Residents of long-stay hospitals.
- People attending a resource centre: 2 groups.
- People in supported employment.
- People using respite care services.
- People using advocacy schemes.
- People from minority ethnic groups.
- People using few or no services.
- Older people aged 55 and over.

## **Family carers (7 groups)**

- Parents of pre-school children.
- Parents of school age children with learning disabilities.
- Parents of school age children with profound impairment.
- Family carers of adults with learning disabilities: 2 groups.
- Family carers of adults with profound impairment.
- Relatives of people from minority ethnic groups.

In only one case did it prove impractical to include a particular 'target group': it had been planned to include a group focusing on use of primary health care services. Attempts to convene such a group were made through three different sources, one of which involved lengthy negotiations which did not come to fruition. However, data about use of primary care was obtained through several of the other groups listed above. It was not feasible to explore the experiences of people with profound impairment within the time available. This would have required lengthy observations. However two groups were held with relatives. It is worth adding that, as part of its current review of services to people with learning disabilities, The Scottish Executive has set up a number of task groups, including one focusing on people with complex needs.

In order to protect individuals' confidentiality, the agencies through which each group was set up, and their locations, will not be identified. Clearly it was not feasible to cover every part of Scotland in the time available. However, efforts were made to take in as much of the country as possible, and to include both rural, urban and 'small town' settings. Groups were held in Inverness, Elgin, Inverurie, Aberdeen, Dundee, Cowdenbeath, Edinburgh, Prestonpans, Falkirk, Bathgate, Glasgow, Paisley, Ayr, Dumfries and Hawick. The most glaring omission is North West Scotland and the islands. However, Enable and the Scottish Down's Syndrome Association are carrying out complementary consultation exercises which will cover some of these areas.

Included in the 25 focus groups are two pilot groups, one with adults, one with children. Following the first pilot, which comprised six people, agencies were asked to invite four individuals, preferably two men and two women, to participate in each group of people with learning disabilities and six people in the carers' groups. In practice, however, numbers in each group varied from two to nine (the latter occurring when couples attended a carers' group), with most groups having four or five participants.

In setting up groups, wherever possible people with learning disabilities were asked to nominate their own representatives or ask for volunteers. Where this was not possible, the relevant agencies were asked to select individuals randomly within the gender and age requirements. When asking people to take part in the research, the purpose of the study was first explained, individuals were told they would not be personally identified in the report and that they would not suffer in any way if they were critical of current service provision. They were asked to give verbal consent to taking part. People were told they could change their minds at any time, again with no adverse consequences to themselves.

Topic guides were produced for each group, setting out the areas to be covered in the discussion and tailored to suit participants' particular circumstances and experience (see Annex 2). Each discussion began with an introduction reminding people of the purpose of the group and a warm-up exercise to help participants feel comfortable. Groups attended by

adults with learning disabilities were then shown a video prompt of a man with Down's Syndrome talking about the different supports in his life, containing a mix of positive and negative comments. In addition, where appropriate, photographs were used as visual prompts to introduce different topics.

The groups with children were run a little differently. While aiming to cover similar issues, more use was made of visual prompts including computer-produced drawings pasted onto card illustrating various activities, professionals and services. The children were also asked to complete a spidergram setting out their views about school. In nine cases, children were accompanied by their parents who also contributed to the discussion at times.

Priority was given to ensuring that the groups were accessible in every sense. Travel expenses were paid to participants. The groups were designed to last two hours with a twenty-minute break for refreshments although some, including those with children, finished earlier if it seemed that participants were tired. Each group was attended by two members of the research team, one to facilitate discussion, the other to observe and record. With participants' permission, the discussions were also tape-recorded.

### **One to one supported interviews**

As it was not considered feasible to obtain the views of people with communication difficulties in one focus group, face-to-face interviews, or guided conversations, were conducted with six individuals recruited through Speech and Language Therapy teams in Glasgow and Falkirk. These interviews covered similar topics to the focus groups. This work was carried out by Jill Murray, an experienced speech and language therapist, using a technique called *Talking Mats* (Murphy, 1997). Here, symbols for key issues and influences are presented on textured mats. The symbols are attached to the mats with Velcro and can be moved around as required. Interviewees select issues which are important in their lives. Symbols for emotions are also available to enable people to express their feelings about key issues. Other methods of communication used during these interviews were photographs, Makaton, facial expression, gesture, voice and individuals' personalised communication aids.

Ms Murray met each person prior to the interview to establish his or her communication style and level of comprehension, and to allow the individual an opportunity to meet her informally prior to data collection.

### **Pen profile proformas**

One useful lesson from the pilot was that it would be helpful to have some background or biographical information about individuals prior to the group discussion, since people do not always place their comments in context. Individuals were therefore asked to sit down with their key worker some time before the group and complete a short pen picture of themselves on a proforma provided. The form gathered background information including their gender, living arrangements, daytime, evening and weekend activities and contact with services (see Annex 1). Participants were asked to complete and return the form before the group took place so that group facilitators had some background information about them. Family carers attending focus groups were asked to complete a form about their relative.

Although 124 people took part in the research, a total of 79 proformas were returned by participants. The discrepancy between these two numbers can be accounted for by the facts

that in some cases both parents of one person attended the focus group and that nine parents accompanied children to their groups. In addition, the six people who took part in supported interviews were not asked to complete proformas. 29 proformas were not completed, due to the short notice at which groups had to be arranged and other demands on staff time.

Fifty proformas were returned by participants with learning disabilities. Of these, 16 were from school age participants and 34 were from adult (post school) participants. 29 were returned by carers. Of these 13 were carers of school age children and 16 were carers of adults (post school) people.

### **Data analysis**

Notes of the discussions were taken during each group and written up in detail as soon as possible afterwards. The groups were also tape-recorded and while there was not time to transcribe these data, they proved a useful 'back-up' when required. The supported interviews were not recorded as such but photographs were taken of the completed mats. Ms Murray then summarised these data in writing. The written recordings were analysed manually: it was not possible to use a qualitative data analysis computer package which requires considerable time to be spent coding data. Instead, all the data were read through carefully by the two principal facilitators who re-ordered them under the topic headings provided by The Scottish Executive. A third member of the team analysed the data from the pen profile proformas: this was a quantitative but small-scale exercise conducted manually. Finally a fourth person re-read all the data, identifying emerging patterns, common themes and key points and brought these together in writing the report.

### **REFLECTIONS ON METHODOLOGY**

This is not the place to discuss in detail the advantages and disadvantages of using focus groups with people with learning disabilities, although it is worth noting that they have been relatively little used elsewhere and in that sense the methodology employed in this study can be described as innovative. The focus groups were a pragmatic way of collecting data from a relatively large number of respondents in a short time and indeed all the participants contributed to the discussions. Had more time been available, it would have been better to have had the opportunity to visit all the respondents prior to data collection: this is generally recognised as good research practice with people with learning disabilities in order to increase trust and rapport (Atkinson, 1993). This in turn can strengthen the validity of the data. Similarly, the quality of the data might have been enhanced had we been able to meet people to seek their views on more than one occasion: this would have given them time to reflect on the topics and provide fuller answers. Similar comments can be made about the supported interviews. Although these individuals were visited by the interviewer twice, more time to get to know them, explain the process and 'practice' the *Talking Mats* would have been beneficial.

## **FORMAT OF THE REPORT**

The report begins by presenting two individuals' stories. Chapter 3 describes some basic characteristics of the study participants. The structure and content of the report then largely follows the topics set out by The Scottish Executive, each chapter covering one subject. The final chapter draws out conclusions and implications for future service development.

The report includes extracts from our recordings of the focus groups and some verbatim quotations from participants. All real names have been changed.

## **CHAPTER TWO TWO VIGNETTES**

### **INTRODUCTION**

Before looking at the data in a more analytical way, here we present, with their permission, vignettes of two individuals who participated in the study. It should be stressed that these two men are not 'representative' of the people who took part in the study, but they have been chosen for two reasons. First, each person felt he had come a long way in terms of establishing independence and achieving inclusion. Both men had spent many years in a long-stay hospital (not the same one) and now live in different parts of the country. Their accounts remind us that major developments and improvements have taken place over recent years in the type of support available to people with learning disabilities and, indeed, the way individuals are treated on a day to day basis. It is important to acknowledge that achievement and to read the rest of this report, much of which is critical of current service provision, in that context.

Secondly, each man gave detailed and vivid accounts of his life, past and present, and his future aspirations. Their two stories bring alive many of the themes discussed in this report, but convey a rich sense of how the issues are experienced in the context of individuals' lives. Such themes include:

- The sense of injustice which flows from being denied respect and the right to make choices about one's own life.
- The importance of family.
- The value placed on existing social contacts and friendships along with a wish to extend them.
- The importance of inclusive and ordinary activities and of 'belonging'.
- The value placed on mainstream employment and the sense of self-worth derived from being seen as a trusted employee.
- The key role which can be played by local voluntary organisations in helping individuals achieve what they want.
- The importance of self-advocacy.
- The lack of available speech therapy.
- The high levels of support which may be needed when someone initially leaves hospital, or sets up supported living arrangements, may be reduced over time; the important thing for some people is knowing that support is available if required.
- The importance of people having a choice of key worker and some means of redress if the latter should prove unsatisfactory.

What follows are edited versions of our fieldnotes: real names and places, and some autobiographical detail, have been changed.

### **BILL'S STORY**

Bill works full time in a restaurant, doing the dishes and cleaning. He enjoys this work and has had it for a number of years. He left hospital twenty years ago. When he moved out, they just told him who he would be living with and where. As the other people in his house were

from the same hospital, he knew them and got on well with them. He subsequently moved to Seatown which he 'packed in' and moved to another house in Redborough which he asked to do.

He likes his present job because he gets to meet other people, for example, his work mates who are friends. He visits one of his sisters on his days off or else she comes to see him. He also visits another sister who lives a few miles away, or has him come and visit. He has a brother who visits Bill in the evenings sometimes for a cup of tea. Bill lives on his own. He's pleased with this. He got help to do this through a local voluntary organisation. Bill also has a social worker who is nice and helps him with a lot of things, for example, with getting the house. She has been his social worker for two years. Prior to this he had another social worker who left. He was also 'alright'.

Bill says he meets other people besides his family. He referred mainly to his mate Brian. They go out for a couple of pints. Brian also comes to Bill's for tea. They know each other from a home they both used to live in. Bill says he sees a lot of people in Redborough, in the city and 'all over the place'. He knows these people from the hospital.

Bill goes to a literacy class once a week. This helps a bit but he finds the reading difficult. After the class he goes to his sister's for lunch and then he goes to work. One night a week he goes to a club where he plays dominoes, darts, and pool. There is a mixture of people who go to the club, with and without learning disabilities. He likes this; he gets a cup of tea and a biscuit. Other times he visits Brian. Most nights he does this if he isn't going to stay at his brother's or visit his sister. He also goes to the cinema if he isn't busy. Bill knows the people in the pub when he goes out with Brian. Asked again if he liked work, Bill was very certain that he did. This is paid work. He couldn't think of anything that he doesn't like about where he lives or what he does. Every other week he goes to a meeting in the community centre where he talks about himself and speaks up for himself. This is for people with learning disabilities. When asked if he had heard of advocacy groups he didn't know the word 'advocacy' but he thought the group he goes to was like an advocacy group. Asked if it has helped him, he said it's difficult but he's getting there.

Bill would like there to be more activities for people of his age to do but couldn't think what kinds of activities these would be. He then spoke of going with his support worker to buy furniture for his flat which he has chosen. Bill sees his support worker once a week. His support worker helps him with his finances although Bill said he also helps her with the counting. He says he only needs help with reading and writing, and with his speech impediment. He doesn't get help with this. He used to have help a long time ago but it just stopped and Bill can't remember why this happened. He hasn't asked anyone for help and he hasn't been asked by his social worker.

Bill would like to meet more people - 'any kind of people'. He would like to get to know them and he enjoys meeting people. He meets people at the club who he sees around the town. They stop and speak to each other. Bill then spoke of going to play pool in a training/day centre where he used to work. This is for people with learning disabilities. Asked if he gets enough help Bill said he would like more help with reading and writing.

Bill's routine is much the same at the weekends and this can be busy when he is working at the restaurant. It isn't hard but it does get busy and you have to keep going. He got the work through the College who took him there to see what it was like. Bill chose to work there and

he had enough help to settle in at the beginning. He says he is a good worker and now they can't let him go. He sees some of the people he works with outside the job. Sometimes he goes to parties with them where he enjoys dancing and drinking.

Bill said that a few years ago he didn't have any choice over his life but now he does. Other people used to make all the decisions for him, he had to do what people said, and he didn't like this. It's different now. He can do as he pleases and he feels good about himself. He used to feel angry. The voluntary organisation has helped him to have more choice. They have helped him to go to college, to get a house, and to get a job. Nobody makes him do things now. If he wants to change things he can tell his support worker or his social worker and they listen to him.

Talking about his retirement Bill said he will stop when he is 65 but then said he would try and get a part time job. He would like to carry on working. He hasn't spoken to anyone about this although shortly he will do so, but he hasn't been thinking about it.

Bill said his family was very important to him. He doesn't have parents. They died a long time ago. He was put into an institution as a child. He didn't like it. He was locked up at night and there wasn't much to do during the day, just games. He was bored and he couldn't make any decisions. It's great to be out of there. He feels he has had enough support moving into a place of his own and although it was difficult at first it is getting easier.

## **CHRISTOPHER'S STORY**

Christopher began by talking about the advantages of being out of the hospital. Christopher had been there since he was a teenager. He said that for much of the time he was battered by staff and kept drugged to the eyeballs. Now he says he has nobody picking on him. Staff at the hospital had lied to him about his family saying his mum had died when he was born. Christopher didn't know he had a family. This has been an important discovery for him since leaving the hospital. He has started to track them down and make contact.

Christopher shares a flat with his partner Jane. They moved on 12 May 1996. The first night was quite scary; he spent much of it thinking about his family. Initially they had support workers coming for sleepovers but this has gradually been withdrawn, as has their presence at other times. They meet their support workers to go shopping or to the bank. Christopher talked about being able, and having the opportunity, to do things on his own, like going to the cinema. Asked what was different about having his own flat, he returned to the subject of his family. With help from Elaine, his support worker, he approached an adoption agency, and has located his sister, a brother and his niece, and his mother. He met his sister for the first time recently. 'It was like God bringing them together'. He has quite a lot of contact with her now and she's there whenever he needs her. Christopher has spoken to his mother and hopes to meet her soon. He also spoke of his family history, citing relatives that he has found out about and what they used to do. He said this with pride.

Christopher likes being able to choose when he can go out and come back. In the hospital they had to be in the wards for counting at each staff change over, and they had to inform staff of where they were going. He also enjoys having friends to visit, making his own decisions, and finds the neighbours very helpful and supportive. They have helped him, for example, when people have come to the door trying to get money out of him by selling out of

date football coupons. Having people coming to the door asking for things is the only bad thing about where he lives. Besides his neighbours he also knows people living across the road.

Twice a week Christopher goes to a gardening class. He goes because it gets him out. He would like a job, and is looking but he can't find anything. He had gone to College but they wanted him to do cooking. He knows how to do this already and doesn't feel it is relevant.

When asked how he and Jane had chosen the area they live in, Christopher said they were told about it and were taken to see it. They had to wait some time while it was renovated/decorated. The flat is near the shops. He talked about choosing all the furniture and wallpaper. Sometimes his brother comes and sleeps over. Christopher has tried everything to get work. He had worked on an odd job team in the hospital. The manager had bossed Christopher about and made him carry on working when he had injured himself. If you stepped out of line they 'jagged' you i.e. put you to sleep with injections. He had complained but nothing was done. Staff would often wind him up and call him names. At times he would be scared to go back because of what they would do to him. He talked of being punched and dragged along the carpets. At other times, residents would pick fights and the staff would blame Christopher for causing problems. He has suffered a lot of abuse during his time in institutions.

Christopher chose where he wanted to live and also had choice over who were his key workers. He had interviewed prospective ones and has had to get rid of a few. When they have had problems with staff they report them to (the voluntary organisation supporting him) who take steps to change the situation.

Christopher said he has a good social life. He then spoke of how he has changed completely. Whereas before he used to get upset and angry he now feels able to control his anger and wind himself down. He added, however, that there are people he can ring if he needs help. Christopher also spoke of feeling confident enough to work things out if he gets lost or doesn't know how to do things as opposed to panicking.

Christopher says he feels like a new man since leaving the hospital. He is cheery, happy and lively since leaving and is glad that it is being shut down. He feels sorry for the others still there. Staff in the hospital predicted to Christopher that he would be back because he wouldn't be able to cope. He spoke of other people who do go back in, and how some people don't feel confident about moving out. Christopher said that where he lives now is the best place he has ever lived and that his story has 'a happy ending'.

## CHAPTER THREE THE STUDY PARTICIPANTS

### INTRODUCTION

Here we report some basic characteristics of the 124 people who participated in the research. As noted in Chapter 1, they comprised 74 people with learning disabilities, 41 family carers and 9 parents who accompanied children to focus groups.

### CHARACTERISTICS OF CARERS

The 41 people who attended focus groups for carers comprised 9 (22%) men and 32 (78%) women. The 41 carers included six couples and one mother and daughter. Between them, they were supporting 40 sons or daughters. Three families had two children with learning disabilities and one had three. Three of these four families were from ethnic minority backgrounds. There is no national information on the prevalence of learning disabilities among black and minority ethnic communities, but there is evidence that it is higher than among white children (Baxter et al, 1990). This may be due to a higher incidence of congenital rubella, a higher frequency of marriage between first cousins and also to poverty and disadvantage (Baxter et al, 1990).

### CHARACTERISTICS OF PEOPLE WITH LEARNING DISABILITIES

Seventy-four people with learning disabilities took part in the research - 58 adults and 16 children. The adults were made up of 25 men and 33 women and the children, of 9 boys and 7 girls. There are more males than females with learning disabilities in the population so again, our figures cannot claim to be representative. It is possible that women are more likely to volunteer, be invited or agree to attend focus groups. The children were aged between 7 and 19 years, while adult participants were aged between 21 and 72. Thus the research can claim to have included a wide age range of people. These data are summarised in Table 3.1 below.

**Table 3.1 Summary of characteristics of focus group participants with learning disabilities**

	No	Male	Female	Age range
School age people	16	9	7	7-19
Post school age people	58	25	33	21-72
Total no. of people	74	34	40	7-72

Pen profile proformas were completed for 79 people with learning disabilities. The information presented below is an analysis of data which was gathered directly from 56 people with learning disabilities and indirectly from 29 carers via the proformas, supplemented by data gathered from the six people who took part in supported interviews.

## HOUSING CIRCUMSTANCES OF PEOPLE WITH LEARNING DISABILITIES

Participants were asked to identify where they or their relative with learning disabilities lived. The majority of people (75%) lived with their family. Families are recognised as the single biggest source of support for people with learning disabilities (Simons, 1998). Watson (1996), in a survey of 10 English local authorities, found that 53% of adults continued to live in the family home. A further 14% lived in a community house with other people with learning disabilities. The remaining 11% either lived in a hospital, alone or with a 'foster family'.

**Table 3.2 Housing circumstances of people with learning disabilities**

	<b>School age people</b>	<b>Post school age people</b>	<b>Total</b>
With family	29	35	64
In community house	0	12	12
In hospital	0	4	4
Lives alone	0	4	4
With 'foster family'	0	1	1
<b>TOTAL</b>	<b>29</b>	<b>56</b>	<b>85</b>

## CHAPTER FOUR PARTICIPATION IN COMMUNITY LIFE

### INTRODUCTION

Most people have always lived 'in the community', and the vast majority of people with learning disabilities who lived in long-stay hospitals has now moved out. One of the major driving forces behind the move towards de-institutionalisation was the ethos of normalisation (Wolfensberger, 1972, 1983) although this has not been without its critics (e.g.: Smith and Brown, 1992). In terms of enabling people to become part of their communities, O'Brien's (1987) 'Five Accomplishments for Service Delivery', based on normalisation but emphasising the importance of individual choice and control, have been enormously influential. The 'accomplishments' are targets at which community services should aim if they are to enact the principles of normalisation. They comprise:

- **community presence**, meaning that individuals should make use of ordinary, mainstream activities;
- **choice**, whereby people should have support to make their own choices about day to day matters and major life events;
- **competence**, or creating opportunities for people to reach their full potential by developing a range of skills;
- **respect**, referring to people's right to occupy a valued role within a network of reciprocal roles;
- **community participation**, meaning the importance of being part of a growing network of friends.

Unhappily, much research to date suggests that, for many people with learning disabilities, there is a long way to go before these five dimensions become regular features of their everyday lives. Myers et al (1998) in a review of the literature on the 'integration' of people with learning disabilities, draw the conclusion that while most individuals are now living in the community, very often they are not part of it. Myers et al's choice of the term 'integration' rather than 'inclusion' is a little puzzling. The former implies assimilation and thus some pressure to blur or even conceal difference, while the latter implies a positive accommodation and welcoming of difference.

Many studies compare the quality of life experienced by people with learning disabilities in the community with that available within institutions rather than that enjoyed by the general population (Emerson and Hatton, 1994). Inclusion is most often 'measured' in terms of the number and type of activities in which people engage and the range and nature of their relationships with others. In this study, we were specifically asked to address 'participation in community life'. We did this by asking people about their activities - what they did, where and with whom.

### FOUR PEOPLE'S EXPERIENCES

The overall picture to emerge was one of social isolation with many people having few friends outside family or the service system. Some examples of individuals' accounts of their lives will illustrate the point. One man who had unhappy experiences of living in hospital was keen to return to his hometown on discharge. However, he found that, after many years'

absence, he had lost contact with friends and relatives. He was offered no support from services in establishing new social contacts. This man, who lives alone, now has 'a couple of friends' made through membership of a self-advocacy organisation and one older non-disabled friend who assists him in applying for benefits and similar matters.

A mother in a different part of the country spoke about the disabilities her young son encountered in finding friends to play with. Because he attends a school outwith his local area, the children in his own neighbourhood do not know him very well, and so cannot understand his behaviour and feelings. Similarly, the fact that his school-mates live some distance away makes it hard for him to play with them outside school hours. This mother believed that much depended on the willingness of other parents to 'take on' her son.

One of the older participants attends a resource centre and lives with a community landlady. Although there are three other people living there, they are not particular friends of his and he finds them too noisy. There is very little for older people to do where he stays. This man would like to meet more non-disabled people but does not have much opportunity to do so. He has told his social worker he would like to get out and about more, but nothing has been done. He would also like a holiday, but no one has asked him about this.

These stories are fairly typical of the data but there were exceptions. One man had studied music at college and joined a band there. As a result he had made a good number of non-disabled friends and participated in 'ordinary' student activities. He remains in contact with one or two of these people, has another 'really good friend' with whom he can discuss anything, and 'a good social life'. Although he lives with his mother who was clearly important to him, he would consider moving away from his home town for work. This man was one of only two people in the study to have a full-time job for an 'ordinary' wage. His experience suggests that having the opportunity to participate in inclusive education and to share an interest or activity with non-disabled people are important facets in promoting participation.

## **ORGANISED ACTIVITIES**

Throughout the groups, people talked about various organised activities they took part in or community facilities which they used. Residents of a group home for example attend literacy classes, a women's group, art classes at college, social clubs where they play dominoes and have a disco. They go to a bingo club, shopping, to church, the pub, a gym, a bowling alley and the swimming baths. On the face of it, this sounds like a good example of community participation. At least five of these activities however were segregated ones, while others were pursued with other people with learning disabilities or a staff member. The visits to church were an exception as the two ladies in question were accompanied by a family friend. A man in another group described a long list of mainstream activities on offer at the respite care unit he stays in, but added that these were normally attended by a group of eight people from the home accompanied by two members of staff. Similarly, people attending resource centres had opportunities to leave the building and utilise various community facilities, but generally in groups.

The extent to which services were inclusive or segregated will be explored in a later section of the report but it is clearly relevant to community participation to note the general predominant pattern of service use. We are not suggesting here that individuals should not

spend time with other people who have learning disabilities, an implication of normalisation which has been criticised elsewhere (Smith and Brown, 1992). However, spending all or most of their time with other disabled people, particularly in segregated settings and without having any choice in the matter, is clearly not indicative of inclusion.

## **PARENTS' CONCERNS**

One of parents' major concerns was that their children were socially isolated and that this was likely to increase as they grew older. Indeed participation was seen as easier when children were young and the differences between them and their peers less evident. Parents repeatedly emphasised the importance of their children being able to play, but this was difficult for various reasons. Their children were ignored or tormented by other children; they were unable to understand the 'rules' of play and lacked the cognitive and social skills required; they lacked a sense of danger and might run across roads. Other children were sometimes described as bullies, with disturbing examples of name-calling and aggressive behaviour being reported; for example, one boy had been called 'dafty' and 'monster'.

There were a few exceptions to this - one boy, whose mother felt he had been 'cocooned' at a special school, was now at a mainstream establishment where both he and the other children were able to learn and benefit from each other's presence. 'He's gleaning things from other children; the children are accepted and he has a huge fan club'.

If children's attitudes were sometimes less than positive, unhelpful and even hostile responses on the part of adults were more common. Sometimes these were described in general terms, as reflected in perceived public opinion; for example, one woman argued that 'people with learning disabilities should be allowed into places'. Sometimes specific instances were cited; for example, one person had stopped going to football because people 'had made a fool of me'; other parents sometimes removed their children from a playground when learning disabled children appeared, and strangers had remarked that such children should not be seen or allowed out. When one family visited a pub, another patron had commented, 'you don't see many of them about these days'.

Again, there were exceptions, with some examples of more positive responses being given. One mother said it was a 'normal reaction' for strangers to approach her and comment on how nice it was to see her son out and about enjoying himself. Another commented 'people go out of their way to be pleasant'. The point was made more than once that a vicious circle obtains, whereby the exclusion of people with learning disabilities from community participation breeds ignorance, fear and hostility, which in turn serve to perpetuate exclusion. Obversely, inclusion was seen as likely to promote better understanding, and acceptance.

These findings are far from new. Myers et al (1998) note three different types of community response to people with learning disabilities. First, there is a lack of awareness of their presence, secondly, a 'wariness bordering on hostility' and, thirdly, 'a preparedness to relate to people, whether as customers, neighbours or possible friends'. Clearly the challenge is to identify those individuals who are positively disposed to people with learning disabilities and encourage them to act as bridges to greater community participation, for example, as natural supports to facilitate people's access to a range of activities. Equally it is important that those who hold negative attitudes are educated into a more positive way of thinking.

A lack of social and recreational activities was widespread particularly, for children and young people, after school and in the holidays. Provision for the 5-14 age group was said to be particularly poor. It was suggested in one area that where activities were available for disabled children, these took the form of arts and crafts rather than physical activities which some children preferred. In addition, it was said that children often attended activities not because they had chosen that specific event or project, but due to the lack of any option. Similarly, the fact that they were associating with other children using the same scheme did not mean that these particular children were friends. It is a common, and rather convenient, assumption among service providers that people using the same provision are necessarily friends.

There was a widespread perception that social work departments did not see the provision of social activities, or the promotion of participation, as part of their remit. The fact that parents took this view is clearly a matter of concern, since social work departments do indeed have powers to promote inclusion under both the Social Work Scotland Act 1968 and the Children Scotland Act 1995. Indeed, under the latter legislation local authorities have a duty to design services in such a way as to 'minimise the effects of disability' on children and enable them to lead lives which are as normal as possible.

Parents, of children and adults, in all the groups emphasised their sons' and daughters' dependency on them in terms of both community participation and simply pursuing everyday activities. Statements like 'he goes everywhere we go' were not uncommon. One parent had made an arrangement with two other mothers that her child should play with their children. In other cases it seemed that children could end up being indoors all the time - 'they are not allowed to be children' was one comment. A number of adults apparently spent most of their free time sitting in their bedrooms watching TV or listening to music. Parents felt the responsibility of organising their children's' social life was an inappropriate - and sometimes unwelcome - task, believing that more external support should be available.

## **USERS' CONCERNS**

That participation was important to people was evident. It has been noted elsewhere that relationships and friendships are highly valued by many people with learning disabilities (Simons, 1995, Cavet, 1998) and the participants in this study were no exception. To many people, family members were clearly of importance and individuals often referred to their relatives as key people in their lives. This was true of those who lived with their family and those who had moved on to more independent living. For many of the latter, visits to and from relatives were a source of pleasure. One young woman who described herself as a 'party animal' went on to talk about attending family parties. For another woman, the subject of her sister was the only topic she discussed with any animation. One woman was proud that she was about to become a grandmother. One or two people mentioned missing their family while in short-term care, another that his mother missed him.

Not everyone had family contact however. Several people spoke about relatives who had died. Again, there is evidence from elsewhere that bereavement is an unresolved experience in the lives of many people with learning disabilities (Oswin, 1991) and one in which they are not adequately supported. One older participant was reduced to tears talking about her mother's death, which had occurred forty years earlier. However the mother of another person emphasised how important it had been for her daughter to attend her grandmother's

funeral and go through the grieving process in the same way as everyone else. Another person, living in long-stay hospital, carried with her photographs of her parents, whom she still saw, and of herself as a baby shortly before she entered the hospital, perhaps suggesting a mourning of a different kind.

Despite the fact that many people valued their close family involvement, a significant proportion also craved greater independence and did not necessarily relish spending all their free time with their parents. This was recognised by all the parents in one group - 'they don't want us... they want to do teenagery things.' A woman in another group however described her mother as unnecessarily restrictive, for example, not wanting her to go out alone or see her boyfriend. However this is not an atypical conflict between parents and young adult children.

At the same time, other individuals expressed contentment with the present state of affairs, were quite happy living in the family home and did not foresee moving out. It was noticeable - and remarked on by one parent - that younger people tended to have higher expectations and be more likely to articulate a desire for greater independence, although there certainly were exceptions. It was not clear how far this was because younger generations of parents tend to have higher expectations than older ones, or because older people with learning disabilities may have become accustomed to having their expectations disappointed, or both.

While it is important to acknowledge and respect the very important place that family had for many people, it is also legitimate to wonder if relatives continued to occupy such a key role in adults' lives because these relationships had not been complimented by the development of a range of friendships as people grew older. Having friends was also important to people. Many said they would like to meet more people and make new friends. It was interesting that some specified they would like to meet non-disabled people, some preferred to be with other people with learning disabilities, while one or two would opt for 'a mix of people'.

This is not the first study to report that those described as friends were often, although not always, people who were paid to spend time with individuals. Befrienders played an important role in several people's lives: as they were described as friends, the origin and nature of the relationship was not always clear at first. Clearly there is a need for more schemes of this kind and for schemes to be better resourced in order to recruit and support more volunteers. Another source of support for a few people in the study was the Independent Living Fund, through which individuals had been able to employ their own personal assistants. These were often young people who enabled individuals to become involved in activities of their choice and extend their social relationships. Initial apprehension felt by one mother that these carers might be an intrusion on her daughter's privacy had given way to seeing them as extended family. Others had never heard of ILF, indicating a lack of accessible information. These findings also indicate the potential importance of the Community Care (Direct Payments) Act 1996 in opening up new opportunities, although recent research shows that this mechanism has been relatively little used by people with learning disabilities to date (Ryan, 1999).

Not surprisingly, having interesting things to do was also important to people. Some individuals were clearly very bored in their free time due to lack of social stimulation and company. Those who did participate in activities were generally keen to talk about them and clearly looked forward to them. Several people wanted to take part in more inclusive activities, while others expressed a preference for segregated ones. It has been noted

elsewhere that it is difficult for people to choose to do things which they have not previously experienced, or which do not appear to be open to them. Some people may initially be reluctant or resistant to participating in new activities until 'tasters' are provided, (Stalker, Duckett and Downs, 1999, forthcoming). Having practical experience of a different way of doing things often changes minds.

## **BARRIERS AND BRIDGES TO PARTICIPATION**

People were not specifically asked about the factors which aided or prevented community participation: the data here are by no means comprehensive. Nevertheless, certain key themes emerge which are worth highlighting since they indicate barriers which need to be challenged and bridges which should be further extended. Two factors which have already been highlighted in this chapter as barriers to participation, and which will not be rehearsed, are the *lack of social and recreational opportunities* and *public attitudes*.

### **Transport**

Transport was a barrier to community participation for several people. A number of different aspects were mentioned - a poor service in rural areas, the inaccessibility of buses for people with physical impairment, the need for bigger signs on buses and at bus-stops for those who have trouble reading, unhelpful attitudes on the part of some bus-drivers and the need for more support to enable people to travel independently.

### **Location**

Those living in rural areas suggested that social isolation was a particular problem because of the lack of organised activities and available transport. However it was noticeable that many of those living in cities were experiencing similar isolation. However two or three of the individuals whose situation was atypical, that is, who did report that they had friends and appeared well settled in their local communities, lived in small towns. It seems that in these small communities where people had lived for many years, sometimes all their lives, they were 'well-kent' faces with a niche in the neighbourhood. Parents of one young man related how everyone in the community knew their son; he was 'not treated as a curiosity' but went everywhere they did. However it was not clear how far these acquaintances were really 'friends'.

### **Domestic Setting**

The type of setting in which people live is closely associated with degrees of community participation (Myers et al, 1998) Not surprisingly, hospital residents generally experience the most isolation. One person living in hospital, asked if she knew people in the local town, replied that she was not allowed to talk to 'strangers'. Her comment reveals rather graphically the absence of any concept of community participation on her part, (as well as the child-like way in which she had been spoken to). In another case, the parents of a young man had fought for ten years for their son to move into supported accommodation. This had recently been achieved and the fact that he was now living 'in the village' with people his own age as opposed to 'on the outskirts' with his parents was felt by them to have increased his inclusion in the community. As we have seen, many people living with their parents, and this included older adults with ageing parents, tended to share the latter's social life and activities.

Although only a small number of people lived alone or had supported living arrangements, most of them had relatively well developed social networks and a more active social life.

### **Inclusive education**

The nature of people's educational experiences was seen as key to community participation. Some of the parents who were struggling to reduce their children's social isolation saw inclusion in mainstream schools as having a 'civilising' effect on non-disabled children. They appreciated activities organised by the school such as swimming and riding which enabled children to mix with non-disabled peers. As we have seen, children attending schools outwith their own area could be isolated in their community and more likely to be marked out as 'different'. The importance of schools accommodating difference in a positive way is further discussed in the next chapter.

### **Paid employment**

Similarly, having a proper job was associated with greater community participation, as previous research on employment among the general population has established. The four people in the supported employment focus group were extremely positive about the 'passport' benefits that came with the job - getting out of the house, meeting other people, both as colleagues or, depending on the nature of the work, members of the general public. Paid employment also brought people some extra money which again enabled them to access certain leisure activities, or go on a 'real' shopping trip, as opposed to 'window shopping'. It was important to one woman that she sometimes met her colleagues while out shopping and would stop for a chat with them. The two people in the study with full-time 'ordinary' jobs had particularly well developed social networks: one went to parties with his workmates out of hours. However, there are a number of 'benefits traps' which militate against people working, (Simons, 1998). For example, people are not allowed to earn more than £15 per week without losing benefit, and this prevented some individuals in the study from working as much as they wished.

## **CHAPTER FIVE THE AVAILABILITY AND ACCESSIBILITY OF A FULL RANGE OF MAINSTREAM SERVICES**

### **INTRODUCTION**

Shortage of provision, lack of choice and difficulty in finding out what is available have been recurring themes in research on services to people with learning disabilities and, indeed, within the community care field generally (e.g.: Marchant, 1993, Baldwin and Carlisle, 1994, Walker and Walker, 1998). In its recent initiative, *Modernising Community Care: An action plan* (1998), The Scottish Office highlighted the importance of local statutory agencies developing better information systems for users and carers, so that people have a better understanding of what is available, what choices are open to them and what the cost implications may be.

The recent inspection of services to people with learning disabilities in England (SSI, 1998) is entitled '*Moving into the Mainstream*'. The title denotes the fact that major changes have taken place over the last 20 years, with the gradual closure of long-stay hospitals, the introduction of some disabled children to inclusive education and the development of more ordinary housing. The SSI inspections found examples of good practice across England in terms of:

- an expanding range of accommodation;
- more diverse day services, moving away from the traditional ATC model;
- employment schemes;
- respite care;
- domiciliary care services;
- specialist services for special groups, for example, people with additional disabilities and needs;
- improved access to further education.

(p.3-4).

At the same time the SSI notes that the availability of services varied throughout the country. The report title also indicates there is still a long way to go before 'inclusion' is achieved. How does Scotland fare in comparison?

In this chapter, we look at the extent to which people were using segregated or mainstream services. We then discuss users' and carers' views about the availability and quality of information about mainstream services, levels of service provision and the amount of choice on offer. Finally we consider various aspects of accessibility.

### **SEGREGATED AND MAINSTREAM SERVICES: PATTERNS OF USE**

The majority of services used by most people were segregated. Some people, who lived in hospital or residential services, spent the majority of their time in segregated services. As Table 3.2 shows, of the 79 people for whom we have proformas, and the six participating in supported interviews, 64 lived with their family, 12 in community homes, four in hospital, four alone and one with a foster family.

Of the 50 adults for whom we have proformas, 35 (70%) attended a resource centre during the week, for between half a day and five days. Over a quarter attended full-time and over half attended for more than half the week. Some people attending resource centres were supported in community-based as well as centre based activities. Work-related activity was a very small part of some people's week. Of these 50 adults, only 9 spent some time in a work setting. All but one of these had part time jobs. Others had part-time work or 'work experience' for between half a day and 2.5 days a week. Many of these work opportunities were in mainstream employment settings. Jobs ranged from work in a charity shop, in a playgroup, in a college or hotel kitchen, in a clothes shop, a supermarket and cleaning. One person had three different cleaning jobs. One individual spent half a day a week in a sheltered workshop.

Sixteen of the 50 people attended college, none on a full-time basis. Levels of attendance varied between individuals from half a day a week up to 4.5 days per week (although only one person spent that much time at college). Half of the 16 people attending college did so one day a week or less. College courses included basic adult education, office skills, computer skills, preparation for daily life such as cooking, communication, sculpture, drama, advocacy and *World of Work*. Although this course took place in Further Education Colleges, most were part of a special education curriculum attended only by people with learning disabilities. A small number of people attended community centres or clubs. Most of these were segregated activities although there were some exceptions.

Four of the six people participating in one-to-one interviews attended day centres and three went to college. One woman living on her own with a support worker attended neither but went to a dance class and a gym. Most had some non-segregated activities in the evenings and weekends.

Some people had been using the same segregated services for many years. Some had been in hospital for decades, others had been going to the same day centre for years, one person for 17 years. People often travelled to and from their activities in 'special' transport. As noted in chapter 4, when they did use non-segregated activities it was often in a group of other disabled people. The mother of a school age child commented 'there is a prejudice about groups of children getting together. They should be meeting 'ordinary' children.'

## **LACK OF INFORMATION**

Information has been described as the 'fourth right of citizenship' (quoted in Hasler,1993). Lack of information, or insufficient, inaccurate or inaccessible information is disabling. The problem most frequently raised by family carers, reflected in the title of this report, and one which had caused them great frustration over the years, was the lack of accessible information concerning what services or support were available. These comments were made about social work and health provision, and sometimes about their relative's condition, as the following quotations and extracts from recordings demonstrate:

- You have to find out about services for yourself. No one comes to you automatically to inform you of what services there are... or asks you if there is anything you want to know.

- (The mother of a young child) said she finds out about services 'by chance' and 'is never told anything'.
- I need to know more about Down's Syndrome.
- Clare knew there were other issues and therefore sought out help herself, eventually identifying a support group from which she could get information.
- She didn't know she could have a social worker and wondered what they would be able to do for her. She suggested that more information should be available from Social Work about services available.

The lack of information available in community languages was cited as a very real problem for families from ethnic minority backgrounds and one which had an adverse effect on their ability to establish what support was available and how to access it. A young black woman commented that she did not know what services were available locally because information was seldom printed in minority languages. This issue will be explored in more detail in Chapter 10.

There was evidence that people with learning disabilities were not particularly well informed either. One young woman said that she did not know what a review was. A parent commented that 'there was no point' asking the children what they wanted because they did not know what they were entitled to nor what the options might be.

## **A CONSTANT FIGHT**

Because of the lack of information around, many parents, and some individuals with learning disabilities, had discovered that the only way to find things out was by constantly being proactive and 'hassling' professionals to answer their questions. The way this process was experienced by people is graphically illustrated by the language chosen to describe it - 'a fight', 'a struggle', 'a battle' as the extracts below illustrate. Incidentally, a similar comment about 'fighting talk' was made by Baldwin and Carlisle in 1994, suggesting that little has changed over recent years:

*'When asked about how they got information and access to services Mark and Paula talked of it being a battle from the start, the authorities only doing anything if they were a "right nuisance", that their determination keeps them going and that if they sat back the authorities would "sweep them under the carpet". Things haven't got any better over the years and as their son's needs change they go back to the beginning. Despite hearing stories about changes to do with money, housing and education, nothing ever happens. '*

*'Jill says she always has to fight and won't settle for anything less than the best and gave the example of having to struggle to keep her son in hospital when he was in plaster rather than have him sent home where she wouldn't be able to cope'.*

The comment about 'hearing stories' may be a reference to information gleaned from other parents. Family carers often described other parents as the best source of information. In

addition, parents had sometimes become so desperate to see some provision in place that they had got together to set up some form of provision to fill a perceived gap, usually a social club or playscheme.

Another view expressed more than once was that families had to be desperate before they would get support. One mother said she 'has to kick up a fuss' to get anywhere: she had 'to threaten that she was on the point of having a breakdown'. In another group, this time of carers of people with profound impairment, parents were astonished at one carer's account of lack of support. Our recording of the discussion notes:

*'They thought she must have been communicating to the services that she could cope. She should emphasise that she can't, as this is the only way to get services. Pam said that she wouldn't know what to say. The response to this was to tell social work about her worst day in order to convey her situation.'*

However, at the same time it should be stressed that parents thought it unacceptable that they had to be 'down on their knees' before they received help.

## **GAPS IN PROVISION**

In different parts of the country, gaps were identified in specific types of provision. In some cases it was hard to avoid the conclusion that the reason no information was available was simply that there was no service. It would be unfair to identify which particular areas were said to be lacking specific types of provision, especially as the data represent snapshots rather than systematic enquiry. However, provision of social and recreational opportunities, particularly ones that were welcoming to disabled children, were frequently highlighted as missing. Short breaks were said to be lacking in a number of areas. One woman with learning disabilities thought there should be 'more centres and places throughout Scotland for people who need support and training.' The following recording refers to parents of adults with learning disabilities, living in a rural area:

*'Martin and Diana said there is only the day centre to come to. There is nothing else. Craig spoke of the youth club which ran for years. It finished two years ago and was for people with learning disabilities.... He had heard that it closed down because of 'red tape and new regulations'. Pauline felt there isn't much support from the social work department.'*

Some people described the allocation of provision, both in the sense of whether a particular service existed and whether an individual gained access to it - as a matter of chance or accident. Their perception was that services existed on a random basis without any apparent logical planning. As we shall see in chapter 10, however, other carers took a different view, believing that services were targeted at certain groups or individuals, but not always for what they considered the 'right' reasons.

It should be stressed that where gaps in services or organised activities were identified, this was generally by carers. People with learning disabilities were much more likely to identify *gaps in ordinary opportunities*. While opinions differed to some extent, many people wanted to go out and about more, to have friends or 'someone' to go out with and to have a job. One young person suggested the new parliament should focus on 'allowing people to do what

they want to do with support workers'. These findings indicate a potential conflict between people's aspirations to lead ordinary lives and parents' demands for more services such as respite. However, it is also important to stress that some parents, particularly younger ones, believed that their children's needs were the same as those of any other children and that they must have the same opportunities as everyone else.

## **RESTRICTED OPTIONS**

If a service was not available in a local area, clearly people had no choice about whether or not to use it. Where there was only 'one' of something, it was a case of Hobson's Choice - take it or leave it. A number of people cited occasions when they had been 'told' they were going to live somewhere, or with somebody, with no apparent say in the matter nor any other option being made available. It was felt that options decreased as people became older. Sometimes this led to people being offered a form of provision which they considered quite unsuitable. For example, two carers in one area reported that the only respite care they had been offered for their middle-aged son or daughter was in a nursing home. Gaps in provision, and the limited choice available, might mean that people were less likely to complain in case they ended up with no service at all.

## **PERCEIVED SHORTAGE OF RESOURCES**

One of the main reasons cited by carers for the difficulties they experienced in accessing services was a perceived lack, or in some case misallocation of resources. References were made to specific services being cut, for example, the provision of speech and language therapy and occupational therapy. One young person expressed anxiety about proposed cuts in disability benefits. One man was recorded as describing his day centre as follows:

*'He has been coming for fifteen years and there was more to do before but now there have been cutbacks introduced by the manager. He said the staff asked what he wants to do but then nothing happens'. This man's recommendation to The Scottish Office was that there should be more money available so he could meet more people.'*

Even once allocated to an individual, certain professionals could be very hard to get hold of:

- (One mother) said her main complaint about social work was that she rings the department but can't speak to anyone. No-one can tell her the hours the person works or when they will be available.
- Tom didn't have a social worker but had one in the past who was 'very busy' and he wanted one now.
- June wanted to ask the manager in the resource centre (about work) but they are always too busy.
- Christine said her social worker was helpful but sometimes she said she would phone and then she didn't.

Although these kind of comments seemed to be made about social work more than other professions, similar comments were made about speech and language therapists, occupational therapists and occasionally GPs.

Another experience shared by several users and carers was that of staff promising to do certain things which never materialised. Examples given included carrying out a community care assessment, setting up an advocacy scheme or changing activities within a resource centre.

Parents sometimes felt that the outcome of assessments depended on what was or was not available rather than what was needed by the individual and that financial considerations were paramount. Shortage of resources leads to rationing and waiting-lists. One carer had experience of having to book respite a year and another, 18 months in advance.

## **PHYSICAL ACCESS**

Even where a service was available, gaining physical access to it could be less than straightforward. Sometimes the problem concerned transport. Again a number of issues concerning transport have been noted in relation to facilitating, or obstructing, people in community participation. One school insisted that children must travel in and out on the school bus. Parents were not allowed to bring children in themselves - apparently because it was feared they would not collect them at the end of the day. Apart from the inflexibility of this arrangement on a day to day basis, there were times when the bus could not reach certain areas because of snow, resulting in children being obliged to miss school. One mother was angry that her daughter had missed three or four days of education - to which, the mother said, "she was entitled" - because of this policy. Conversely, at another school in the same authority, the head teacher had made it clear that it was parents' responsibility to collect children. A third parent reported that her child's school insisted that if parents took a pupil to school they must also collect them that day. However she had found a way to by-pass this rule by coming to an arrangement with the child's taxi driver.

A significant proportion of people with learning disabilities have mobility impairments and cannot enter inaccessible buildings. It is perhaps surprising that only one person mentioned physical design - of mainstream services generally - as a barrier to participation. Whether this was because most of those participating in focus groups or their relatives did not have mobility difficulties - or simply that it did not occur to them as an issue - is uncertain.

## **SUPPORT WITHIN MAINSTREAM SERVICES**

Another vital ingredient in enabling people to use mainstream services was that the right kind of support should be available. One parent gave the example of leaving her pre-school aged daughter in a children's club, having explained to staff that she required careful supervision. Her daughter disappeared from the premises and was eventually found walking down the street. Attitudes displayed on the part of the general public put some people off using mainstream services. As already mentioned, several examples were given, by parents and by children, of other children being unkind to them in mainstream play provision. One boy reported that he had gone to 'a big club near my house' which he had not enjoyed because the children were 'not nice to me'. He was now well settled at a club which, although having an

inclusive policy, was only used by children with autism. Adults too did not always understand or accept disabled children's behaviour, tending to see them as 'naughty' or worse. This was especially true when the child had no visible impairment and 'looked normal'.

If mainstream services are to include disabled people in a way that works, they need to recognise and accommodate difference. This can be illustrated through parents' reports about school. One parent was concerned that because her two children were the only ones in their mainstream school to have Down's Syndrome, both they and their parents felt isolated at times. There was a feeling that these children were expected to 'fit in' without acknowledgement that they needed extra support with some aspects of school life if real inclusion were to be realised. What help was available centred on the curriculum and not on social participation. Conversely, the father of the child described earlier as having 'a huge fan club' reported that inclusion policies at this school had been thoroughly thought out; the learning support unit had been specially built as opposed to being 'shoe horned into a corner' and he was satisfied that his children, and others at the school, were benefiting.

## **CHAPTER SIX RECOGNITION AND ASSESSMENT OF SOCIAL NEEDS - EXPERIENCES OF SOCIAL SUPPORT**

### **INTRODUCTION**

The recent inspection of services to people with learning disabilities south of the border (SSI, 1998) found that assessment systems specifically designed to identify the needs of people with learning disabilities, such as Individual Programme Plans, had generally been replaced by generic assessment and care management systems, many of which had little relevance for these users.

This section begins by looking at what users and carers had to say about the extent and ways in which their needs for social support were recognised and assessed, both in formal assessments and on a more general level. Various factors which impinged on the process are discussed. We then look at recognition and assessment of need within the context of specific services: examples of what were perceived as 'good' and 'bad' assessments are given. The aspirations of people with learning disabilities are considered. Finally we look at the extent to which siblings' needs are recognised.

### **AWARENESS OF FORMAL ASSESSMENTS**

The lack of knowledge among family carers and service users about the assessments to which they were entitled was striking. Not only did most people seem unaware of the availability of Community Care Assessments under the NHS and Community Care Act 1990 or the Carers (Recognition and Services) Act (1995), several were uncertain whether or not they had undergone either assessment. One mother for example commented, when asked if her son had had a community care assessment, 'yes, more than one year ago, I can't remember, somebody came to the house and did an assessment.... not exactly like an assessment.' The record of a discussion with a group of young people, asked if any had had a Community Care Assessment, is as follows:

*' Jack said 'no'. Robert was uncertain. He thought he had but said it depended on what it meant. Having been given a description he said he has had one and it was useful. He said he had 'loads of forms' to fill in and then, upon further clarification about a Community Care Assessment, he decided he hadn't had one. Monica has not had one.'*

Only one carer reported having had a carer's assessment and she considered the financial element of it 'unfair', as it involved means-testing. Most carers were quite unaware that they could request an assessment of their own needs.

Parents were better informed about education legislation and were familiar with the Recording of Special Educational Needs set up under the 1980 Education (Scotland) Act. Nevertheless, some reported that they did not understand the operation of the Record of Needs. This should be carried out annually and parents should be consulted in case they want it changed. Parents reported that they are 'just given it and told to fill it in', without adequate guidance.

Corresponding to the findings of the SSI (1998), there was no mention of specialist assessment procedures. More surprisingly, perhaps, there was little reference to Person-Centred Planning, which is increasingly used with people with learning disabilities in Scotland.

## **EXPERIENCES OF ASSESSMENT IN GENERAL**

Because so few people spoke about formal assessments, the rest of this chapter deals with recognition and assessment of need on a more general level.

Family carers often saw themselves as experts on their sons' or daughters' needs and circumstances but their knowledge and expertise was not always listened to by professionals. They emphasised the need to treat each person, child or adult, as an individual rather than making assumptions about what a person's needs might be, or how best to meet these, based on her perceived membership of a particular category. An occupational therapist, for example, asked to provide a bath for a man who liked to 'have a good soak', had apparently replied 'disabled people have showers'. Some parents felt an element of judgementalism could creep into professional assessment of need. One carer related an anecdote about a parent who had been turned down for a respite service when the social work department discovered she had been out shopping while the child was in short-term care.

People felt under strong pressure to fit in to professionals' preconceptions - the word 'stereotype' was used - and to whatever service or facility was available. Assessments were sometimes carried out too quickly, without taking the time to get to know the individual.

People also felt that assessment was often driven by financial concerns rather than careful consideration of an individual's needs. The type of service offered was cost-driven. Linked to this, but part of a wider issue, was the feeling that people were constantly being assessed in various ways but with no tangible outcome emerging. Professionals of various kinds would come and ask what people needed and nothing more would be heard about it. Incidentally, a similar concern was expressed about the present research exercise - people were giving up their time to attend the focus groups and share their views - would anything concrete come of it?

Assessments carried out under community care and education legislation is intended to be multidisciplinary: meeting the needs thus identified may well involve co-ordination between different agencies. Although respondents were not asked specifically about this topic, several identified gaps in what is intended to be a seamless service. Carers were unanimous about the need for collaboration, with social, health and education services coming together. However parents could find themselves caught in the middle, going from one agency to another and having to repeat the same information several times. This could delay the assessment process and, in one case, waste what was seen as precious time. There was also a feeling that each agency tended to work in isolation and would rather come up with its own response than bring in a professional from a different agency who might be better placed to respond appropriately.

The need for services to recognise the cultural requirements of families from minority ethnic communities is clearly paramount. This issue is discussed in Chapter 10.

## EXPERIENCES OF SOCIAL WORKERS

Participants reported a low level of support from social workers. Among the 79 people who featured in the pen profiles, only two children and eight adults saw a social worker at least once a month. Incidentally, the numbers with regular contact with occupational therapists was lower - two children and three adults. However, OTs might be more likely to undertake task-centred and time-limited interventions whereas social workers might be more likely to have an on-going involvement with some people. The general pattern seemed to be that people either did not have much social work contact or only did so when an impending or actual change - or crisis - occurred in their lives. Some people saw their social workers only occasionally, for example, at an annual resource centre review. However there were exceptions, with some carers and users listing various things their social worker had done.

Given that many people described services as inaccessible and did not know what was available, this low level of input is not surprising but may be a cause for concern. In one area we visited, parents reported a dearth of any support besides the voluntary organisation through which that focus group had been organised. One mother commented that she did not know she could have a social worker and wondered what one could do for her. By chance, on the following day we learnt that a social work team dedicated to families with disabled children had been set up in that town some months previously. While most people do not need to have frequent social work contact, the fact that in many cases there had been little or no such contact indicates a need to review many individuals' situations to identify their current needs and what type of support they require.

However, to offset these more negative experiences, the following account from one focus group discussion provides a more positive account of ways in which social needs can be recognised and met. The key theme here, closely linked to parents' feelings of satisfaction, is their sense of having control over the situations:

*'A couple of the group had very little to do with social workers. Ruth had found them useful in the early days with liaison between different social work departments, decision making and dealing with forms. Jenny felt that whereas before the social workers had been involved in crisis situations, they had changed the way they operated away from this. She now has one with whom she has had contact over several months. She finds this helpful; she can bounce ideas off her social worker who isn't just another professional. She gets help with practical things, for example, respite care, arranging transport, getting information or they can just "blether". Jenny feels in control and able to conduct the relationship on her terms. However, she also feels that the service depends on the social worker you get and in what area you are based'.*

## RESOURCE CENTRES

Resource centres and respite care accounted for a considerable proportion of the support received from social work departments. However, resource centres were widely seen as failing to recognise and meet people's needs. With only a few exceptions, people attending resource or day centres reported that they were boring, as research elsewhere has also found (eg: Beyer and Kilsby, 1995). In one centre, participants said they were bored 'sometimes' and on occasions 'all day'. Activities in which they took part included cookery and a 'news

team' which made posters and kept a record of events within the centre. Participants said they could talk to their key workers if they wanted to change their programmes: one person had asked the manager for changes and the manager was 'thinking about it'. Participants also expressed great displeasure about a recent change in key workers about which they had not apparently been consulted. Two people had lodged complaints about this matter but stated that nothing had happened as a result of their action. There was also considerable unease about the appointment of a new senior staff member who was seen as 'very bossy.' In addition, the staff sometimes shouted at the users.

These comments provide ample evidence that in one centre at least people's needs were not being recognised and met - both at the level of having stimulating and valued occupation but also in terms of being listened to, treated like adults and respected. Members of another group complained that the only activity on offer at their centre was hoovering!

In contrast, another group comprising people attending a resource centre had some more positive experiences to report. Here participants reported a number of activities they enjoyed, including days out from the centre, described the staff as helpful, and said they had choice about what to do. Yet here too there was a member of staff described as 'bossing people about': one person commented 'it upsets me that she told me to do what I don't want to do'.

As reported in the previous chapter, most centres had arranged for people to have 'work experience', voluntary work or sometimes limited amounts of paid employment. These activities were clearly valued by people: however, they generally lasted only a few hours per week. Several people said they would like to have a proper job.

Parents tended to be more positive about resource centres than their sons and daughters, one father describing his local centre as 'fantastic - it stretches them'. Clearly the quality of support offered in resource centres varies both between and within regions, depending on a number of factors. In addition, from parents' point of view, they serve the function of providing respite care by another name. However the consensus among those attending such centres was that they offered little of interest and much of boredom. Again this reflects the findings of other research (e.g.: Beyer and Kilsby, 1995).

## **SHORT-TERM (RESPITE) CARE**

Short breaks came up in many focus groups, although only one group was specifically focusing on this topic. Parents did not say a great deal about the assessment process for respite although one person commented that the means testing involved was unfair. She had been assessed as requiring 20 hours respite care which was to be charged at £6.50 an hour. When she refused to pay for this, the offer was reduced to nine hours. A carer elsewhere reported that she had waited a year for a link family to be arranged, during which time her family's needs and circumstances had changed. Several carers commented that rather than feeling their need for a regular break was being recognised, professionals made them feel they were being given a favour.

As noted in the last chapter, a lack of sufficient and/or appropriate provision was identified in various parts of the country. For example there was said to be only one short breaks service in one large local authority. There was also some feeling that respite was aimed at particular groups of people and excluded others.

The importance of short-term care being a flexible service has been identified elsewhere (e.g.: Lindsay, 1996) but this was one aspect which came in for criticism. One family reported that respite had to be booked a year in advance while another reported that 18 months' notice was required. Not surprisingly, parents were concerned about what would happen if an emergency arose and they needed respite at short notice. At one home the breaks offered did not correspond to typical holiday booking periods, i.e. Saturday to Saturday, resulting either in holidays being difficult to organise, cut short or parents having to take more time off work.

Other research has indicated that respite is often organised primarily with carers' needs in minds and that the needs of those in direct receipt of the service are secondary or indeed not taken into account (see Stalker, 1996). Parents in this research stressed that respite should be a positive and stimulating experience for the individual, for instance, that children should have fun. Another mother believed her daughter benefited from the breaks because they were a preparation for the future when her parents would no longer be around.

People attending respite of various kinds were generally positive about their experiences. They enjoyed the activities on offer and got on well with other users and staff. One person commented 'the staff, meeting people, it's friendly, really nice, like a community here - it's perfect'. Another commented on getting out and about from the respite unit, visiting the pub and making new friends. Clearly these were services which did recognise individuals' social needs and were adept at meeting them.

Short breaks did not necessarily involve people going to stay outside the family home. Other forms of support which have been mentioned previously in this report, such as personal assistants employed through ILF monies or befrienders organised through social work or voluntary organisations, were universally praised because they involved a recognition of people's need for friendship, social stimulation and the chance to pursue activities of their own choosing. Indeed the primary purpose of these services was not to provide respite but to offer more choice, control and social stimulation for the individual. Where that person lived with family, there was the added bonus to the latter of a short break. If more respite were organised along these lines, the indications are it would be more acceptable both to parents and individuals with learning disabilities.

## **VOLUNTARY ORGANISATIONS**

Three carers contrasted the support available from local authorities with the support they had received from voluntary sector organisations. One couple, recruited through a social work department in the central belt, reported that 'voluntary groups are more flexible. They respond to, adapt to the needs of kids. Health Board or state-run are more rigid'. A parent in the north of Scotland commented that the 'most useful' services were those provided by voluntary organisations but added that access was sometimes dependent on area of residence. A parent in a third group commented 'There is hardly any respite from the council - you have to go to the voluntary sector.' It should be pointed out that many participants were recruited to the study directly through voluntary organisations with which they were in contact. At the same time, social work support should be available to anyone requiring it and most of these carers had experience of it or of trying to access it.

In some cases a particular voluntary organisation was seen as a lifeline which acted as a bridge for people securing a range of other support they had not previously known about. Such organisations were also invaluable sources of information. In both ways, they played an important part in recognising people's needs and, if they were not directly involved in assessing their needs, referring them on to other organisations to do so. These tended to be agencies with specialist aims, for example supporting people with a particular type of impairment, families from ethnic minority backgrounds or those whose children had recently been born or their condition recently diagnosed.

Given that parents often felt they had to organise support and services for themselves or each other, it was perhaps surprising that more people did not refer to the need for carers' support groups. This again may have been because such a concept was unfamiliar. Such groups were mentioned in two areas and were considered very useful.

## **FINANCIAL NEED**

The pen profiles show that ten people (or their families) had regular contact, meaning at least once a month, with the Benefits Agency. Several people mentioned the difficulty they encountered in obtaining information through the Benefits Agency about financial entitlements. The assessment process attached to applying for benefits was experienced as extremely cumbersome and complex. The forms for Disability Living Allowance (DLA) for example were described as 'horrendous and ridiculous'. Some people felt that these forms with their repeated questions were like 'a trick', trying to catch them out, as if assuming that claims were likely to be fraudulent. There also seemed to be unexplained variation in people's experiences of applying for benefit. One family had applied for DLA only once while another family had been asked to go through the procedure several times. Again the message conveyed - or picked up - here was that some parents might not report a change in circumstance which could alter their entitlement. It was suggested that there should be some sort of 'forum' informing people of their entitlements.

If carers found these application forms hard to complete, so too did people with learning disabilities. One person commented: 'The Benefits Agency has no time to help you out. They ask so many questions, do a quick assessment and miss what you need.'

Another way in which the social security system failed to recognise people's needs affected those in work or wanting to work. As already discussed, due to various complex regulations, many people with learning disabilities are unable to work other than on a very part-time basis, often about four hours a week. One person in supported employment wanted to work more than he was allowed to. Others however declared themselves satisfied with part-time employment.

## **THE NEED TO RECOGNISE PEOPLE'S ASPIRATIONS**

As other research has also shown (Simons, 1995), people tended to voice very ordinary aspirations - to make choices about their lives, to have a job, to have a house of their own, to have a partner, to marry and to have children. Only five of 79 people about whom we have information from the pen profiles saw a careers officer regularly. A number of people occupied caring or helping roles such as looking after a niece and nephew, walking other

people's dogs, cooking for a widowed father, caring for a sick mother. These roles, in which people with learning disabilities had a chance to give to others, were clearly important in terms of self-esteem.

## **PLANNING FOR THE FUTURE**

Families felt that assessments did not take account of their sons' and daughters' future needs. More than that, there was a dearth of co-ordinated planning specifically aimed at providing for the time when parents would no longer be around. Again echoing the findings of numerous previous studies, one of parents' principal anxieties concerned what would happen to their children at that point. One parent spoke for many when she identified a need for a planning framework in which parents and adults with learning disabilities were involved and which would result in everyone knowing what was going to happen in the future. There was a feeling that people should be eased into support gradually before there was a pressing need for it, the worst scenario being that a person might be 'put somewhere he's never seen.' Another parent was worried that her son would not receive a sufficient level of support - that he would 'end up in independent living when what he needs is twenty-four hour care'. Her comment reveals a misconception shared by a number of parents, presumably due to poor information, namely that 'independent living' and 'twenty-four hour care' are mutually exclusive: they are not. Several parents had raised their concerns about the future with professionals but with little practical result.

## **THE NEEDS OF SIBLINGS**

Research findings about the impact of a disabled family member upon his or her siblings have been mixed (Baldwin and Carlisle, 1994). We did not ask about siblings but this was a topic which carers raised on several occasions.

The fact that many people with learning disabilities had a restricted social life could impact on siblings. One mother described how one of her children had been hitting her son with learning disabilities because the latter was receiving more attention. Sometimes parents felt siblings were put under pressure to entertain the person or to help increase his or her inclusion in the community. A few parents were concerned about the issue of intrusion on siblings' friends. Some parents also felt they relied on their non-disabled children to provide back-up support when necessary. One had found that as her other children grew up, they no longer wanted to fulfil this function and therefore the responsibility fell back on parents. It was felt that siblings' needs were overlooked by parents and service providers and that more sibling support groups should be available.

These rather negative comments from carers about relationships between their learning disabled and other children should be set in the context of comments made by people themselves. Brothers and sisters played an important role in some people's lives. For some, siblings were the only close relatives alive or with whom they had contact. Their accounts of these relationships indicate that siblings did not necessarily experience their disabled brother or sister in the 'burdensome' way suggested by some of the parents. Only one sibling attended the focus groups: she was the adult sister of a 39 year old woman. She accompanied her ageing mother, with whom her sister lived, to the group and was clearly concerned to support

the former in her role as carer. However, she also acted as a direct support to her sister when the latter 'fell out' with Mother.

## **CHAPTER SEVEN RECOGNITION AND ASSESSMENT OF HEALTH CARE NEEDS: EXPERIENCES OF HEALTH SERVICES**

### **INTRODUCTION**

There is evidence from other research that the health care needs of people with learning disabilities are often neglected. Langan et al (1995) found that insufficient attention is paid to people's needs in the areas of health promotion, health screening and regular hearing and sight tests. A teaching package was developed by Dodd (1999) to improve knowledge and awareness among people with learning disabilities about their health needs and how to communicate with primary health care teams. Evaluation showed this had proved effective, with people gaining a better understanding of the process of visiting their local surgery. Research in Scotland however found that some GPs have expressed reluctance to accept former hospital patients onto their lists (Stalker and Hunter, 1997).

### **USE OF SERVICES**

The present research was not designed to establish the level of use people made of services but rather their views about them. However, some data about use of provision was gathered on the pen profile proformas and those relating to use of health services are summarised below. Forms were completed for 79 people. People were asked to identify which professionals they saw at least once a month. As Table 7.1 overleaf shows, the findings indicate a high use of GPs, with 27% of the sample seeing their doctor at least once a month. This was twice the number of people seeing speech therapists, which was the next 'most often seen' professional.

### **ACCESS**

As in relation to social needs, a major problem in the recognition and assessment of health care needs was that, without access to services in the first place, people could not hope to have their needs picked up. While people did not have the same problem finding a GP as they sometimes did with securing a social worker, there were some difficulties regarding continuity of professional input. The comment was made by a carer and echoed by a user that 'when you go to the doctor you never see the same doctor twice.' Not having the opportunity to establish an ongoing relationship meant that regular monitoring of a person's condition could be jeopardised and that changing needs might be less likely to be picked up. It could also mean that family carers' needs might not be recognised. Due to the demands being made on over-stretched resources, people could be kept waiting a considerable length of time for an appointment with a consultant.

**Table 7.1 Health Care Professionals Seen Regularly (sample=79)**

Professional	School age people	Post-school people	Total
GP	4	17	21
Community Nurse	1	8	9
Community psychiatric nurse	1	0	1
Physiotherapist	2	2	4
Speech therapist	11	3	14
Dietician	1	4	5

## THE ASSESSMENT PROCESS

Some people were also concerned about insufficient time being spent on assessments. They felt that a doctor did not see what someone was 'really' like or simply failed to go into her situation in enough detail. One mother commented 'they do a 20 minute assessment – we're doing a 24 hour assessment.'

Again like the experiences of those using social work supports, there was considerable frustration that parents' own knowledge and expertise was sometimes undervalued or even discounted, with professionals, usually hospital consultants, seeing themselves as *the* experts. A parent commented: 'the experts read it from books; they don't live with it'. One mother had requested a gastrostomy tube for her son who had 'lost the power to eat' but in response she was told she was not feeding him properly. The professional involved proceeded to give a demonstration. This mother said she had felt patronised and ignored, indignant at being told she did not know how to feed her own child. In addition, her son suffered considerable discomfort as a result of the way he was fed by the professional.

Elsewhere several other carers questioned the way assessments were conducted. One mother's experience was that of a stream of different professionals coming into her home, each carrying out a string of tests, and simply listing what was wrong. This mother felt that a diagnosis was less important than practical advice about coping with day to day life. There was also a suspicion among some parents that the knowledge on which health care professionals based their assessments and drew conclusions was wanting. The father of a pre-school aged child said, 'people *guess* what is wrong with your kid'.

Above all, carers wanted their relatives to be treated as individuals. However, a tendency to label and stereotype people could distort professionals' ability to recognise need and carry out accurate assessments. One mother talked about the dismissive treatment she had received from a consultant examining her son's eyes for a squint. She was told there was no problem with his eyes, his problems were due to the shape of his head and the fact that he had Down's Syndrome and nothing could be done about it. However, when the family took the boy to an optician, the latter said that he had 'never seen such a classic case of a need for glasses because of a squint'. Similar comments about health professionals failing to see beyond a diagnosis and attributing medical problems to the child's 'untreatable' condition were made by the parent of a woman with cerebral palsy. Another parent said that a consultant talking to junior doctors had described her son as a 'mongol', adding 'here we have a social problem'.

## **OUTCOMES OF ASSESSMENT**

In common with experiences of social work, another issue was the lack of any useful outcome from assessments. Sometimes this was because little or no feedback was received: 'professionals, such as those at the children's hospital, OTs ..... carry out tests but you never find out about results. You simply go away and come back six months later for the next appointment.' Similarly, sometimes there was a considerable wait before the needs identified in the assessment were met, by which time the situation could have changed.

Several carers criticised the way they were informed of the outcome of assessments. One mother had been given a diagnosis of a life-limiting condition for her child and told to 'go home and get on with life'. She found this advice insensitive, since she could not hope to carry on as normal knowing that her son was going to die. Underlying the way this kind of information was conveyed to families there appeared to be some disturbing attitudes towards people with learning disabilities. One mother reported that she had been given the diagnosis of her son's autism in a 'rather flippant' manner. Another disturbing story came from a mother who was advised to:

*'abort my son. At 22 weeks, they said that he had all these things wrong with him and that I could stay in (hospital) and they would get rid of him. I said I needed time....my brother has a learning disability and we lived with it. We wanted to go ahead with our baby'.*

## **EXPERIENCES OF HOSPITALS**

People's experiences of hospitals were varied. Some carers felt that hospitals either did not recognise the level of support or supervision required by their relative or else were unable to provide this level of support. As a consequence carers felt they had to stay with their relative for the entire length of the admission. Lack of stimulation in hospital was a worry for some families.

The importance of seeing people as individuals with their own particular needs was also made in relation to the inflexibility of hospital routines and the inability of some staff to deviate from set procedures. For example, a nurse had insisted that a young boy should eat toast before he was discharged after having his tonsils out, despite the fact that he did not normally eat toast and the experience of doing so after tonsillectomy proved 'very traumatic'. A picture emerged of some disabled children being treated in ways that would be considered quite inappropriate for non-disabled children, indicating a failure on the part of some professionals to realise that these children have the same needs as any others. In one instance, staff had wanted to sedate a child when he was in hospital while another child was left in nappies.

The issue of inter-agency collaboration, raised in chapter 6 in relation to social support, applied equally to health care. In particular it was felt that the social implications of health care were not always recognised. Some people wanted to be able to transfer the care they received at home into the hospital setting but this proved difficult due to the separate organisation and funding of services. Personal assistance was still needed in hospital. When this was not available through the usual channels, again it fell to parents to provide much of the care and support their relative needed.

However, other people had very different experiences of hospitals. One father described the local hospital as 'tremendous'. The same establishment was experienced by another family as 'wonderful from reception all the way through'. In this case, a nurse had been with the individual all the time and there had been no expectation that his parents would be in constant attendance. A couple of people who had been in hospital also described the experience in positive terms, apparently enjoying the 'busyness' of the environment. One person who had attended an eye hospital had appreciated the fact that everything had been explained to him clearly and he had not been treated in a patronising manner. While some parents suggested that their positive experiences of hospital were attributable to the fact that they lived in a rural area where there was less pressure on services, parents in another rural location were by no means satisfied with their local hospital. The findings indicate that there was considerable disparity in people's experiences according to the area in which they lived.

## **EXPERIENCES OF PRIMARY CARE**

Overall, it should be stressed that GPs were seen in a positive light. They were generally described as more approachable, both on a personal level and in terms of 'the system', than hospital consultants. Carers were appreciative of GPs who recognised *their* needs as well as those of their relatives. However, much depended on individual professionals, some being more knowledgeable and / or helpful than others. One mother said: 'Mike's doctor was good too. He took out all these manuals to show us about hydrocephalus. My doctor gave us no information. It depends what doctor you get what you find out'. Similar points were made in different parts of the country about particular health visitors and dentists.

Most of the people with learning disabilities described their GP as 'nice' or 'very nice' and several added that the GP talked to *them*, rather than or in some cases as well as any carer who accompanied them to the surgery. The only exception to this was a young girl with autism and a speech impairment, whose GP generally addressed himself to her mother. Most people seemed to know their GPs although they did not have a great deal to say about them, perhaps reflecting the important point that, as one person observed, 'I just see my doctor when I'm ill' or in the words of another, 'I don't see a doctor because I am healthy'.

## **SPEECH AND LANGUAGE THERAPISTS**

There was virtually unanimous agreement that speech therapy was useful and important but, despite the findings shown in Table 7.1, very thin on the ground. This is discussed in more detail in Chapter 9 in relation to help with communication.

## **CHAPTER EIGHT CONSULTATION AND INVOLVEMENT IN DECISIONS ABOUT HOW PEOPLE'S NEEDS ARE MET**

### **INTRODUCTION**

The importance of involving people with learning disabilities and other user groups in decisions affecting their own lives is now widely recognised. In terms of service provision, the concepts of choice and empowerment are fundamental to the National Health Service and Community Care Act of 1990. The exodus of people from long-stay hospitals into more independent living, the development of self-advocacy by individuals and groups and, more recently, the introduction of direct payments schemes are all illustrative of a movement towards greater self-determination for people with learning disabilities. While the lives of many individuals are still dominated by service provision, the right to exercise choice and control is - in theory at least - generally recognised as essential to a good quality of life.

In reality, however, although many people with learning disabilities are able to make choices about day-to-day matters, they are rarely given the opportunity to make decisions about major life events. A recent review of the literature concluded that a number of barriers restrict opportunities for people with learning disabilities to exercise choice. The nature of services provided and the beliefs and attitudes of staff are critical factors (Stalker and Harris, 1998). While ability clearly plays some part in choice making, this review found evidence that everyone could make decisions for themselves at some level.

### **TYPES AND LEVEL OF INVOLVEMENT**

People were involved in making decisions about how their needs were to be met at both individual and group levels. The former could involve informal discussion with social workers or other key workers, and sometimes with family or an advocate but some decisions were made in a more formal setting such as a resource centre review or a Future Needs Assessment. At the group level, participation generally took place through groups such as tenants' organisations or members' committees in resource centres, set up by professionals with the purpose of consulting service users about various aspects of service delivery. The exception to this pattern was People First Scotland, the national self-advocacy organisation, which differed from others in that it was set up and is controlled by people with learning disabilities independent of service provision. A small number of participants were members of People First.

The extent to which people with learning disabilities were involved in making decisions about their lives varied tremendously. Fiedler and Twitchin (1992) identify a continuum of participation by disabled people in service planning and delivery. It ranges from information giving, at the lowest level, through consultation and partnership to delegated control, at the highest level. The latter involves giving authority and resources to disabled people to plan and implement services.

At the bottom of the scale, so to speak, people reported they had simply been told they would be doing something or going somewhere. For example, one woman said she had known nothing about moving to a group home until her social worker found her a place and introduced her to the other residents. Another woman reported she was 'put' into a home. A

man using respite care said 'I didn't choose to come here, my mum just put my name down'. Four people attending one focus group were all in the same class at Further Education College. Asked how they had come to be in that class, the response was that they had all been 'picked' for it and there was room for them. They went on to say they were 'told what to do' at college. Residents of a group home who exercised a fair amount of choice over other aspects of their lives were not involved in staff recruitment; rather, they were introduced to new workers once appointed. Feelings were running high in one resource centre following a recent reallocation of key workers. Service users had not been consulted during the process and were most dissatisfied with the outcome.

In the cases above, people had apparently been presented with a *fait accompli* and so any response they had was reactive. A second scenario was found in which people had apparently identified for themselves a preference or a view about something that was important to them but they had not articulated this to staff. On a number of occasions, people shared with us a hope or ambition which they had not voiced to those who, it might be assumed, were in a position to act on it. One woman said 'some people have been rotten to me...like going to the dentist, they say horrible things to me...I'm not sure about telling people about it.' A man who identified various jobs he would like to try added 'I'm thinking of telling someone'. Similarly, a woman living in a long-stay NHS unit spoke of 'having to put up with it' while another resident who found the environment too noisy had not complained to anyone. If people felt able to make these comments to facilitators in a focus group, why had they not shared their views with staff working with them on a regular basis? Some possible reasons are discussed below.

A third scenario was that people with learning disabilities had expressed their views but these had either not been listened to or not been acted upon. In some cases people had made their feelings known without being asked to do so. In others, their views had been sought, or they had used a recognised mechanism for voicing an opinion, but with no satisfactory outcome. In these cases it appeared that mechanisms were in place but, for whatever reason, were not effective. At the centre where members were incensed about the recent change in key-workers, two people had used the formal complaints system to register their protest, but with no response from staff. Elsewhere, a man who found his co-residents too noisy had spoken to staff about the problem but had been told he would have to get used to it. He reported that 'staff ask what I want but then nothing happens'. Another person attending a day centre where 'you could only tidy up or just sit' had told staff he wanted to work with animals or children but nothing was done about it.

Happily there were other people who not only felt well involved in decisions about their lives but also saw their expressed wishes being acted upon. With the exception of staff recruitment, residents of one local authority home were consulted about most aspects of their lives through a residents' committee. On an individual level, people could decide what they wanted to eat, where to go on holiday, when to get up or go to bed, and who should be their key worker. The father of a man attending a resource centre praised the review system there, adding that staff were 'very approachable, you just have to pick up a phone.' Other parents echoed this view. However another parent, while appreciating the format of the meeting, felt that staff asked questions in the wrong way, such as 'Are you happy? Do you still like to live at home?' She felt that asking these direct questions simply resulted in acquiescence on the part of the individual. There has been considerable debate in the literature about acquiescence on the part of people with learning disabilities (Sigelman et al, 1981, Rapley and Antaki, 1996) but

it is generally accepted that the way questions are phrased can have a significant effect on the way they are answered.

Another young woman reported that her 'leaver's review' meeting at school had discussed a number of options, including independent travel, getting her own home in future and getting married. She had welcomed having these possibilities put to her. Two young women elsewhere felt they were being given options to move away from the family home which they did not want. The important point however is that such options had been raised. As the vignettes in Chapter 2 illustrated, a small number of people with low level support were in a position to exercise considerable control over their lives - these examples come near to 'partnership' between professionals and people with learning disabilities.

Overall, there seemed to be a fair amount of involvement in making decisions about everyday matters such as what to eat or when to get up, but less participation in decisions about where to live or with whom. In some cases it was a question of Hobson's Choice - people seemed to be introduced to one particular service in the hope that it would work out, rather than having a range of options from which to choose.

## **SPEAKING UP**

As already indicated, people differed in the extent to which they were prepared to speak up. Some felt they just had to put up with things as they were. The focus group facilitators noted of a few individuals that their body language, facial expression and general demeanour seemed to indicate a certain resignation or even apathy, as if they saw little point in expressing their views. As we have seen, some people had certain opinions they would have liked to express to staff but were still 'thinking about it'. It is generally recognised that many years in the service system and long experience of powerlessness can teach people that life is easier when one keeps a low profile. One or two individuals in the focus groups sought reassurance that their comments would not be passed on to their parent or a member of staff.

In four focus groups and one supported interview, participants expressed great concern about a particular member of staff in a service they used. In each case this person was seen as 'bossy'. One group felt they had to be careful what they said in relation to a manager of their service. The recorder noted 'they did not want to elaborate too much. They seemed to see this person as in charge of what they could and couldn't do.' A group elsewhere was unhappy with a staff member who was bossy, telling them to do things they did not want to do. At a third setting, as mentioned before, a new manager had recently been appointed whom people again described as 'bossy', adding that staff at this establishment sometimes shouted at them. Not only do these accounts give cause for concern about people being disempowered in terms of expressing views, they indicate a lack of respect for people. Clearly when individuals have experience of staff treating them in these ways many may become fearful of speaking up. These examples also illustrate the importance of staff being prepared to give up some of their power if they are to 'empower' others.

Among those who did speak up and clearly wanted to have a greater say in their lives were the younger participants. Several of them felt frustrated that they were not allowed to make as many decisions as they wanted, or to do certain things they would like. In these cases it was generally their parents who were perceived as setting restrictions. One young woman reported that her mother shouted at her and her father 'bosses her about'. She commented: 'I

just want to move. I can't wait'. Another young person felt she was not trusted to go out alone or after dark, and that her parents were 'always interfering'. To a large extent, their experiences are typical of adolescents and teenagers feeling over-protected by their parents and wishing to assert their independence. In the case of people with learning disabilities, however, parental control invariably lasts longer than is usual for non-disabled people, and indeed may never be removed.

Some individuals however were not prepared to accept the limitations placed on their lives by others and had fought over the years to exert choice and control over their own lives. A middle-aged man now using few or no supports gave the following account:

*'Just before I came out of (the hospital) they gave me a welfare officer - but she didn't help much. I did go to her with problems I had but she said there was nothing she could do. Certain staff in the hospital tried to get your money from you. I told people but it was just swept under the carpet. They never do listen to patients. The welfare officer just left me to get on with it. I had to fight to get a house of my own. I was put under pressure to go into a hostel by the welfare officer and hospital staff but I didn't want to. I fought for 18 months to get my own house. I applied to different places but Newtown came up within three months. The welfare officer didn't want me to take it but I wanted to get out and get away. She wanted me to wait for something better. I was glad to leave. I was ready to get out. I didn't want to stay any longer. '*

## **ADVOCACY**

It was striking that advocacy did not appear to play a large part in most people's lives, suggesting a significant gap in the range of support available. While advocates can support people in a range of ways, clearly their main purpose is to enable people to have a greater say in decisions affecting their lives. Simons (1993) identifies four types of advocacy - citizen advocacy, self-advocacy, class advocacy and professional advocacy. He defines citizen advocacy as:

*'the development of a supportive, one-to-one relationship between an unpaid private citizen and someone who is vulnerable or at risk of isolation, with the aim of offering some protection to the latter and help to achieve his or her personal goals' (p.3).*

In other words, citizen advocacy is one way of enabling those who may have difficulty speaking up for themselves to do so, and thus can be key to involvement in decision-making.

Two people who had advocates through a citizen advocacy scheme attended one of the focus groups. They described the advocates' activities as both instrumental (task-centred) and expressive (providing friendship and emotional support). One person commented 'I just know her - she is my friend. Me and my friend go out places. I don't see my social worker very often... she always seems to be very busy or not there when I phone, but Elena (advocate) is there and Elena helps me. ' Both individuals spoke highly about their advocate and clearly appreciated the fact that the latter were 'there' for them. No one else referred to having an advocate, although we did not ask about this systematically.

A small number of people reported being involved in self-advocacy. Simons (1992) notes that this term is used to denote a range of activities, including personal development or 'consciousness-raising'. He goes on:

*'more often it refers to the activities of groups of people with learning disabilities who have got together to voice their collective concerns. Self-advocacy is very much about people finding their own unique voice. The growth of a vibrant self-advocacy movement over the last decade has had a profound impact on services, and will doubtless become even more significant in the future.'* (p4).

People were involved in self-advocacy within resource centres, at college or through People First Scotland. Each felt they benefited as a result, through helping themselves, supporting each other, and 'speaking up for yourself', for example, about parents being overly restrictive or the right to work. One person thought that more self-advocacy groups should be developed, a point that is endorsed by guidelines to good practice in advocacy issued by The Scottish Office (1997), although these relate specifically to the NHS.

Finally it is worth re-iterating what has been implicit throughout this chapter, people want to be consulted more often and have greater involvement in decisions about how their needs are met. Returning for a moment to Fielder and Twitchin's continuum of participation, the findings here suggest that some services had not progressed beyond informing people what was to happen, while others did consult, although not always with tangible results. Only a minority of arrangements came near to partnership. One person spoke for many when she said 'other people choose for me. I would like to choose a bit more.'

## **CARERS' VIEWS**

A recurring theme in the carers' groups was anger and frustration that parents are not consulted or involved enough in decisions concerning their sons and daughters. Indeed some parents felt that at times they had not been consulted at all. As discussed in the previous chapters, parents often felt that their own valuable knowledge about their child and their expertise in responding to her needs was ignored by professionals. The following points from parents illustrate the point:

- No one comes to you to ask you what your child needs.
- The only people who'll take time to listen are other parents. Professionals don't take time – they are watching the clock.
- Parents should be more consulted and involved, and consulted about what works and what doesn't.
- (We want) services that listen to you – don't patronise or look down on you.
- Our daughter was assessed as having a mild learning disability. We're trying to get a case conference together. We're not convinced about diagnosis. She is getting worse, she's slipping but no one is hearing us.
- Top doctors decide how your life goes if you've got special needs. It depends who it is if children are listened to.

In the most worrying cases, parents believed that real damage may have occurred to their son or daughter as a result of professionals having excluded them from discussion. One mother had long thought that the medication prescribed for her son's epilepsy was not controlling his

seizures adequately but that the consultant did not listen her to. One day her son had a bad fall during a major seizure, resulting in brain damage and confining him to a wheelchair. His mother believed this outcome might not have occurred had her son's medication been changed, as she had requested. Several other parents had similar stories to tell.

However a minority of carers did feel they were involved in decisions about their child's needs as the following extract from a recording illustrates:

*'The community health nurses from the Health Centre are excellent. (The mother) heard about them through the school. She is visited at home and again it's on her own terms. She's asked if there's anything she wants or anything they can find out for her. She feels this is something you need and this should be promoted.'*

Some parents also felt strongly that many professionals did not listen to their sons and daughters, particularly while they were still children. They made a strong plea that both health and social care services should make the effort to listen to their children. However, as the latter became older, the situation could become more complex, with some signs of tension arising between parents wanting to be consulted and involved in decisions while their adult offspring wanted to assert their own independence. Although this was not stated explicitly, in some cases it seemed that as professionals sought to support individuals with learning disabilities to become more independent, parents consequently felt their views were becoming marginalised. One parent commented: ' They had a review at her centre. Cathy speaks up for herself. I wouldn't say I'm consulted and involved enough.'

Another issue for parents was that, in order to make their views heard, they often felt they were seen as 'pushy' - 'too aggressive, too demanding and only interested in your child'. The view was expressed that a parent would not be consulted about medical treatment if he were 'mousey'. This observation illustrates some people's view that to some extent it was up to them, and the 'persona' they projected, whether or not they were involved in decisions about meeting their relatives' needs.

Finally, it should be emphasised that a number of parents raised challenging questions about the present study. They questioned the point of it, suggesting that money could be better spent on direct service provision rather than further research. Carers wanted to know if the findings would be implemented, if the report would be published and whether or not they would receive a copy of it. Carers whose first language was not English stated that the full report, and not just a summary, should be made available in community languages. Despite the perceived lack of consultation, many carers were clearly weary of being asked their views and opinions about services and then finding that little or nothing had changed as a result.

## **CHAPTER NINE THE AVAILABILITY AND QUALITY OF HELP WITH COMMUNICATION**

### **INTRODUCTION**

The recent inspection of services to people with learning disabilities south of the border (SSI, 1998) heard criticisms about communication from 'almost all users and carers' (p4). Many people wanted better access to speech and language therapists.

The people with learning disabilities who took part in the focus groups used speech to communicate and many of them were very articulate individuals. Some were less so. The one to one interviews were conducted with people who used a range of communication aids, including an Alphatalker, an Orac, communication books, and Makaton. Family carers attending focus groups had relatives with a similar range of communication styles. One mother described her son's speech as 'perfect' while another reported that her daughter communicated with her eyes. However, the parent of one person with profound impairment made the very important point that although children are not listened to as they should be, 'they *can* communicate their points'.

### **THE IMPORTANCE OF TAKING TIME TO COMMUNICATE**

Good communication is vital to inclusion. As one mother said, 'It must be awful not being able to communicate'. (Here she was not suggesting that her child could not communicate, but commenting on the fact that the help she received learning Makaton had been withdrawn). Elsewhere, a father described his daughter's communication as 'very poor', adding 'it makes her very isolated - very different.' Some parents believed that attitudes had improved over recent years. In one focus group, there was unanimity that both GPs and nurses took time to communicate properly with people.

However, a number of parents felt strongly that professionals did not always take the time to listen to or converse with their sons or daughters. Again, a number of examples were given to make the point. One mother described how during a stay in hospital her son had not received any pain relief medication. When challenged on this, she was told by nursing staff that this was because "he hadn't asked for any." Another mother felt she needed to be with her daughter when she went into hospital because of communication problems. On one occasion, she reported, when her daughter had been feeling upset about something, staff had mistaken the signs of the girl's distress for symptoms of illness. As a result, the girl had been given tranquillisers, inappropriately in her mother's opinion. A parent elsewhere said of one respite unit that no one took time to understand how the children communicate. She said it was 'disgusting' that staff 'treat them like dummies'.

### **SPEECH AND LANGUAGE THERAPY**

Most help with communication is provided through speech and language therapy. There was strong feeling about this service. People whose relatives had difficulties with communication felt that speech therapy was absolutely vital. As Table 7.1 on page 42 shows, speech therapy was the health care professional seen most regularly after GPs, usually by children. Yet at the

same time, this service was frequently identified as difficult to access, with a strong feeling that there was not nearly enough available. In more than one group, family carers started laughing when speech therapy was mentioned, making comments like 'I thought they were extinct!'

It was reported that speech therapists saw certain children only four times in a year and carried out assessments with teachers in which parents were not involved. Parents felt that everyone would benefit if they were involved, since they could contribute to assessments and ensure that any therapeutic work taking place at school could be continued in the home. Strangely, having been told that there was no further service available, one parent was then informed by the Special Education Advice Line that, had communication needs been highlighted in the child's Record of Needs, the education authority would have been obliged to make more help available, if necessary, privately. This mother was angry that she had not been advised to put speech therapy into her child's Record and as a result her request had no legal standing.

Another mother met her daughter's speech and language therapist once a year when a review was due. She described the report as 'the same every year' because the therapist had never seen the girl. A little girl attending one of the children's focus groups was accompanied by her mother to help her communicate. Without the parent's help, the group facilitator would have found it very difficult to follow what the child was saying, although she was very keen to say her piece. She had not seen a speech and language therapist for nine months. A meeting of parents had recently been held at her school to discuss the pressing need for the service and to make representations to the authorities that more speech therapy should be made available. Another parent whose child did see a therapist at school reported that the latter was only able to spend five minutes with each pupil.

As we have seen in relation to many other services, parents often felt they had to agitate for support and, in some cases, make suggestions to professionals about what might help their particular child. One mother described speech therapy as 'parent led' - parents would make suggestions about ways to take things forward and the typical response was 'if you think it's helpful, do it'.

A couple of parents in different areas said children should receive help with communication before starting school, one mother noting that her son had come on 'leaps and bounds' since doing so. Prior to commencing school, his only means of communication had been body language.

It is important to stress that, although critical of the scarcity of speech therapy, and the effects of subsequent rationing on the quality of the service, virtually everyone believed it was important and useful. The six individuals who took part in the supported interviews were all in contact with speech and language therapists. All were happy with the quality of help received with communication and only one felt that she did not see her therapist often enough. They each liked their therapist and had a good relationship with her. Those who participated in focus groups said little about speech therapy although again one person said she would like more.

A number of issues arose in the supported interviews which could be read as examples of individuals who have communication difficulties being denied opportunities to communicate, or other people failing to communicate well with them. Several people mentioned that they

did not like staff at certain services they used but felt disempowered to do anything about it. Where there were aspects of their lives that they were unhappy about, they generally had not discussed these with people outside the family. While it may be that communication issues were a contributory factor to these situations, these findings correspond to those arising from the focus groups among people who did not have marked communication difficulties.

## **OTHER FORMS OF HELP**

Few other sources of support with communication were identified. One parent had made contact with the CALL Centre at Edinburgh University, which provides specialist advice and technological aids for children without speech. It was reported that people attending one resource centre were learning communication skills through producing their own magazine. Two people would have liked more help with reading and writing. One man had attended a community education literacy class but was not offered the level of one-to-one support he required. He had wanted to learn how to complete forms for the Benefits Office and was disappointed to find the focus of the class was on 'John Knox and Rabbin Burns'. Reading and writing skills play an important part, often taken for granted by those who possess them, in enabling people to take an active role in community life. The pleasure coming from acquiring such skills is evident in this lady's comment on the progress she was making in her literacy class; 'I like this class... I'm fair chuffed with myself'.

## **CHAPTER TEN THE EXTENT TO WHICH MAINSTREAM AND SPECIALIST SERVICES ARE AGE-APPROPRIATE AND NON-DISCRIMINATORY**

### **INTRODUCTION**

In Chapter 5, we examined the availability and accessibility of mainstream services. Here we consider the extent to which mainstream and specialist services were experienced as age-appropriate and non-discriminatory.

In this chapter, as elsewhere in the report, 'mainstream' refers to services that are - in theory at least - open to everyone, while 'specialist' refers to services designed for people with learning disabilities only. This is therefore a wider definition than that used by the SSI (1998) in which 'specialist' refers to 'special' groups of people with learning disabilities. The latter usage implies that services aimed at the general population of people with learning disabilities (such as resource centres or special schools) could legitimately be called 'mainstream'. This in turn suggests that ordinary services used by the general population are not expected to include people with learning disabilities. In addition, there were no examples of people using services for 'special groups', in the sense used by the SSI (e.g.: units for people with challenging behaviour or dual diagnoses) in this study. Only a very small minority of people receive such support: none of the focus groups was constructed around use of such a service.

### **AGE-APPROPRIATE SERVICES?**

#### **Treating people like children**

There were a few examples of services failing to treat people in an age-appropriate manner. For example, a woman aged 39 attended a club called 'Teddy Bears'. More often however this issue emerged in the way that people said they were spoken to or treated by members of staff. As noted at several points already, there were references to people 'getting a row', being 'bossed about', and being 'told' what to do. In a hospital setting, staff told one person to go to her bedroom when she became 'over-excited'. A woman in another focus group was very upset by the way a member of staff at a further education college had spoken to her just before she joined the group. The recording notes:

*'Morag was very upset. She complained that a woman called Janine treats her like she's three years old, she said she 'felt like dying'. It turned out that during a break (outside) Janine had told Morag not to stand on a slope.... Paula (another participant) started to reason that Janine 'is just worried that we'll hurt ourselves', to which Morag responded 'I am 19. I can look after myself.' She said 'people are too protective'.'*

Apart from these specific instances, on the basis of the findings reported in previous chapters, many services could be described as less than age appropriate in two ways. First, they did not enable people to exercise choice and control over their own lives and secondly they tended to perpetuate dependency, as opposed to fostering independence.

## **Parents' views**

Parents had different views about what was 'age-appropriate'. One carers' group discussed developments at a resource centre. One mother expressed anger that the centre had told her adult daughter she would be getting sex education, apparently as part of a group in the centre. The mother had refused to allow her to attend. This parent took the view that 'they still need looking after'. However another mother in the same group commended the centre for treating people as adults, recounting a story in which a young woman had benefited from sex education.

As we saw earlier in the report, many parents reported that their adult sons and daughters spent most of their leisure time within the family. The mother of a woman in her thirties reported that her daughter accompanied her to the Women's Guild every week, probably not a usual activity for someone of her age. A more worrying example, quoted earlier, of people being routed to services for older people arose when the only 'short break' offered to two middle-aged women was a nursing home.

## **NON-DISCRIMINATORY SERVICES?**

### **Perceived targeting**

A number of parents - but no people with learning disabilities- expressed the view that services were targeted at specific groups or individuals. While there were different views about who these groups might be, the underlying theme common to such perceptions was that services were targeted at people other than themselves and that this was inequitable. Sometimes these comments were expressed with a certain amount of disapproval, as if the people at whom services were aimed were less than deserving. Thus, it was variously suggested that only people in crisis, people who had put their relatives in an institution, those who could not cope, those without a diagnosis, those who were poor, people from minority ethnic backgrounds, people who abused their children, those who shout the loudest or play games or even those who were 'bad' were the fortunate recipients of support.

While it may be tempting to dismiss such claims, there may be some truth in them. Due to over-stretched resources, local authorities do have targeting policies and while these vary from area to area, the thrust of community care is clearly to target the 'most needy'. Several parents noted that they had not received help until they were in crisis and that if families gave the impression that they were coping, support would not be forthcoming. One mother resented the fact that because she was seen as 'respectable and middle class', she received no support. At the same time, although there were only six families from ethnic minority backgrounds, it was striking that they did not receive a high level of social work support, one actually avoiding doing so. Similarly, a parent who was unusual in the carers' focus groups as apparently coming from a disadvantaged background, had less support than most others.

### **Equity across Scotland**

It was also clear from the data that service provision across Scotland is unevenly distributed. Again it was not an aim of the research to carry out a comprehensive mapping of services. However, as already seen, some authorities were said to have only one, or no suitable, respite care service. A few areas have social work teams dedicated to working with families with

disabled children; most do not. Parents' experiences of the way in which hospitals treated their children varied tremendously. Different education authorities appeared to have different policies on inclusive education. While opportunities for supported living or citizen advocacy exist in some areas, in others they do not. There were also indications of variation within authorities, for example, regarding school transport policy.

## **Support for people from ethnic minority communities**

### *Linguistic and cultural requirements*

It has been argued elsewhere that support to people with learning disabilities from ethnic minority backgrounds is poor (Baxter et al. 1990, Azmi et al, 1997). The latter research, carried out with 21 South Asian young people in England, found that they had a positive sense of their ethnic and racial identity but experienced racism and stigma in all areas of their lives. Fifteen were attending some form of day service where they experienced a lack of appropriate cultural practices in relation to dietary, cultural and religious matters. The authors conclude that 'colour-blind' services are inappropriate, noting that providing vegetarian food or marking religious festivals should be readily achievable.

Three people with learning disabilities and six carers from minority ethnic (Asian and Chinese) backgrounds took part in this study, aided by interpreters. One family had three disabled children and another, two. The extent to which services took account of their linguistic needs varied, with education coming out well. Experiences of special schools were positive overall, with evidence that schools were making efforts to include the children. One boy in a mainstream primary school had an auxiliary helper who was bi-lingual. This was proving very beneficial and the parents could see a difference in their son as a result. The only concern was whether or not this support would continue. In addition, volunteer tutors, arranged through a voluntary organisation, visited one or two children at home. It was difficult for some of the mothers to help with homework because they did not understand English very well. Interpreters were provided in the schools when needed.

Health services received mixed reports. One mother felt that a 'language problem' between the family and their GP had resulted in a failure to diagnose her son's condition properly. The condition had deteriorated without proper treatment. The situation had only improved following the intervention of the school doctor. Although another mother was less than satisfied with her GP, this was not related to ethnic background, which they shared.

Most hospitals were said to provide interpreters as and when needed. When one unit did not do so, the mother wrote a letter of complaint and, despite receiving an apology, the same thing occurred on her next visit. There had been no interpreter present when this mother gave birth to her disabled child, leading to confusion about his diagnosis.

A woman from the Chinese community commented that the process of requesting an interpreter was so difficult that her family avoided doing so if at all possible. This meant they also avoided using services. They had tried to rely on asking for help from their GP but this was also difficult because they found it hard making themselves understood. Clearly there is a need for interpreting services to be more readily available to families.

An adult with learning disabilities observed that there was very little information about service provision in minority languages. She did not know what help was available.

Overall it seemed that people's cultural and religious requirements (as opposed to linguistic ones) were reasonably well met by services of all kinds. Schools were said to provide appropriate diets, although a man attending a Skillseekers Course, which involved going to college and a work placement, had found that at neither place was Chinese food provided. A problem for one mother was that a female GP was not always available when she took her child to the surgery, in which case they just had to see a male GP.

Despite some of the points made above, when asked if they had ever encountered racism in service provision, and if they thought they received the same sort of service as white families, carers found it hard to reply. Because of language difficulties, they had never discussed such matters with people outwith their own communities.

### *Relative isolation*

Families from minority ethnic backgrounds appeared to be relatively isolated. One mother described her son as lonely and needing someone to take him out. A 27 year old woman reported that she 'stays in the house a lot, watches TV and lies in a lot on her own'. She had no friends. Although one person had a social worker who visited regularly and was extremely helpful, the others had little or no such contact. Much of the support these families received had been arranged through a local voluntary organisation working with people with learning disabilities from ethnic minority communities. Prior to their involvement with this agency, these families had little support from any source. The agency concerned was a small and unusual one, in that it catered specifically for people with learning disabilities from minority ethnic backgrounds. It is likely that many other families remain isolated.

Lastly, it is worth stressing that these people's ambitions were very similar to those of white people with learning disabilities, as were their families' aspirations for them. One mother wanted:

*'more attention to what happens when (they) grow up, work, independence, employment for special children, their career more training and more like normal people.'*

For this reason, she was concerned that her son was not receiving any help to learn Chinese which would be necessary if he were to follow the family trade.

### **Discrimination on grounds of gender or sexuality**

There were no reports of any service discriminating against people on grounds of gender although we did not ask people about this explicitly. The data suggests that the type of opportunities available to men and women were similar, for example, both were offered college courses in cookery and housekeeping skills. It has been suggested elsewhere that boys are more likely than girls to receive respite care, perhaps because parents are more protective of the latter or want to foster independence in the former. While it would be wrong to conclude that services never discriminate on the grounds of gender, no one complained of it.

Nor were there any reports of discrimination against individuals because of sexual orientation, although again we did not ask about this explicitly.

## **Discrimination on grounds of disability**

However people did have experiences of being excluded from mainstream services on the ground of disability. Usually this took the form of services failing to be welcoming to people, failing to accommodate their difference in a way which would enable them to join in, or actively treating them in a different way from others. While it was not usually the case that people had been told they could not use a particular mainstream service, the practical arrangements or the attitudes conveyed sometimes made it difficult or impossible to do so. This was particularly true of some schools and of several social and recreational clubs, whether for children or adults. The story was told of an autistic boy who had been excluded from Cubs. He was not allowed to take his vow because the person in charge felt he would not understand its meaning and as a result he was unable to earn his badges, including ones which he could have done unaided. Finally he was not allowed to go on a trip because this was seen as 'inappropriate'. The boy had arrived at the club-house for the trip, found the rest had left without him and became very upset, banging on the doors to be let in. When younger, this child had been a member of the Boys' Brigade which had proved very successful. He was described as 'desperate' to get out of the house. Others in this group agreed that people's 'prejudice' or 'stereotypes' could prevent their relatives having ordinary lives.

Parents of children with profound impairment had found that even specialist services could discriminate against their children. Their experiences of respite care had been that children did not receive stimulation or the one to one attention they required. Chapter 5 has already touched on other forms of discrimination.

## **CHAPTER ELEVEN CONCLUSIONS AND IMPLICATIONS FOR FUTURE SERVICE DEVELOPMENT**

In this final chapter, we draw together the main findings of the study. One hundred and twenty-four people took part in the research, including 74 individuals with learning disabilities - 58 adults and 16 children. There were 41 family carers, and nine parents who came to focus groups with their children. Here we summarise what people with learning disabilities and their families thought of current service provision, and the ways in which they would like to be supported in the future. Some implications for future service development are drawn out.

### **THE CURRENT PICTURE**

The current findings need to be placed in the context of the significant change and improvement which has taken place in the last twenty years or so in terms of supporting people with learning disabilities. Such positive changes were illustrated in the opening vignettes. Nevertheless, the overall picture to emerge was one of people living in the community but remaining socially isolated, with few friends outside their family and the service system. Most people were bored with the activities - or sometimes the lack of constructive activity - on offer in day centres. However, they valued the arrangements now in place at most centres for people to undertake some form of work or to attend college. Everyone made some use of community facilities but this was often as part of a group or with a staff member. There was a lack of inclusive social and recreational opportunities for people of all ages.

There were some notable exceptions to this general pattern. A few individuals had well-developed social networks, including several who lived in small towns where they were well known. Some enjoyed 'doing their own thing' or going out with a particular friend. Two had full-time 'ordinary' jobs at the going rate, and one had also been to a mainstream college. It was striking that through these inclusive experiences both individuals were very much part of the mainstream. A small number had supported living arrangements which enabled them to exercise a high level of choice and control over their lives. We were aware of only one participant living with a partner and one being a parent.

All those receiving short-term (respite) care spoke positively about it. Sometimes this gave people the opportunity to do things they would not otherwise do at home. However, this again was sometimes in large groups. People who had befrienders or who could employ personal assistants through ILF monies were enthusiastic about these because they provided a means of one-to-one involvement in age-appropriate activities of their own choosing. Carers also valued these links.

A continuum of involvement in decision-making was identified, ranging from people merely being informed that a decision had been made on their behalf through to individuals being actively consulted and seeing their views and wishes put into effect. However it was a common experience for people to be told what to do, sometimes by 'bossy' members of staff, or to have expressed views which were apparently not 'heard'.

Two major issues emerged from the consultation with carers - information about service provision is very hard to come by and it is a constant struggle to secure the right support.

Parents often felt their own knowledge and expertise was ignored by professionals, who did not always see beyond the labels and stereotypes attached to children with learning disabilities. Carers reported gaps in particular services, especially short-term care, social activities and speech and language therapy. There was a sense of inequity in provision across Scotland, both between and within authorities, with the standard of service received often depending on the individual professional. The needs of siblings were often over-looked.

## **BARRIERS TO BE OVERCOME**

The social model of disability (Oliver, 1990, Shakespeare and Watson, 1997) defines disability in terms of the material, social and attitudinal barriers which disable people, rather than individual impairment or 'dysfunction'. Throughout this report, reference has been made to a number of barriers preventing people from realising many of the wishes and ambitions listed above. These barriers were:

- \_ unhelpful, negative and sometimes hostile attitudes on the part of non-disabled children and adults, including professionals;
- \_ social security regulations preventing people from working as much as they wanted - the 'benefits trap';
- \_ the failure of many mainstream services and facilities to accommodate difference in a positive way;
- \_ various aspects of transport policies.

## **HOW PEOPLE WOULD LIKE TO BE SUPPORTED IN FUTURE**

People with learning disabilities had very ordinary aspirations. Many wanted to have more friends and particularly someone to go out with. There is a need for more people to act as bridges into opportunities that are already out there, that do exist, but which people are currently unable to access. Ways to do so might include developing more befriending schemes, ensuring that those who may be eligible for ILF funding are supported in applying for it, and exploring the potential for a wider use of the Community Care (Direct Payments) Act.

Many people wanted something interesting to do during the day, to work or to work for longer hours than at present. To meet these ambitions, a range of initiatives could be developed such as co-operatives, social firms and more supported employment schemes. Simons (1998) sets out a number of constructive suggestions for how the thorny and complex issues surrounding restrictive social security regulations might be tackled.

A few people wanted their own home and several, particularly younger participants, wished for more freedom and independence. Many wanted to exercise more choice and control over their lives and have greater involvement in decisions affecting them. Only two people in the study were known to have citizen advocates but each was very positive about these relationships, suggesting that more people would benefit from having citizen advocates. Overall, most people did not choose to talk about what kind of services they wanted in the future, but rather about opening up access to the same kind of opportunities as everyone else.

If inclusion is to become a reality, it is vitally important that services recognise the importance of people's ordinary aspirations - their need to have lives similar to anyone else's - and find ways to respond to them. This involves enabling people to have responsibilities and develop reciprocal relationships with others, rather than being the passive recipients of care.

The findings underline how important it is that mainstream services acknowledge and accommodate difference in a positive way, by providing the right kind of support tailored to individual need. One participant said that services must become more 'person-centred', meaning they should offer personalised support around individual choice and need, and not be tied to buildings or specific services

A priority for most carers was that their children lead lives as similar as possible to that of non-disabled children. More play provision is required - which children also identified as wanting for themselves - after school and in the holidays. It was important to parents that professionals should listen to their children. Children in Scotland (Griffiths et al, 1998) have produced a training manual aimed at helping professionals involve disabled children and young people in decision-making. This may be a useful resource for statutory and voluntary agencies.

Several parents called for more respite services. In responding to this need, it is important that models of support which keep people in segregated settings are not reproduced. There are many ways of providing short breaks for adults and children which offer them an enjoyable and stimulating experience, as well as giving parents a rest. These include one to one leisure opportunities, lasting from a few hours up to weekend or holiday breaks, co-operative sitting arrangements, summer camps, inclusive playschemes and 'special child-minders' (See Robinson, 1986).

To meet the need for better information dissemination, one parent suggested that a national information and advice agency be set up. If people are to make informed choices, they will require information about a whole range of options, including new and innovative models of support. Families from ethnic minority backgrounds called for information to be available in community languages.

While some people were receiving good support from their local social work department, overall the level of input was low. Many parents and some service users expressed the need for greater assistance and in some cases better information about the ways in which local authorities could help them. Social work departments might begin by ensuring that all those eligible for formal assessments are offered one. People also wanted more tangible outcomes from social work and health assessments, an objective already identified by The Scottish Office (1998) for community care generally. Several parents would like to see more support being made available to their non-disabled children, whose needs could also be addressed through holistic family assessment.

Some carers identified a need for better inter-agency collaboration, for more efficient exchange of information between organisations and for more constructive partnerships between professionals and carers, in which the latter's knowledge and expertise is drawn on. They would like to see this being a continuous and integral feature of service planning and delivery rather than an occasional 'add-on'.

As sons and daughters became older, again some parents wanted them to have the same opportunities as others, with recognition of people as individuals in their own right. For other parents the main priority was security: the need for long-term planning, especially for a time when parents would no longer be around, was a concern for several.

The crucial role played by other people's attitudes in affecting the quality of individual lives has been a recurring theme in the research. This finding indicates a need for a public education exercise to help foster awareness and understanding of disability issues generally.

It should be pointed out that the implications of the study's various findings vary considerably in terms of the costs and timescales associated with addressing them. For example, changing the attitudes of bus-drivers may not be expensive but could take a long time, while meeting unmet needs for respite services could be costly in the short term.

We close by returning to where this report began. The two men whose stories appear in Chapter 2 are leading active and generally fulfilling lives. One lives alone, the other with his partner. One has a full-time job and a reasonable income; the other would like this. Both have a low level of support from a local voluntary organisation. Each has lived through and had personal experience of the major developments and improvements which have taken place in services to people with learning disabilities over recent years. Sadly, their present situations are atypical. The rest of this report has shown that most people are still confined to segregated settings for many of their domestic, occupational and leisure activities. Scotland has a long way to go before people with learning disabilities are truly part of the mainstream.

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**ANNEX 1: THE PEN PROFILE PROFORMAS**

**QUESTIONS TO GET READY FOR THE FOCUS GROUP: CHILDREN**

**WHAT IS YOUR NAME?**

**WHERE DO YOU LIVE? (please tick one box)**

I live with my family

I live somewhere else

If you live somewhere else, please tell us where you live-  
.....

**WHICH SCHOOL DO YOU GO TO?**  
.....

**WHAT DO YOU USUALLY DO IN THE EVENING?**  
In the evenings I usually go to .....  
.....

I usually go there with .....

**WHAT DO YOU USUALLY DO AT THE WEEKEND?**  
On Saturday and Sunday I usually go to  
.....  
.....

I usually go there with .....  
.....

THANK YOU FOR TAKING THE TIME TO FILL IN THIS FORM. WE WILL HAVE A CHANCE TO DISCUSS IT AT THE FOCUS GROUP MEETING.

**QUESTIONS TO GET READY FOR THE FOCUS GROUP**  
**ADULTS**

**WHAT IS YOUR NAME?**

**HOW OLD ARE YOU?**

**WHERE DO YOU LIVE? (please tick one box)**

- I live in a community house with other people with learning difficulties       I live with my family
- I live in hospital       I live alone
- I live somewhere else

If you live somewhere else, please tell us where you live-  
 .....

**WHAT DO YOU DO DURING THE WEEK?**

	Morning	Afternoon
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		

**WHAT DO YOU USUALLY DO IN THE EVENING?**

In the evenings I usually go to .....

.....

I usually go there with .....

.....

**WHAT DO YOU USUALLY DO AT THE WEEKEND?**

On Saturday and Sunday I usually go to

.....

.....

I usually go there with .....

.....

**DO YOU SEE ANY OF THESE PEOPLE ON A REGULAR BASIS (AT LEAST ONCE A MONTH) ?**

Family doctor or GP

Social Worker

Community Nurse

CPN

Physiotherapist

Speech Therapist

Dietician

Occupational Therapist

**HAVE YOU EVER MET ANY OF THESE PEOPLE?**

A housing officer

A benefits adviser

A careers officer

A Disability Employment Adviser (DEA)

THANK YOU FOR TAKING THE TIME TO FILL IN THIS FORM. WE WILL HAVE A CHANCE TO DISCUSS IT AT THE FOCUS GROUP MEETING.

**QUESTIONS FOR CARERS/FAMILY MEMBERS ATTENDING THE FOCUS GROUP**

**WHAT IS YOUR NAME?**

**WHERE DOES YOUR RELATIVE LIVE? (please tick one box)**

In a community house with other people with learning difficulties       With his/her family

In a hospital       He/she lives alone

He/she lives somewhere else

If your relative lives somewhere else, please tell us where they live-

.....  
 .....

**WHAT DOES YOUR RELATIVE DO DURING THE WEEK?**

	Morning	Afternoon
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		

**WHAT DOES YOUR RELATIVE USUALLY DO IN THE EVENING?**

In the evenings he/she usually goes to .....

.....

He/she usually goes there with .....

.....

**WHAT DOES YOUR RELATIVE USUALLY DO AT THE WEEKEND?**

On Saturday and Sunday he/she usually goes to .....

.....

He/she usually goes there with

.....

.....

**DOES YOUR RELATIVE SEE ANY OF THESE PEOPLE ON A REGULAR BASIS  
(AT LEAST ONCE A MONTH) ?**

Family doctor or GP

Social Worker

Community Nurse

CPN

Physiotherapist

Speech Therapist

Dietician

Occupational Therapist

**HAS YOUR RELATIVE HAD ANY CONTACT WITH ANY OF THE FOLLOWING PEOPLE?**

A housing officer

A benefits adviser

A careers officer

A Disability Employment Adviser (DEA)

THANK YOU FOR TAKING THE TIME TO FILL IN THIS FORM. WE WILL HAVE A CHANCE TO DISCUSS IT AT THE FOCUS GROUP MEETING.

## **ANNEX 2: TOPIC GUIDES USED IN FOCUS GROUPS**

### **CONSULTATION WITH USERS AND CARERS: INTRODUCTIONS AND ICEBREAKERS**

#### **For adults with learning difficulties**

*Facilitators begin by introducing themselves*

Explain that the government is looking into services that people get to help them in their lives. The government wants to find out if they are any good and if they should make any changes in them. So they have asked us to go round Scotland talking to a lot of different people to see what they think of the services they are using. Reassure people about confidentiality and no comeback if people say they don't like something about services. No right/wrong answers - just want to hear what people think about the support they get. Any questions?

Then do an icebreaker. e.g.: talk to your neighbour for a couple of minutes to find out:

- their name;
- who they live with;
- what they like doing at the weekend.

Facilitators join in with this. Each person then tells the group about themselves.

Then show the video.

#### **Parents/ carers groups**

Suggest facilitators introduce themselves, say something briefly about SHS.

Ask participants to introduce themselves and say something briefly about their relative.

Facilitators then say something about the Scottish Office review and the importance of hearing parents'/carers' views. Thank people for giving up their time to talk to us. Ask if any queries at this stage.

Then go on to topics.

#### **Children's groups**

1: Thank the children for coming. Say there will be a mixture of games, drawings and asking you some questions about yourselves, your school. My name's ....but I don't know your names so we're going to make up badges with our names on....(give out star badges, felt tips, glitter etc). When badges are made, get children to wear them and call out their names.

# CONSULTATION WITH USERS AND CARERS

## TOPIC GUIDE 1: PARENTS OF PRE-SCHOOL CHILDREN

### **Recognition + assessment of social needs**

How good are social work services at picking up on children's needs?  
How well have these needs been met so far?  
Have families been asked for their views on needs and how to meet them?  
Have family carers been offered a Carers' Assessment in their own right?

### **Experiences of health services**

How good are health services at picking up children's health care needs?  
How well have these needs been met so far?  
How far have families been consulted and involved in decisions about health care?

### **Help with communication**

Do their children need help with communication?  
If so - what support has been offered?  
From whom?  
How helpful?  
Support from other sources: e.g.: voluntary sector

### **Quality of information available**

How easy has it been to get hold of information about  
- child's diagnosis and condition?  
- supports available?

### **Mainstream versus specialist services**

Have children been offered mainstream or 'specialist' services? (e.g.: do they attend inclusive playgroups/nurseries?)  
What do parents see as the strengths and weaknesses of these? (i.e. the fact that some services may be 'segregated')

*What recommendations would they make to The Scottish Office for future services?*

## CONSULTATION WITH USERS AND CARERS

### TOPIC GUIDE 2: SCHOOL AGE CHILDREN (DESIGNED FOR YOUNGER KIDS: ADAPT FOR OLDER ONES)

*(NB: need to take drawing pad, pens, picture cards and spidergrams)*

**1: Thank the children for coming.** Mixture of games, drawings and asking you some questions about yourselves, your school. My name's ....but I don't know your names so we're going to make up badges with our names on....(give out star badges, felt tips, glitter etc). When badges are made, get children to wear them and call out their names.

#### **2: Now I want to find out what you all like doing...**

*Show children the picture cards with 'I like' activities*

Do you like doing any of these things?

What are your favourite things to do?

Who do you do that with?

#### **3: School**

*Ask children to fill in a spidergram : to fill in some boxes showing what they like about school in one colour and what they don't like in another colour.*

*Questions to ask as prompts if they get stuck:*

What's your teacher like?

Have you got any special friends?

Have a little chat about as a group about some of the good/bad things.

#### **4: 15 minute break**

#### **5: Services and support**

Sometimes children get help from people outside the family.

*Show children, one by one, cards with pictures of services/professionals and ask some of the following questions as appropriate*

Has anyone ever had a social worker? (refer to pen profiles for prompts if necessary)"your Mum told me that Ann comes to see you"

What does she talk to you about?

Does she ask you what you would like to do/ what you think about things?

*OR (for a buildings based service)*

have you ever been to a hospital? what happened there?

What was it like in hospital?

*Cards are of social worker/ doctor / hospital/ respite care unit/ link family/ club*

Is there anyone else who helps you with things?

#### **6: If you had a magic wand and you could make a wish, what would it be?**

## **USERS AND CARERS' CONSULTATION**

### **TOPIC GUIDE 3: PARENTS OF SCHOOL AGE CHILDREN**

#### **Recognition + assessment of social needs**

How good are social work services at picking up on children's needs?  
How well have these needs been met so far?  
Have families been asked for their views on needs and how to meet them?  
Have family carers been offered a Carers' Assessment in their own right?

#### **Recognition and assessment of health care needs**

How good are health services at picking up children's health care needs?  
How well have these needs been met so far?  
Have families been consulted and involved in decisions about health care?

#### **Help with communication**

Do their children need help with communication?  
If so - what support has been offered?  
From whom?  
How helpful?

*Support from other sources:* e.g.: voluntary sector

#### **Mainstream versus specialist services**

Have children been offered mainstream or 'specialist services? (e.g.: do they attend inclusive playgroups/nurseries?)  
What do parents see as the strengths and weaknesses of these? (i.e. the fact that some services may be 'segregated')

*What recommendations would they make to The Scottish Office for future services?*

## **USERS AND CARERS' CONSULTATION**

### **TOPIC GUIDE 4: TEENAGERS AND YOUNG ADULTS**

#### **Community participation**

You've already filled in these sheets of paper telling us what you do during the day (if this info is not available, facilitators will need to ask people what they do/where/who with?)

What's it like going to (college etc)? do you enjoy it?

What are the best things about it?

What are the worst things?

Are there other things you would like to do?

Barriers to doing these things?

Ask similar questions about what people do in evenings and weekends. Try to focus on how inclusive the activities are and what people's views of them are.

e.g.; those at college - do they get a chance to meet other students? would they like to spend more time with other students?

What supports/services are they using? (consult proformas)

What has been most helpful?

What has been the least help/not very helpful?

#### **Consultation and involvement in decision-making**

Do they have enough say in their lives?

Are there any things in their lives that they would like to change?

If so, have they told anybody?

What would they like to do in the future? (college, work, relationships, where to live)

Has anyone asked them what they want to do in the future? (if possible, ask if they have had a Community care assessment or similar - was it helpful?)

What sort of support might they need to help them do what they want in the future?

*What should the government do to make things better for people with learning difficulties?*

## **CONSULTATION WITH USERS AND CARERS**

### **TOPIC GUIDE 5: PEOPLE LIVING IN A LOCAL AUTHORITY GROUP HOME**

#### **Quality of life in the home**

What's it like living in (name of home)?

What are the best things about it?

What are the worst things about it?

If you took over the manager's job and it was your job to run (the home), what changes would you make?

#### **Consultation and involvement in decision-making**

Who decided that you would come and live here?

How does it compare with other places people have lived?

Does the home have a residents' committee?

If so, what does it do?

Are residents asked what they think about the way the home should be run?

Do the staff do what the residents suggest?

What sort of things do the residents choose for themselves in (the home)?

(e.g.: time to get up, what to eat, keyworker, staff recruitment, new residents)

#### **Participation in community life**

Evening activities: are these in the home/outside?

are they with other residents? or other people?

Do visitors come to the home? (who?)

Do they know their neighbours? (how well? do they visit neighbours or do neighbours visit them?)

use of local facilities - eg: shops, pub, cinema, church etc., and who with

# **CONSULTATION WITH USERS AND CARERS**

## **TOPIC GUIDE 6: PEOPLE LIVING WITH FAMILY RELATIVES**

### **Living with family**

What's it like living with your family?  
What are the best things about it?  
Are there any things that are not so good?

### **Consultation and decision-making**

How much choice do people have about where they live?  
Is there anywhere else they would like to live?  
If so - have they discussed this with anyone?  
Who makes choices at home? eg- when they get up, what they eat, what they do at weekends.

### **Community participation**

Daytime activities - how much time spent at home - elsewhere/doing things with family or others  
Evenings and weekends - how much time spent at home/elsewhere?/doing Things with family or others? (consult proformas)  
Their views on this - how satisfactory?

### **Recognition and assessment of needs**

Experience of social workers - how helpful?  
What is the most helpful support they have or have had?  
What has been the least helpful?  
Experiences of family doctors  
Do they get enough support in their lives?  
If not, what would they like more support with?  
Anyone ever feel they get more support than they need?

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 7: PEOPLE LIVING ON THEIR OWN WITHOUT FORMAL SUPPORT**

**Reasons why people are not using social work services** (eg: resource centres, social worker)

**Have people used social work services in the past?**

*If so - how helpful were they?*

good/bad experiences

Do services help people become part of their community?

experience of using health services - how helpful?

good/bad experiences

what are the good things about not using services?

Do people ever feel under pressure to use services?

Do people know where /what support is available if they wanted it?

Do people have other forms of support outside services?

What should the government do in the future?

– to make services better

– to support people with learning difficulties have a better life?

Any other comments?

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 8: PEOPLE IN SUPPORTED LIVING**

#### **Choice and decision-making**

How did you come to live in your present home?  
What's it like living there?  
What are the best things about it?  
Are there any things that are not so good?  
Is there anything you would like to be different?  
Who decides what happens in your home?  
eg: when you get up  
What you eat  
Who else lives there?  
Do you have any choice about the staff who live there?  
Has your life changed in any way since you came to live here?  
How does it compare with other places you've lived?

#### **Daytime Activities (see proforma)**

What do you do during the day?  
How happy are you doing that?  
Would you like to do anything different?  
What do you do at evenings/weekends?  
How happy are you about that?  
Would you like to do anything different?

#### **Support generally**

Do you get enough support in your life?  
If no, what would you like more support with?  
Do you ever feel you have too much support?  
Any other comments?

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 9: FAMILY CARERS OF PEOPLE WITH PROFOUND IMPAIRMENT**

#### **Community participation**

Extent to which individual is part of 'the community'

- any barriers to inclusion

What activities are they involved in (see proformas)

relationships with people outside family

How far do formal services help or hinder community participation?

#### **Recognition + assessment of social needs**

How good are social work services at picking up on people's needs?

Experiences of social work/community care assessment - have people had a community care assessment?

Any comments on this process: how helpful?

Were relatives and the individual asked for their views on needs and how to meet them?

Have family carers been offered a Carer's Assessment in their own right?

#### **Help with communication**

Do their relatives need help with communication?

If so - what support has been offered?

From whom?

How helpful?

How good are professionals generally at communicating with the individual?

#### **Experiences of health services**

How good are health services at picking up the individuals' health care needs?

How well have these needs been met?

How far have individuals and their families been consulted and involved in decisions about health care?

*What recommendations would people make to The Scottish Office about future services?*

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 10: PEOPLE USING ADVOCACY SCHEMES**

Why did you become involved in the advocacy scheme?  
Whose idea was it that you should have an advocate?  
What does your advocate do?  
Does the advocate ask you what you think about things?  
Has having an advocate helped you in any way?  
What are the best thing about having an advocate?  
Are there any things that are not so good about having an advocate?  
What does your family think about you having an advocate?  
What do staff people (social worker/ resource centre) think about it?  
If you were running the advocacy project, would you do anything differently?

#### **Community participation**

You've already filled in these sheets of paper telling us what you do during the day (if this info is not available, facilitators will need to ask people what they do/where/who with?)

What is that like/do you enjoy it?  
Are there other things they would like to do?  
If so - have they talked to advocate about it?

Ask similar questions about what people do in evenings and weekends. Try to focus on how inclusive the activities are and what people's views of them are.

Do people have enough say in their lives?  
Are there any things in their lives they would like to change?

What should the government do to make things better for people using services?

## USER AND CARER CONSULTATION

### TOPIC GUIDE 11: PEOPLE IN SUPPORTED EMPLOYMENT

(Check we have details of people's work on proformas)

How did you get your present job?

How long have you been there?

What's it like having a job?

What are the best things about it?

Are there any not so good things (eg: lost any benefits, under more pressure)

What are the other people at work like?

Have you made any new friends there?

(if so) Do you ever see them outside work?

What does your family think about you having a job?

Do you need any support to do your job?

If so, who supports you? (job coach, colleague at work?)

Do you get enough support?

Do you ever feel you get too much support?

Would you like to change anything about your job?

Have you had other paid jobs before?

If so - what were they like?

Have you ever been to a resource centre or a day centre?

If so, what was it like compared with having a job?

Do you want to carry on working?

If not, what would you rather do?

What should the government do to help more people with learning difficulties get jobs?

## **USER AND CARER CONSULTATION:**

### **TOPIC GUIDE 12: RESIDENTS OF LONG-STAY NHS UNITS**

**Where you live:** (check we have details on proformas)

What's it like where you live?

Who else lives there?

How do you get on with them?

Do you have a bedroom to yourself?

Who decides things in (name of unit)

When you get up

What you have to eat?

Were you asked if you wanted to live there?

What are the staff like?

How do you get on with them?

Would you like to go on living in (name of unit)?

Have you ever thought about going to live somewhere else?

If so, where would you rather live?

Have you talked to anyone about that?

You've already filled in these sheets of paper telling us what you do during the day (if this info is not available, facilitators will need to ask people what they do/where/who with?)

What is that like/do you enjoy it?

Are there other things they would like to do?

If so, have you told anyone about that?

What do you do at weekends? (as above)

(try to focus on how inclusive these activities are and their views of them)

What do you do in the evenings? (as above)

Is there anything in your life that you would like to be different?

## **USER AND CARERS CONSULTATION**

### **TOPIC GUIDE 13: FAMILY CARERS OF ADULTS WITH LEARNING DISABILITIES**

#### **Community participation**

Extent to which individual is part of 'the community'  
- any barriers to inclusion  
What activities are they involved in (see proformas)  
Relationships with people outside family  
How far do formal services help or hinder community participation?

#### **Recognition + assessment of social needs**

How good are social work services at picking up on people's needs?  
Experiences of social work/community care assessment - have people had a community care assessment?  
Any comments on this process: how helpful?  
Were relatives and the individual asked for their views on needs and how to meet them?  
Have relatives been offered a carers' assessment in their own right?

#### **Help with communication**

Do their relatives need help with communication?  
If so - what support has been offered?  
From whom?  
How helpful?  
How good are professionals generally at communicating with the individual?

#### **Experiences of health services**

How good are health services at picking up the individuals' health care needs?  
How well have these needs been met?  
How far have individuals and their families been consulted and involved in decisions about health care?

*What recommendations would people make to The Scottish Office about future services?*

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 14: PEOPLE WITH LEARNING DIFFICULTIES FROM MINORITY ETHNIC GROUPS**

You've already filled in these sheets of paper telling us what you do during the day (if this info is not available, facilitators will need to ask people what they do/where/who with?)

What's it like going to ....?

What are the best things about it?

What are the worst things?

Are you able to do things the same way at the day centre/the respite care home? as you do at home? (eg: same kind of food, a time and place to say prayers)

If not - have you talked to anyone about this? (staff, family)

Do the staff in the day centre/respite home speak your language?

If not, how do you get on talking to each other?

Are there other things you would like to do during the day?

#### **Community participation**

What do you do in the evenings and weekends? (see proformas)

-try to focus on how inclusive these activities are and people's views of them: are there other things they would rather be doing?

#### **Consultation and involvement in decision-making**

Do they have enough say in their lives?

Are there any things in their lives that they would like to change?

If so, have they told anybody?

What should the government do to make things better for black people with learning difficulties?

## **CONSULTATION WITH USERS AND CARERS**

### **TOPIC GUIDE 15: RELATIVES OF PEOPLE WITH LEARNING DIFFICULTIES FROM MINORITY ETHNIC GROUPS**

#### **Recognition + assessment of social needs**

How good are social work services at picking up on people's needs?

Experiences of social work/community care assessment - have people had a community care assessment?

How aware are services of families' cultural requirements (eg: dietary, personal care, religious needs)

How good are they at meeting these needs?

Have relatives been offered a carers' assessment in their own right?

#### **Experiences of health services**

How good are health services at picking up individuals' health care needs?

How far have individuals and their families been consulted and involved in decisions about health care?

How aware are health services of families' cultural/religious requirements?

How good are they at meeting these needs? (any examples of good/bad practice?)

#### **Where English is not first language, what support has been offered (by services generally)?**

To child/to family?

How helpful?

How good are professionals generally at communicating with the family?

Overall, do families feel they receive the same sort of quality of services as other families?

Have they come across any racism in services?

If so, of what kind?

*What recommendations would they make to The Scottish Office for future services?*

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 16: PEOPLE USING SHORT-TERM RESPITE SERVICES**

Check which short-term care services people are using (should be on proformas)

What's it like going to....?

When do you go there? weekends/evenings, holidays etc.

What do you do there?

Who with?

Were you asked if you wanted to go to...?

Why do you go there?(i.e. what is their understanding of the reason?)

What are the best things about going there?

What are the worst things?

Do you do anything at (name of place) that you don't get to do at home?

Do you miss out on anything at home when you go to (name of place/family)

Would you like to go anywhere different for a break?

If so, where?

Are there other things you would rather do at the weekends (or whenever they go)?

If so, what?

Have you been anywhere else for a break?

If so, where ?

What was that like?

Was it better or worse than where you go now?

Any other comments about the breaks?

What should the government do to make things better for people using services?

## **USER AND CARER CONSULTATION**

### **TOPIC GUIDE 17: PEOPLE ATTENDING A RESOURCE CENTRE**

#### **Community participation**

What do you do at the centre?

What it's like going to the centre?

Are there interesting things to do here?

Do you ever feel bored?

What are the best things about it?

What are the worst things?

Do you come to the centre every day?

If not, where else do you go?

(College, work experience, paid/voluntary work: see proformas)

Are there other things they would like to do?

Barriers to doing these things?

Ask similar questions about what people do in evenings and weekends. Try to focus on how inclusive the activities are and what people's views of them are.

#### **Consultation and involvement in decision-making**

Do they have enough say in their lives?

Who decides - what they do during the day/ weekend?

Does anyone ask them what they would like to do ? if so, who?

Are there any things in their lives that they would like to change?

If so, have they told anybody?

What supports/services are they using? (consult proformas)

What has been most helpful?

What has been the least help/not very helpful?

*What should the government do to make things better for people with learning difficulties?*

# **USER AND CARER CONSULTATION**

## **TOPIC GUIDE 18: OLDER PEOPLE**

### **Community participation**

What do you do during the day?

(See proformas - try to focus on extent activities are inclusive and people's views of them)

What are the best things about (coming to the centre/ whatever else they do)?

What are the worst things?

Are there enough interesting things for people of your age to do?

Are there other things they would like to do?

Do you enjoy spending time with people the same sort of age as you?

Would you rather spend time with people of all different ages?

Ask similar questions about what people do in evenings and weekends.

### **Consultation and involvement in decision-making**

Do they have enough say in their lives?

Who decides - what they do during the day/ weekend?

Does anyone ask them what they would like to do? if so, who?

Are there any things in their lives that they would like to change?

If so, have they told anybody?

What would you like to do when you retire?

What should the government do to make things better for older people with learning difficulties?