



# Make my day!

*The same as you?*  
**National Implementation Group**

**Report of the Day Services Sub Group**



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scotland**  
SCOTTISH EXECUTIVE

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***The same as you?***

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# Foreword

I was very pleased, as someone with learning disabilities, to be asked to co-chair this working group.

The Day Services Sub Group was set up to look at how day services in Scotland are putting the recommendations of *The same as you?* (SAY) into practice.

We did this by putting out questionnaires to each local authority, to service users and carers. We analysed the information we got back, picking out the key themes which you will read more about in this report.

Having been a member of other SAY working groups, I have to say that this one, on day services, has been more complex than some.

Historically there has been little overall agreement about what day services are actually for and what they are supposed to achieve. Some people with learning disabilities I know feel that day centres have been, at least partly, places to go through the day just to pass the time so our parents and family carers get a break and know that we are 'safe'.

I went to day centre for 8-9 years and for most of that time it was mostly the same routine week after week and at times I felt that I wasn't listened to. I didn't realise it could be any different until I got involved with People First (Scotland) and then got the offer of a part-time job with proper wages in a college where I taught self-advocacy to young students with learning disabilities who were in the same position as I was when I attended a day centre.

I am really pleased to see that day services are now changing for a greater number of people with learning disabilities across Scotland. Key themes are emerging. Service users are being listened to more than in the past. People are becoming more involved in their local communities. Services are becoming more flexible. More people with learning disabilities are getting jobs and more people are getting the opportunity to go to college.

However, some people who are going to college still feel that they are not getting the opportunity to gain the skills and knowledge they need to get jobs. Services need to make sure that they continue to listen to what people with learning disabilities really want and need so they can take their places in their communities where they rightfully belong.

It is clear that there has been a major positive shift in some places and we look forward to seeing other areas build on these positive examples. Let us keep up the good work.

Finally I would just like to thank everybody for their contributions to this piece of work which wouldn't have been possible without the co-operation of the local authorities, the independent sector, users and carers and the hard work of my Sub Group colleagues.

**Steven Robertson, People First (Scotland)**

# Introduction

*The same as you?* review of services for people with learning disabilities was published in 2000. It set out a 10-year programme of change that would support children and adults with learning disabilities and Autism Spectrum Disorders (including Asperger's Syndrome) to lead full lives, giving them choice about where they live and what they do. People with learning disabilities and family carers were involved at all stages of the review and their experience of life with learning disabilities shaped the vision for the future.

Day services have played an important role for people with learning disabilities and their family carers. *The same as you?* (SAY) recognises the importance of these services but also recognises that people were not getting opportunities to express what they wanted to do, many spent years attending a day centre without ever being formally assessed.

*The same as you?* said that the following should happen in respect of day services:

*'The role of day centres should change. They should increasingly become resource centres, offering only some in-house activities and support. They need to use more community resources and help people with learning disabilities get continuing education and development, real jobs, and more involved in sport and leisure activities. Community education also has an important part to play. Local authorities are currently drawing up their first community learning plans which have to include the needs of people with learning disabilities. Nobody should go to a day centre fulltime, but they could use it as a base to identify and go to activities in the wider community. In some areas day activities can come to the person (for example one-to-one outreach), or to a group.*

*'Local authorities will want to give particular care and attention to how day opportunities can meet the needs of people with multiple and profound disabilities or those who may not be able to benefit from employment or continuing education. Opportunities will vary from person to person but need to focus on personal and social development. Services will need to be available for people with specific and other health needs. Good day opportunities are particularly valuable to people who have challenging behaviour. Organisations will need to provide appropriate staff training to support these changes.*



*'Local authorities need to review their day care services. In doing so, they will want to be sensitive to the anxieties and views of users and carers so that they help the person with disabilities and prevent family breakdown. Good personal planning for the person with learning disabilities will take full account of the needs of their carer.'*

*(The same as you? 2000, pp. 56-7)*

The main SAY recommendation about day services was

***Local authorities and health boards should both examine what they provide and develop more modern, flexible and responsive services which support people in the community through employment, lifelong learning and getting them involved socially. Day healthcare services for people with learning disabilities should be mixed with those in the community.***

*(Recommendation 15, The same as you? 2000, p. 57)*

These issues were of key importance to the Sub Group that worked on this report, which is why the report is structured to show the varied views. Chapter 1 looks at research into day services for people with learning disabilities; Chapter 2 contains the views of people with learning disabilities. Chapter 3 explores the views of carers, who often express concerns that people with complex needs, such as those with Autism Spectrum Disorder (ASD) or profound and multiple disabilities, are not fully considered when day services are being changed.

This report then goes on to give examples of services that have been collected from local authorities and the independent sector (Chapter 4). There are examples of services that are based in special buildings, those that are based in the community, and those that use a combination of the two. The aim of sharing these examples is to demonstrate what kinds of services are available and how successful they are in meeting the needs of people with learning disabilities and in providing a variety of opportunities to suit people's individual needs and wants. Stories about personal experiences have been anonymised.

The final two chapters examine the key themes that the Group has drawn from the information it has gathered and highlight the potential for developing alternative and improved day opportunities and what can hinder the development of such services.

## Who wrote this report?

*The same as you?* National Implementation Group (SAYIG) was set up in 2001 to assist implementation of *The same as you?* The Scottish Executive believed that the involvement of people with learning disabilities and family carers in implementing the findings of the review was just as important as it had been in carrying out the review. Members include 5 people with learning disabilities and 2 family carers. The Group identified a number of priority areas that would be the main drivers for delivering the change programme. Day services was recognised as one of the areas that needed to change, to improve quality of life and to open up other opportunities such as education and employment. There are clear links between this report and the SAYIG report on employment *Working for a change?*<sup>1</sup>.

There have been three SAYIG Sub Groups running since 2004 looking at Advocacy, Children's Services and Day Services. This is the report of the Day Services Sub Group. A list of members of the Group and the organisations they represented is in **Annex 2**. When it commenced the Group decided it would focus its remit on examining the progress that had been made in implementing Recommendation 15 of *The same as you?* (see above).

This report **contains the views of** people with learning disabilities and their carers, including their personal experiences of day services; what difference changes have made and what is good and bad about the services they receive. It also contains examples of day services provided by local authorities; it does not attempt to evaluate these services.

## Who should read this report?

This report will be of interest to people in local authorities, involved in the delivery or development of day services, voluntary and independent organisations providing day services and also NHS Boards.

This report will also be of particular interest to individuals who currently use day services, or that may use day services in the future, and family members.

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<sup>1</sup> *Working for Change?* (2003) Report of *The same as you?* Implementation Group on Employment (The Scottish Executive)

## How many people are using day services?

At the outset it is important to set out the number of people with learning disabilities who access day services, and how this figure has changed. In 2000, when SAY was published, the research showed that 8,300 people with learning disabilities were using a day service. This figure had increased from 4,400 in 1980.

From the information collected to prepare the SAY Statistical Bulletins published in 2003 and 2004 we can look at how many people are using day services now and what alternative opportunities are available. In a typical week in September 2004, 7,080 adults with learning disabilities attended a day centre in Scotland. This accounted for an estimated 32% of all adults known to local authority social work departments nationally and represents a drop of 353 adults (roughly 5%) since May 2003.

There are substantial differences in the proportion of people with learning disabilities attending day centres in different areas. In 3 local authorities (namely Aberdeen City, Angus and East Dunbartonshire) more than half of all known adults with learning disabilities attended day centres. In other Local Authorities, this was a much smaller proportion; for example, in both North Lanarkshire and Dundee City the figure was 17%.

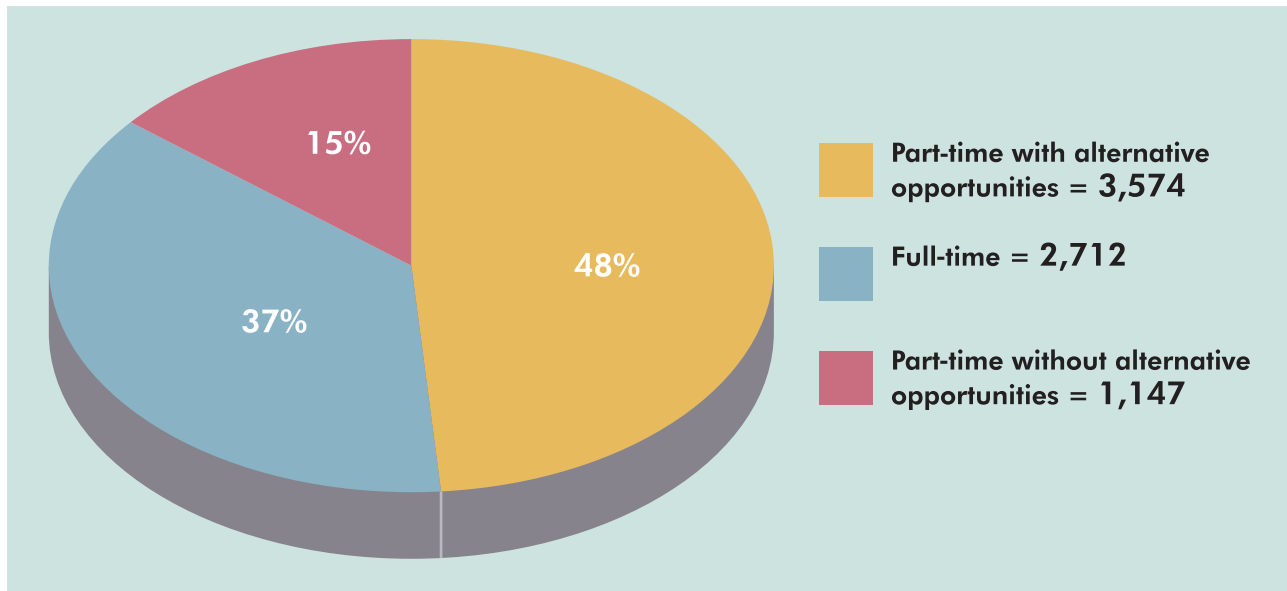
There is also considerable variation in the proportion of people who attend full-time. In Aberdeen City, 14% of all adults known attended a day centre for 5 days a week, (which is a quarter of all adults attending a day centre). Figures for West Dunbartonshire are similar. By contrast, in Angus only 3% of all adults known attended 5 days a week (7% of adults attending a day centre).

(**Annex 1** provides full details of all local authorities' use of day centres.)

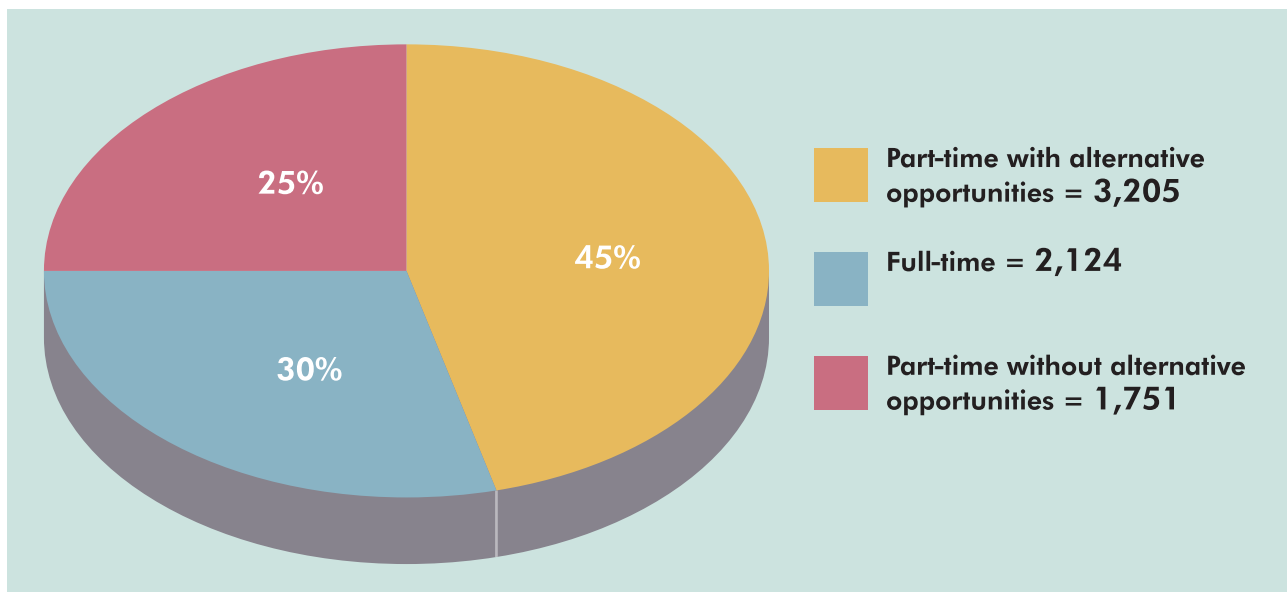
**When comparing the findings of the survey in 2003 and 2004, and considering the information from it used here, it is important to bear in mind that some of the differences could be the result of improved data collection rather than a change of service provision.**

**Charts 1 and 2** show the national breakdown of those visiting a day centre during a typical week in 2003 and 2004.

**Chart 1 – Adults with learning disabilities attending day centres 2003**



**Chart 2 – Adults with learning disabilities attending day centres 2004**



From the information provided by local authorities the figures indicate that there have been the following changes since we started collecting this information:

- 7,080 adults with learning disabilities attended a day centre in a typical week in 2004, in 2003 there were 7,433.
- In 2004, 45% (3,205) spent less than 5 days there and had alternative day opportunities for some of the remaining time. In 2003 this was 48% (3,574).
- In 2004, 30% (2,124) were there on a full-time basis (5 full days) compared to 37% (2,712) in 2003.
- In 2004, 25% (1,751) visited a day centre on a part-time basis (spent less than 5 days there) and had no alternative day opportunities. This compares to 15% (1,147) in 2003.

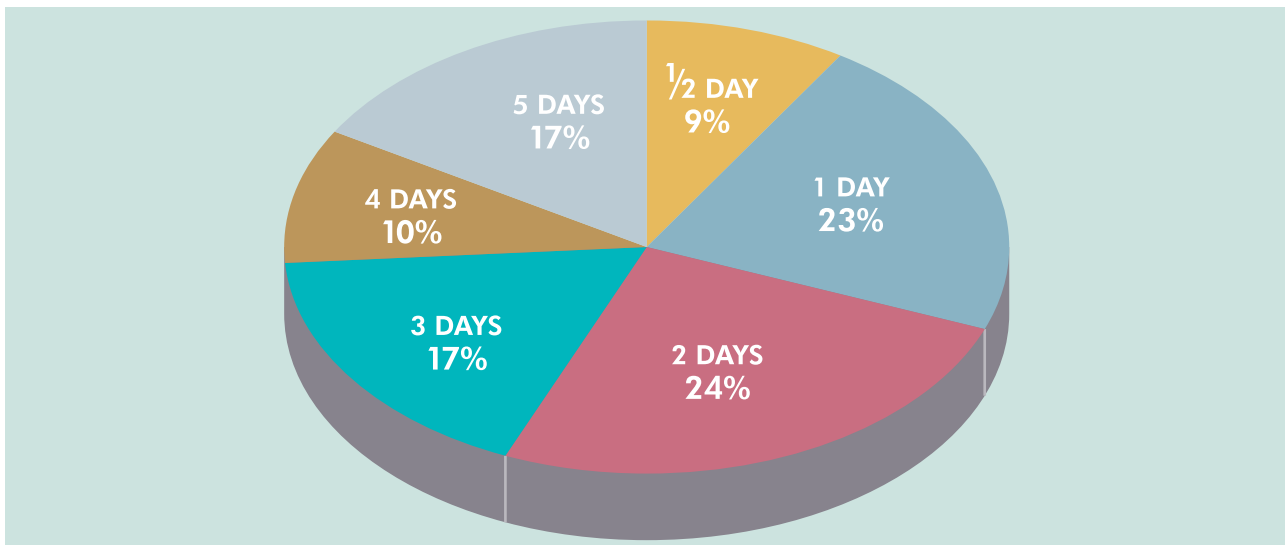
This shows that the number of people attending full-time has decreased, but also that the numbers attending part-time with alternatives has decreased, whereas the number who attend part-time without alternatives has increased. The statistics do not tell us what the people who no longer use day services are now doing instead.

Availability or access to alternative day opportunities varied widely, nationally 45% of those attending a day centre also got some form of alternative day opportunity during the same week. In East Renfrewshire everyone (100%) of those attending a day centre also took part in some form of alternative activity. This can be seen on an authority by authority basis in **Annex 1**.

## Duration of alternative day opportunities

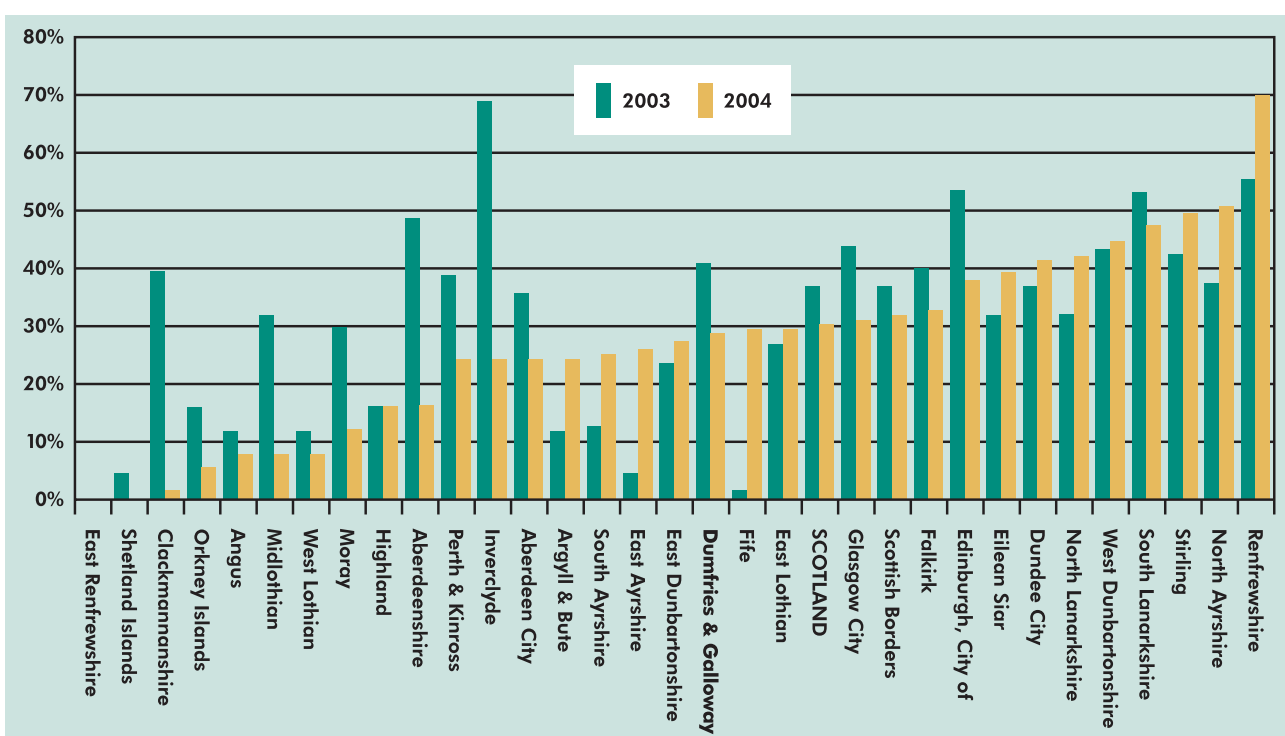
**Chart 3** shows the proportion of time adults with learning disabilities who received alternative day opportunities spent involved in these activities during the typical week. 32% of adults spent one day or less taking part in alternative day opportunities. 17% of adults taking part did so on a full time basis (they spent the full five days engaged in alternative day opportunities). The majority of adults took part in alternative day opportunities for more than one day during the typical week but not for the full week (51%, 2-4 days).

**Chart 3 – Adults with alternative day opportunities by length of time spent during typical week**



**Chart 4**, shows the percentages of all adults attending day centres who did so on a full time basis in 2003 and 2004 for all local authorities. The percentage of adults attending on a full-time basis had fallen in 19 of the 32 local authorities. The biggest drop in these percentages occurred in Inverclyde where it had fallen from 69% to 24%. The largest increase occurred in Fife where the percentage attending 5 days a week went up from 2% to 29% of those using day centres.

**Chart 4 – Percentage of all adults attending day centres who do so on a full-time basis, 2003 and 2004**



In addition to the 3,205 adults who both visited a day centre and had alternative day opportunities during a typical week, a further 2,435 had alternative day opportunities but did not visit a traditional day centre. This figure has risen by almost 500 from 1,969 in 2003 (a 24% increase). This means that 43% of the estimated 5,640 adults engaged in alternative day opportunities in a typical week in September 2004 did not attend a day centre.

Further information on the provision of services for adults with learning disabilities is published in the **'Adults with Learning Disabilities – Implementation of "The same as you?" Scotland 2004'** statistics release, which can be found at:

<http://www.scotland.gov.uk/Publications/2005/05/23160344/03460>

Updated statistical information will also be available on the Scottish Executive publications website.









## CHAPTER 1

# What we know from research

## Introduction

It is important for people who plan services to draw on research accounts and evaluations to identify what has proved successful elsewhere. Research can also help clarify our thinking about the overall aim of services for people with learning disabilities.

This chapter describes some of the main conclusions of research into day support for people with learning disabilities. It is mostly based on Simons' and Watson's review of research done in the 1990s and some later publications. There is a need for more research on day opportunities for people with learning disabilities.

This chapter begins with research on the purpose of day services and evaluations of 'day centres' (building-based services). It then discusses the research on various activities, for example, work, volunteering, leisure, education and arts.

## What are day services for?

There is still considerable confusion about the purpose of day services. This makes it hard to decide if they are doing a good job (Simons and Watson, 1999). It also makes it hard to know what skills and training staff need and to plan improvements in services (Felce, Lowe, Perry *et al*, 1999).

Various purposes that have been suggested are:

1. To support people to be included in society – to be the 'same as you'. This is sometimes called social inclusion. It means that day services should help people to develop friendships and use 'natural' supports – that is supports that are not paid for by the local authority. (Whitehead, Bates and Love, undated).
2. To give carers some time for themselves. This should be seen as an important purpose, even if it is not the main purpose (Dawson, 1998).

3. To help develop people's life plans. Services should help people think about what they would like in their lives and finding out what is available in the community. This is sometimes called community mapping. Services should then help make these resources more accessible to people who want to use them. This includes supporting people to travel to activities and participate in them (Kennedy, Sanderson and Wilson, 2002).
4. To provide a base for people with complex health needs and to prepare older carers for change (Seed, 1996).
5. To improve people's quality of life (Wertheimer, 1996).

Some research studies have looked at the problems of fulfilling these purposes. For example, service managers and staff have suggested that lack of money stops them providing person-centred, individual supports for people to be out and about (Ritchie, Jones and Broderick, 1996). There is a lack of good person-centred planning in services (Smart, 2004) and staff attitudes can stop change happening (Wertheimer, 1996).

Research also shows, sadly, that people with more complex needs are not usually asked what they want (Cameron, 2002). People are often consulted, but say that nothing then happens to change things the way they want them changed (Dowson, 1998).

## Do day centres work?

Overall, the research on 'day centres' (referred to here as buildings based services or day centres) gives a negative picture of the outcomes for the people who use these services. The research also concludes that, despite this, most day services are buildings based. When asked to give examples of good day services most organisations describe their non-day-centred-based services. Although usually only a few people get to use them.

The research is as up to date as published research can ever be (allowing also for the time it has taken to draft the report).

- Services that are based in buildings are not good for social inclusion, neither are services that work only with people with learning disabilities (Simons and Watson, 1999).

- Services that are buildings-based cannot be person-centred. The way they are staffed, the rules and procedures, and the way the money has to be spent mean that running the service is more important than what people want to do; they are just 'fitted in'. Everyone becomes institutionalised as happened in the long-stay hospitals (Dowson, 1998).
- Day centres do not support people to have good daytimes. As an example, people with higher support needs are only likely to be actively engaged for 12% of the time and the most able people are only engaged 66% of the time (Simons and Watson, 1999).
- Services that have moved from larger buildings to smaller resource units find that the service is no better and is often worse. This is because there are fewer staff and so fewer activities can be supported (Simons and Watson, 1999).
- Day supports that are part of people's housing can offer activities that are less service led. Where people live also makes a difference to the type of things that they do in the daytime. The smaller the supported housing, the more likely the residents are to have more individual activities (Felce, Lowe and Perry *et al*, 1999).
- Older people often have limited access to any day services (Thompson, Ryrie, and Wright, 2004).

Systematic evaluation is needed to establish the availability, use and outcomes of these services 'with and without walls'.

## Work

Employment is of great importance to people with learning disabilities and the research conclusions on employment are:

- There many people who want to work, but who do not have jobs. Many staff think that people do not want jobs when they do. Some carers are worried about their sons or daughters getting jobs (Beyer *et al*, 2004). It is estimated that about two thirds of people with a learning disability would like a paid job. This is about 13,000 people in Scotland. Over 3,000 people get some sort of employment opportunity (*Working for a change? SAYIG*, 2003).

- Day centres vary in how good they are at helping people get into work. Some centres provide a broad range of general activities – sports, arts and crafts, but little work related activity so few people get work. Many centres provide work preparation including courses and work activity programmes but people often do not get paid work. A few centres have employment teams and support people into paid work. They use supported employment methods such as vocational profiling, job matching, on the job support and career review to help people into paid employment (Beyer *et al*, 2004; Glenn and Lyons, 1996).
- Businesses that are just for people with learning disabilities can isolate people. Job coaches do not work as well as getting support from the other workers, for the same reason (Simons and Watson, 1999).
- Running businesses and getting people into work are not social work skills. It is usually better to work with agencies whose job it is to get people into work. It helps to also have staff with the right experience in day services whose job it is to support people into work (Beyer *et al*, 2004).
- Local authorities need to share information and learning on how to support people into work (Beyer *et al*, 2004).
- The welfare benefits system stops people from working as much as they would like to (Beyer *et al*, 2004).

## Education

- More people with learning disabilities want to have more training and there is an unmet demand. People with more complex needs are mainly excluded from education (Simons and Watson, 1999).
- Training can be just a replacement for day centres. Much college provision is segregated with people with learning disabilities having little contact with other students. Training often does not have a purpose that relates to what people want to do. Most training does not help people with their careers (Simons and Watson, 1999).

## Volunteering

- Volunteering is good for organisations and individuals. People can feel better mentally and physically if they volunteer (Schwartz and Sendor, 1999). It is essential to choose the right job and to have support. If the job is wrong, the support is inadequate, or if problems are not sorted out, then volunteering can be bad experience for everyone involved. (Cleary, 2003).

## Art

- Creative art mainly happens in segregated places, with only a few people using resources in the mainstream. Pottery and painting are the main activities; opportunities to act are rare (Reynolds, 2002).
- Doing art can be fun for people. It is also a good way of helping people to say what they want and to be included; and it can give people confidence (Simons and Watson, 1999).
- A group of people with learning disabilities who did an art history course had 'deep and remarkable' responses to the paintings (Logan, 2002).
- Barriers to doing art in community settings include lack of staff and transport and concern about not being made welcome (Reynolds, 2002).

## Leisure

- People with learning disabilities who take part in leisure activities mainly do so in day centre time, not in the evening or at weekends when most other people have leisure time (Beart, Hawkins and Kroese *et al*, 2001).
- There is more chance of success where paid staff work with 'natural supports' rather than just supporting people themselves. Natural supports are people who are not paid by social work or health; they may be friends or other people doing the activity (Simons and Watson, 1999). Community development and individual personal assistance are very different types of activity. We should not assume that the same staff can do both.



- People say that the barriers to taking part in more leisure activities are lack of transport and not enough carers or friends to go with (Beart, Hawkins and Kroese *et al*, 2001).
- Sport is not an easy option. Frequently people fail to understand that involvement often relies on being able to win at sport. (Felce, Grant and Todd *et al*, 1998)
- People would generally like to go on longer and more adventurous holidays. (Kane, 2000).

### Faith and spirituality

People say that their spiritual needs are met through friendships, belonging in the community, getting in touch with nature, and through expressive art (Swinton and Morgan, 2004). Friendships with people who are not relatives or paid to be with them are important. Faith communities are a potential source of friendship, although some need to think more about how they can include people with learning disabilities better (Hatton, Turner and Shah *et al*, 2004).

### Black and ethnic minority communities

Currently, little is known about how people from black and minority ethnic communities experience day services. However; it is likely that much provision is not meeting people's cultural needs (Hatton *et al*, 2004). It is very important to include people from black and ethnic minority communities in the planning and implementation of modernised day opportunities. Facilitators who speak a range of community languages, or interpreters are needed, as is a clear idea of specialist community opportunities for people from black and minority ethnic communities. Staff should reflect the community they serve (Wertheimer, 1996).

These are some key research findings on the development of day services.

- It is important to agree what day services are for (Simons and Watson, 1999).
- It is important to have a variety of opportunities as people will want to do different things (Dowson, 1998).
- It is important to provide enough support that carers can live their lives (Simons and Watson, 1999).

- It is important to employ and train staff who want services to change and believe they can (Ritchie, Jones and Broderick, 1996).
- It is important to budget for good participation and act on what people say (Simons and Watson, 1999).
- Everyone should have their own life plan with enough resources to make it happen (Simons and Watson, 1999).
- It is important to think positively about employment opportunities and to help people get paid jobs (*Working for Change? SAYIG*, 2003)







## CHAPTER 2

# The views of people using services

## Introduction

The three people who have learning disabilities on the day services Sub Group formed a group, We decided that we wanted to ask people with learning disabilities directly about day opportunities. What they thought about new day opportunities; did they feel involved in planning the changes; and were they given enough information. These were some of the questions we wanted to ask people. If we did not we thought that staff, parents and service planners might take over.

Once we had the agreement of the rest of the Sub Group we planned a questionnaire together. We decided to send it to advocacy projects and networks so that people would have independent support to give their views.

We considered whether we should send the questionnaires to day centres and ask day centre officers to support people to complete it. We decided against this approach as the support would not be independent. It might be hard for people to be honest about their day centre whilst they are being helped by a day centre worker; and it might be hard for the day centre worker too.

## The survey of people with learning disabilities' views

The questionnaire asked:

- Can you tell us what has happened to the day services you get? Have they changed at all?
- What do you think about the changes? Please tell us about the good things and the not so good things.
- How are day services different from before?
- Do you think there should be other changes to day services? If so, what do you think they should be?
- What information do you have about the changes?
- Have people with learning difficulties in your area been involved in planning the changes? If so, please tell us how?

43 questionnaires were completed and returned; 16 were from groups which included a total of 141 people. Twenty-eight responses were from individuals. A total of 169 people responded.

It was both exciting and difficult to have so much information to sort through. Eventually NINE different themes emerged:

1. Changes to existing services
2. Involvement with planning
3. Information
4. Choices and independence
5. Out and about in the community
6. Smaller groups
7. Employment
8. Staffing issues
9. Transport

We want to thank everyone who shared their stories, ideas and opinions. We hope that reading about other people's experiences will encourage others to speak up and will inspire people who use services and planners to work together.

## 1. Changes to existing day services

*'Over the last few years they have changed considerably. After 34½ years in a centre I have had more opportunities to be independent.'* (Individual)

People made a lot of comments about the changes that are happening in day services. Some of them were good and some not so good. You will read about the benefits people experience through their new day opportunities under each of the following themes. The things that are not so good seem to be happening in day centres where people are not getting the chance to go out and about. People talk about being bored, sitting about with nothing to do, still spending time with people they have not chosen to be with.

However, some people said they did not see any changes:

*'I am still doing the same thing.'* (Individual)

*'They aren't different.'* (Group)

*'Some people say it's not as good as before. Some people miss friends they used to see at the day centre ... Service users have been scattered to other services or centres.'* (Individual)

## 2. Involvement with planning

In some areas people with learning disabilities had been represented on planning groups or had taken part in conferences and consultations:

*'I represented the group at PiP meetings ... we informed them that our members were not happy about not getting enough information about what is happening to day services.'* (Group)

*'Our groups had a conference in January and we had a workshop on changing day services. This gave us a chance to speak about what we wanted to do during the day. They made sure that the people at the top of social work heard what we said.'* (Group)

Others felt they had a say through their People First group, client committee or other advocacy group. When people had a person centred plan they felt more involved in planning their own service. In one area people with learning disabilities were involved in promoting the new community based service to other service users.

There were a good number of people, however, who said they had not been consulted about the changes or involved in making the plans. Others felt they had not been involved enough:

*'Our advocacy group met with the day service manager a few times. We told her what things we would like to do during the day but we did not hear from her after that.'* (Group)

*'We got information from our support worker at People First. We feel that more people should have been involved in saying what changes should be made.'* (Group)

Some people felt that when they had given their views they were not listened to:

*'They don't seem to do anything as a result – you're wasting your breath. They didn't take on what we said.'* (Group)

### 3. Information

There are lots of good examples of people with learning disabilities getting information about new day opportunities. People told us about receiving letters, leaflets, newsletters and notes. Some people are involved in groups and committees where information is passed on. Information also comes from staff and key workers.

People in one area know about the changes to day services because there was a big review of the services and a meeting for service users. A video was made at this meeting which other service users have seen:

*'People First members were involved with the day service review and a lot of us went to the consultation day. A video of this day was made and the review report was user-friendly – but things are slow to change.'* (Group)

On the down side some people told us that they got very little or no information at all about the changes to day services. In some places when information did come it was too late:

*'People should be told if their centre is shutting down, not two days before it closes. This made a lot of people upset and worried. Some people had been going there for years. It was such a shock.'* (Group)

### 4. Choices and independence

Some people are really happy about having more choice in what they do during the day. This includes going out more in the community and doing more training and other activities outwith the day centre:

*'We prefer having the chance to go out instead of staying in the day centre.'* (Group)

*'More people can choose to do training for work or college instead of going to day centres. More people choose to take at least 1 day off to do other things.'* (Group)

Some people now get more individual support and this has led to greater choice and independence for them:

*'Because we get individual support it has broadened our minds. We get to choose what we want to do. We also go to college and we get individual support for this.'* (Group)

Generally, where day services had changed, people felt they had more choice:

*'We now have more say in what we do. You can make up your own minds in what you want to do.'* (Group)

*'The changes [are] making me more independent.'* (Individual)

*'I now have more goals to aim for.'* (Individual)

### **Case Study: Val**

*Although I liked most of the people and staff at the day centre, I was inside the building all day long, and I saw the same people day after day. For a lot of this time I was quite bored as the activities on offer such as needlework, painting, and computers were difficult for me as I don't see too well. I also felt very hemmed in most of the time, I didn't get out very much at all and I love being outside. There was no challenge in being stuck inside all day long, sitting in my wheelchair.*

*When I first went out with the alternative service I felt I had choices in life for the first time in many years, and I had lots more to do. Choice and independence are very important to me. For example, I like being asked where I would like to go to have lunch. I like to tell others what I want to do, not have them tell me. I like to meet new people and through some of the activities I have been involved in with them and I have met a lot of new people. This is good fun and is so much better for me.*

*Whilst with the new services I have sat at a woodworking lathe in my mask and helmet and I regularly attend the sports centre where I play curling and carpet bowls. My curling partner is a man called Jim. We like playing together, sometimes he beats me, and sometimes I beat him. Recently I have played carpet bowls with Tracy and Chris. This sports session is good as there are lots of people who go. Every year we all go on a bus trip; this summer we all went to Loch Lomond. After the sports we all go to lunch at a nearby Chinese restaurant, but we can opt out and go somewhere else if we wish.*



*I also go to a craft workshop where I get the right help in painting pottery, I go swimming, I attend college and more recently I get to ride a quad bike every week. These are activities I have chosen to do. No-one has imposed them on me and it feels good as I like to have a go at new things, especially sporting activities.*

*The best thing about the service I get now is lots of activities and lots of choices – and most important – more independence.*

Many people, however, felt they still did not have enough choice:

*'I don't like walking in a big line to go swimming.'* (Group)

*'I think people still do not have enough choice over what they do during the day.'* (Group)

Some people resented the changes because things that they liked had stopped:

*'All the things I used to enjoy, painting, art, drama and pottery is all gone. We had to accept these changes.'* (Individual)

In two areas day services seemed to have taken a step backwards. Some had community based activities stopped. Users had no choice over this, and were unhappy about it. Others had been moved to a larger centre:

*'There are too many people in our new centre. You cannot get any quiet time.'* (Group)

When asked what they would like, people said they would like to do more things outwith the centre:

*'I'd like to get the chance to go out for lunch rather than staying in my day centre for lunch.'* (Group)

*'We should be allowed to do things in the community like going to the gym.'* (Individual)

*'I would like the chance to do other things like work and college.'* (Individual)

Others wanted more advocacy support:

*'There should be more self-advocacy in the centre.'* (Group)

*'People with learning disabilities should receive more help to be independent and be able to use advocacy to help speak up for themselves.'* (Individual)

## 5. Out and about in the community

People told us how they prefer doing things out in the community; going for coffee or lunch instead of staying in the centre; making new friends and contributing to the life of the community. This is helping to change attitudes towards people with learning disabilities.

*'It is great. We are out doing our own thing in the community like "normal" people. The community now treat us as if we are one of their own.'* (Group)

People also told us that sometimes their thoughts and opinions are not valued, that people avoid and ignore them or talk down to them. This will only change when they are included in community life:

*'I think that people in the community need to get used to seeing us out and about because it is a new thing for a lot of us.'* (Group)

### Case study: Gillian

*My name is Gillian and I live in Falkirk. I live with my Mum and Dad at home but one day my ultimate dream is to get a flat of my own.*

*I went to a mainstream primary school to begin with. It was OK to start with but after I had been off sick for about a year people started to bully me. I couldn't keep up with my classmates so I got put back several years. Eventually, when I was about 12, I went to a special school. It wasn't very nice because all my friends were moving elsewhere. I didn't like it because I was still bullied. And I still couldn't keep up with the work.*

*When I was 16 or 17 I left school and went to a residential centre for adults with learning disabilities which provided day care. I went home every Friday and back again on Sunday. I hated doing this. It was OK until we got a new matron who was not very nice. The day care was mainly sewing. I got the very, very thin stuff to sew because I was good at it.*



*After a couple of years I moved to an adult resource centre because I was so unhappy and my Mum and Dad said I should move. It was much better than the residential centre because you got more freedom. There were different classes like cookery, art, PE and education – reading and writing. It got boring after a while though and I was still treated like a child.*

*Now I am in a community-based project. It is fantastic because you don't have to stick to a timetable. We just do our own thing. I go to a Women's Group which is not just for people with learning disabilities, I do voluntary work at a charity shop and I have a paid job as a representative with the SAY project. The staff are there to guide you and take you to places if you need help. They are there to help you do what YOU want to do. I have become more independent and more confident to speak to people since being with the community-based project.*

## 6. Smaller groups

People told us about the benefits of having smaller centres and doing things in smaller groups. They appreciated the service being nearer to their home. They liked going out in smaller groups and felt they got more individualised support:

*'I like my day service in the community. I like to do things during the day and I like being in a smaller group instead of a big day centre.'*  
(Group)

In one area the move to smaller centres led to a more flexible and individualised service:

*'The day centre is more flexible to suit my needs.'* (Individual)

*'More freedom than we had before.'* (Individual)

*'Since we moved we are always being asked what we would like to do and if we are happy.'* (Individual)

Another advantage was that it was quieter. This meant that people could feel more relaxed and less stressed:

*'[The] Smaller centre [is] so quiet. We get peace to just sit and do knitting, watch telly, have a blether with friends, talk about the old days.'* (Individual)

*'I like the small group ... it's much quieter.'* (Individual)

Where services had not changed, people expressed their unhappiness at always being in big groups:

*'I would like to get more support to be able to spend more time with my girlfriend on my own. Usually we just meet in a large group at our day centre.'* (Group)

## 7. Employment

*'I would like to work.'* (Group)

It was very clear that many people who responded to the questionnaire would like the opportunity to work. Those who do have paid employment seem to enjoy this:

*'One member got a job in his local pub. Instead of going to the day centre he now works five days a week.'* (Group)

People told us about their voluntary work. Whilst some people are positive about this, others said they would prefer to be paid for the work that they do:

*'We are not paid for work – there are problems with benefit. There are problems with people not paying when we do their gardening.'* (Group)

Many people talked about going on work skills courses, having job profiles, job coaches and support from employment agencies. This was mainly positive but some felt that these things did not always result in finding them a good job:

*'It's better when you get a job where you can reach your potential instead of stacking shelves.'* (Group)

Many people still lack the support or training they need to find a real job:

*'People need more support to be able to get jobs and make new friends.'* (Group)

## 8. Staffing issues

*'Workers promote independence and person-centred planning, staff work with you so you have more control over your life.'* (Individual)

Some people who have changed from a traditional day centre to an alternative day service talk positively about the staff. They say that staff ratios are higher and that they can talk to them more freely and confidently:

*'I can talk to the staff about my problems. They help me and make me feel better.'* (Individual)

A common theme, however, was a lack of choice over staff and key workers:

*'I am losing my key support worker. I really like him and don't want to lose him but I have no choice over this, especially if I want to spend more time away from the centre.'* (Individual)

*'Most people don't get the chance to choose their key worker.'* (Group)

Many service users also stated that there are still not enough staff and this leads to restricted opportunities. At times activities are cancelled and changed because the service is short staffed:

*'We need more staff to do things like help us get a job, go to the shops and use public facilities.'* (Group)

Some people expressed concerns about staff not being friendly and at having low morale:

*'I don't think the staff are very friendly ... some of them are not happy at their work.'* (Individual)

## 9. Transport

Some people said they are now travelling independently and that they prefer this to being picked up by a centre bus. Where services are more community based people are spending less time travelling:

*'I like to use public transport rather than a special bus.'* (Individual)

*'A small local day service has started, so people don't sit in buses for as long as before.'* (Group)

In some areas, however, there are still transport problems. Some people are continuing to travel on centre buses for a long time:

*'Get rid of those horrible white buses!'* (Group)

*'Transport should be better, no white buses, which are still in use.'* (Group)

A few people, on the other hand, said they like the security of being picked up by the centre bus:

*'I like to be picked up from my house in the morning.'* (Group)

## Conclusion

It is clear that for some people, new day opportunities have led to significant and dramatic improvements in their lives:

- They feel more included in their local communities.
- They have greater levels of choice and independence.
- Services have become more flexible and people do not feel trapped in them.
- They use public transport like everyone else and are free from the stigma of local authority provided 'dolly' buses.
- People do not stare at them so much for being different.
- There is less discrimination.
- Smaller groups mean more choice and more chance to be heard.
- More people are working or going to college and following their dreams.

There is, however, more to be done. These are some of the priorities:

- Whilst some people are enjoying new, flexible services, others were still in the old day centres. In some places these seem to have got worse as resources are directed at new services.
- A clear message from the questionnaires was that people want real jobs for real pay, more training, more choice and more individualised support.

- In many areas service users felt they had not been fully involved in planning the changes and they had not been given enough information. For real change to happen there must be real and meaningful involvement in planning, managing and evaluating services.
- Transport issues need to be resolved.

### **Case Study: Lorraine**

*My name is Lorraine and I live in Glasgow. I spend my week involved in a whole variety of things.*

*I attended St Stephen's Day Centre, due to unfortunate circumstances this centre is now closed. I found it friendly and welcoming, and would like to get this kind of opportunity elsewhere in Glasgow. Sometimes I go out and about and other times I stay in, I also attend college doing basic skills classes in Maths and English. I have been going to various classes for quite a few years. I like to do this because I enjoy learning. I want to improve my skills; literacy – reading and writing and I like getting support and help to do that.*

*I try to be as active as I can be in the community. It is important to me that I get support in the community to be involved in issues that affect me. I want to learn more so I feel that it is very important to get information; to meet other people; to share experiences and information with them and generally to learn from one another.*

*One reason why I take part in lots of groups is because I enjoy learning new things and making changes in the community. Another reason is that I get support in the groups. I am a member of groups which are to do with learning disability and mental health. This includes ENABLE, SCLD and the Glasgow Community Safety Forum.*

*I also am part of a SPRED group which meets twice a month. SPRED helps people who have a learning disability to be more fully included in their Roman Catholic parish community.*

*I like being involved in events and conferences, I enjoy being part of things and feeling like I am helping to make changes, in my own life and by doing the work I do to improve things for other people too.*

*In the past I have been involved in employment training and have had voluntary jobs however I don't feel ready for work just now. I feel that I need the flexibility of going along to things when I feel able to do so. That is why participating in and contributing to various groups works for me.*







## CHAPTER 3

# What family carers told us

## Introduction

As part of the review, a questionnaire was sent out to family carers of people with learning disabilities about developing practice in day services. The questionnaire was written by the carers representatives on the Sub group. It was distributed widely by ENABLE, Capability Scotland, Down's Syndrome Scotland and PAMIS.

The questionnaire was not intended to be a comprehensive piece of research into the opinions of all family carers of people with learning disabilities in Scotland, as this was not practical within the time-scale and available resources. However the 107 questionnaires returned give a vivid and rich picture. They were completed by the families of people with a wide range of interests, ages and needs, from urban and rural areas across Scotland. Families were told that they did not need to give details which might identify the service user and his or her family, although many did.

Families' detailed responses made it clear that the quality of day opportunities, whether good or poor, has a major impact on the lives of their relatives with learning disabilities. This affects families' own well-being. As one parent put it:

*'My husband and I are the only carers for J, and if the changes enhance her quality of life, then we will be happy.'*

Reliable day opportunities can also make a very important difference to family carers' own lives: providing a much-needed break from caring, the chance to lead independent lives of their own, and for some the opportunity of employment. Other family members also benefit.

We are very grateful to families for taking the time to share their experiences, which give valuable insight into how the recommendations of *The same as you?* are being implemented. Their views should inform future practice.



## The survey of families' views

The questionnaire asked families about:

- the person cared for, including age, interests and needs
- the service/opportunity used and who runs it
- changes in the service used
- the reactions of the person using the service to the changes
- any other changes that might be made
- the effect of any changes on the carers themselves and other family members
- consultation with the family about the changes, and if their views actually influenced what was done
- ongoing consultation about the service
- any other comments.

## Key themes

This chapter begins by looking at families' descriptions of changes in day opportunities as they affect people with learning disabilities, their families, and the staff involved.

The next section focuses on what is actually happening in day services: transitions; programmes and packages; reliability and routine; social opportunities and friendships. Overall planning is then discussed, and finally the practicalities – buildings, transport, access, equipment and barriers.

Consultation emerged as a crucial element in achieving a successful service. This must mean real engagement of people with learning disabilities and their families in decision-making, not just a chance to express views without any influence on services.

## People with learning disabilities

### 1. Person-centred practice – respect for individuality

Naturally enough, family carers judge a service by asking the question: ‘can it meet the *individual* choices, aspirations and needs of the person I care for?’ The importance of this person-centred approach was made very clear in their comments.

There were some very positive examples:

*‘B has recently moved to a new unit within the centre ... I believe the changes recognise B’s autistic tendencies and feel that more specialised personal attention will enable her to develop further ... She does appear to have a better daily schedule designed to her needs including regular outings as well as centre activities.’*

*‘P’s package includes 2 days at college, 1 at the adult resource centre, 1 with a community care team and 1/2 day with various community resources. All the services are geared to help P mature and progress. He does not like change but will get accustomed to it. It is necessary if he is going to have any sort of future.’*

Other families had not had good experiences. In some cases, no changes had taken place. One mother was very dissatisfied with their local authority’s failure to make changes to its traditional resource centres. She was particularly concerned about the lack of college places and job opportunities.

However, other families were unhappy with changes that had been made. They thought that they did not offer people with learning disabilities choice – just a replacement service which was not as good as the old one:

*‘People should have choices, not just about new services, but about keeping options which already work well ...’*

Two families had pushed for a placement outside their home areas, having found little locally to impress them. One wrote:

*‘I have filled this in as I feel strongly that many day centres and courses I have spent time in do not have the needs of the individual at heart. Many parents are not lucky enough to be able to work the system as we were and cannot match the services to their son’s or daughter’s needs.’*

Others thought that trends in current thinking did not suit everyone; a mother with a son and a daughter, both of whom have disabilities, said that each needed a quite different approach:

*'I am aware that the present trend is away from day centres with more so-called interaction in the community. This suits my physically disabled daughter and gives her a wider life. My profoundly disabled son with severe learning disabilities and poor eyesight gains little from being pushed around the place in his wheelchair. The weather may be poor and there is little or no social interaction. Outwith the centre he spends most of his time with a single carer.'*

## **2. Involving people with learning disabilities in decision-making**

Many families said that people with learning disabilities should have a say over their services. Good examples included:

*'They have their own council and make their own decisions. The changes are helpful in that it builds their esteem and confidence.'*

But consultation had to be real listening, not just a token gesture:

*'Social work departments and others should make more efforts to engage with people with learning disabilities and not just lay down equal opportunities principles.'*

Several family carers said that their own role was very important in making sure that their relative's voice was heard:

*'As my son's main carer/advocate, I ensured that his views were taken into account when planning his weekly activities ...'*

For people unable to express their views, consulting their families about their interests and needs was seen as essential.

## Families

### 1. Consulting families – planning the service

Families were asked if they had been consulted about changes in local day opportunities. Many said that *meaningful* consultation was very important. It was noticeable that those families who were generally happy with services were also those who said that managers had not just listened to their views but also acted upon them.

An example of good practice is given on page 41.

Others said that their working relationships with professionals had improved since *The same as you?*.

*'We have more say in what our son's needs are. Now [we] feel that help is only a phone call away.'*

However, providers had to be genuinely willing to take families' views into account. One mother had been consulted about planned changes, but felt that they had been pushed through regardless. Others said:

*'We were not really consulted. We were just given the chance to say if we agreed.'*

*'I got the impression they had already decided what they were going to do by the time they talked to parents.'*

Several families who were happy with day-to-day communication with 'front line' services staff, were worried that they might not be consulted properly by managers about future plans, particularly about major changes. An intermediary such as voluntary agency could play a valuable role.

Unfortunately a number said they had not been consulted at all.

### 2. Consulting families – day to day

Many families were kept in close touch with the day-to-day life of the day service through meetings, daily diaries, telephone calls, letters or newsletters. This was particularly important to the families of people unable to speak or make decisions for themselves.

Good understanding between family, staff and other professionals is crucial. A mother decided to withdraw her young adult son with very complex needs from day services altogether, because staff did not accept her advice on how to give him food and drink. He was always hungry when he returned home:

*'My son used to go to the ... but they didn't feed him properly at lunchtime or give him enough to drink. They fed him in the way that the Occupational Therapist (OT) told them to, and would not use the technique we have used for years successfully. Since they also said they could not spend enough time to feed him all his meal I eventually decided to keep him at home, because he was not happy and was going hungry. I want him to be happy.'*

This breakdown in relations about basic care had very serious implications for both the man and his family. His mother thought that a reduction in staffing had had a direct impact on her son's well-being – physically as well as socially.

### **3. Support for carers**

Day services can play a key role in allowing family carers to lead ordinary lives. As a mother with a daughter in a varied community-based programme put it:

*'It looks as though we are going to be able to have a life ourselves!'*

A reliable service was often the critical factor in allowing family carers to work, and it was very important to those already employed that changes were fully discussed in advance.

*'Changes cause anxiety. As a working parent, I need to be sure that services are in place to enable me to work.'*

Single family carers who were also sole bread-winners were particularly dependent on reliable day services. However, where there are two partners, the loss of one income through long-term care commitments also has a serious economic effect. Family carers unable to work lost pension contributions.

For most, a regular routine seemed to provide the best support. However a flexible service had had a very positive effect on one family's whole lifestyle:

*'The flexibility of the service can be bent round to suit all the family. I have stopped smoking, joined the gym and can plan for my son's hours each week from Monday-Saturday, mornings, afternoons and evenings.'*

#### 4. A family-friendly service

The overall picture is that services not only must be person-centred but also *family friendly* too. Key features that support families emerged:

- a 5-day per week service (or equivalent)
- reliability
- trust in service quality
- a willingness to be adaptable
- good communication and understanding between family and staff

#### **Case Study: Good practice in consulting family carers**

*For the last few years, four young people with profound and multiple learning disabilities and complex health needs have been attending a small specialist day service in Fife. Their families feel that it offers a high quality, person-centred approach, with excellent links between themselves and staff. The service operates from a bungalow in a residential area, and supports the young people to join in a wide range of community activities, and the bungalow is also used for an indoor programme, as well as health and personal care needs. Aberlour Childcare Trust runs the service, but cannot provide for adults over 25 years.*

*As the young adults cannot express their own views, their families advocate on their behalf. Four parents are members of the Reprovisioning Group set up to establish a replacement service. One parent said that the prospect of change was very stressful, especially after 'we had battled long and hard for the provision to be set up'. However:*

*'I feel that they have encouraged us to participate in the decision-making process – we have been consulted and involved at every stage, our views and opinions have been listened to. We have really worked in partnership and I hope that the outcome will be a service which meets **all** of my daughter's needs, enables her to reach her full potential and have a good quality of life.'*

*In the Group, families have been key partners in a multi-disciplinary team, with staff from Fife Council, NHS Fife and the voluntary sector (Aberlour Childcare Trust and PAMIS). Families attended all meetings, wrote the service specification, and visited potential providers. They helped select providers for interview and were on the interview panel. Another parent said:*

*‘We were consulted at every stage of the reprovision process.’*

*The Group required the successful provider to continue to work in close partnership with families. Capability Scotland has now been chosen, and will, for example, involve families in staff selection and choice of a building base.*

*The work of the Group was awarded a Scottish Social Services Council/Scottish Executive Care Accolade in 2005 for Best involvement of people who use services in any area of an organisation’s work.*

## Staff

### 1. Day service staff

‘More staff’ was a recurrent theme. One parent said:

*‘He needs far more 1 to 1 than is available to rebuild confidence and engage in activities.’*

Another welcomed moves to a person-centred approach, individualised programmes and much smaller groups within a big centre. However she felt that all these improvements were restricted because the staffing ratio had remained at 1 to 11. Parents of people with complex needs were particularly concerned about staffing levels:

*‘Staffing levels have dwindled and are inadequate for her needs. Increased Health and Safety precautions for staff puts many activities she previously enjoyed virtually out of her reach.’*

Staff continuity was seen as very important:

*‘What helps D greatly is the familiarity and consistency of the staff.’*



Families were aware that providing cover for illness and holidays was difficult and made practical suggestions about rotas. In the absence of increased resources, consulting families and service users about how staff cover should be arranged across the year would seem to be the best approach.

## 2. Other support staff

The use of staff employed directly by people with learning disabilities, is increasing. Almost all appeared to be funded through the Independent Living Fund (ILF). In some areas, small numbers of people with learning disabilities were also receiving Direct Payments, usually managed by their families on their behalf.

Most ILF funded staff worked as one-to-one personal assistants. Increasingly they were expected to support the person to access day opportunities, especially community activities.

One young adult with severe disabilities had a person-centred package, funded through ILF and Direct Payments. His family were delighted with the scheme, which had:

*'... brought normality! He has a fulfilled and stimulating programme each day, so his behaviour is happy and settled. As his parent carers, we can get on with our lives and go out or away for a weekend when we want, and our staff cover ... We now feel autonomous and empowered to run our own lives! ... a wonderful scheme. My son has a life I would never have dreamed possible – independent, flexible, appropriate and most importantly happy!'*

However, families had concerns about the accountability and management of outside support staff.

New packages had benefits but could add to the load on families:

*'Direct Payments and ILF has given them more opportunities but more work for me (mother). Just the day centre was easier but not very satisfactory.'*

A family carer who was basically happy with the scheme thought that the personal assistant was:

*'... very linked to the centre and their activities. Perhaps the worker could be more linked to the lady herself and how she is feeling, and wanting to do that day – for example if she is feeling like a quiet day in the house, the one-to-one worker could support her at home with massage rather than in a large bustling noisy centre.'*

This suggests that there is a risk that services can rely on one-to-one personal assistants to support their overall work. ILF guidance states that:

*'The Funds cannot generally agree to fund 1 to 1 care where the reason for the need is due to the Local Authority directly or indirectly reducing its previous provision ... If the LA have previously been providing a ratio of care sufficient for the clients' needs, but are now requesting ILF to fund this for budgetary reasons, the Funds cannot take this over.'*<sup>2</sup>

Local Authorities that expect ILF staff to cover for staff shortages may be on dangerous ground.

Another parent thought that better day opportunities depended on families' willingness to take up Direct Payments.

Not all families wanted the responsibility of Direct Payments. People with complex needs requiring expensive packages of care may also not be eligible for ILF because of the funding ceiling.

### **3. Staff training**

Staff training was a key element for families. Disability awareness, communication, person-centred planning, moving and handling, epilepsy management (including the administration of rectal valium and/or midazolam), and management of difficult behaviours were given as examples. For people with complex health needs, appropriately trained staff were essential. Otherwise they were excluded from a service or else the service relied on family carers to be 'on call':

*'Day service provision should be able to meet **all** the healthcare needs of my son. At the moment, I am 'on call' if his gastrostomy tube comes out. Recently, I have had to go to his day service to replace his tube because staff had damaged the mechanism ... Either social work staff should be given recognised training to carry out these procedures, or a nurse with appropriate skills should be a permanent member of the staff team in order to meet **all** my son's medical needs.'*

These families were not getting a real break from what was often an extremely demanding schedule of 24-hour care.

In some areas, health and social work worked together to train social care staff in some non-invasive procedures, traditionally undertaken by qualified nurses: for example, PEG nutrition, nebulisation, mouth suction and the administration of oxygen.

Families affected wanted agreement on how to manage other health procedures that social care staff could not be trained to carry out, because they required the knowledge of a healthcare professional such as an experienced nurse or physiotherapist. These included: deep suction; naso-gastric tube feeding; and reinsertion of a PEG tube.

Difficulties also occurred about the rectal administration of medication, such as suppositories or rectal valium. Issues of dignity and privacy and of safe moving and handling (for staff and service user) could be in conflict with the need for prompt treatment to safeguard the person's health. Moving and handling policies designed to protect staff could restrict the leisure activities of a person with disabilities: a family carer said that Riding for the Disabled was no longer available to her daughter since a risk assessment.

The example of good practice given on page 81 comes from a service where a physiotherapist is based at the centre.

Families' experiences indicate that further work at a national level is needed to establish guidelines for good practice. These issues also affect other services such as short breaks and outreach.

#### 4. Support from allied health professionals

A number of families said how important the work of allied health professionals was, such as speech and language therapists, physiotherapists, dieticians, occupational therapists and psychologists. They provided both direct therapy to service users and staff training. Several parents said that more therapists should work in day services.

##### Transitions

*'The Transition Club have activities 3 days per week during the holiday period. The package includes college, work experience with horses, swimming. All elements keep well in contact and have provided innovative new ways to support my daughter's and our needs.'*

Another family had had to take the initiative when their daughter left school to allow her to take part in a community living scheme, made up of time in a centre and home care:

*'All young people should have a similar service and it has been very important that the staff team got to know J before he left school. We had to use ILF money for this to happen.'*

##### Programmes and packages

A number of parents were delighted with the new range of opportunities since *The same as you?* One mother described how her son, who has a visual impairment, had:

*'P spent 34½ years in a day centre before moving to outreach in 2000. P now enjoys more community-based activities and a person-centred approach. People listen to P and P enjoys having a say. P uses public transport and travels independently ... He has not looked back since he started outreach.'*

Another parent whose son has profound and multiple learning disabilities said that it was very important that he could pursue his wide interests in the community:

*'When my son is out of the unit, he comes alive. He enjoys rebound, going out for his lunch, ten-pin bowling, ice-skating and swimming ... He can become lethargic and depressed if he is not kept busy.'*

However, such packages were only as good as the community opportunities available. Although her local social work department were trying to follow the principles of *The same as you?*, there were still many community barriers.

There was still a long way to go with improving public awareness:

*'Things have definitely improved over the years, but if we want people with special needs to be "The same as you?", there is a need for more education/understanding from so-called "normal" people in places such as college, workplaces, etc. I find that epilepsy in particular still sends people into a panic.'*

## Education

Several families praised college placements. Courses included metal-working, music, drama, computing skills and art.

There were nevertheless real concerns about what happened next. A young man who had finished a college course had not been offered a further opportunity:

*'He has missed the stimulation of going to college and doing different work and meeting new people – F is very sociable ... I feel F is not as alert as previously ... He has started doing a little gardening one afternoon a fortnight. At least he appears to be doing less of the walking around town and having the inevitable cup of coffee.'*

Others said that those with complex needs did not have the same opportunities to attend college.

Meaningful programmes for learning and personal development in the centres themselves were important. Some parents felt that their sons or daughters were being left without any stimulus:

*'There should be more realistic choices so that the skills she has already developed should be consolidated ... The family is saddened when we visit the centre and find my daughter sitting around bored and on her own.'*

A family with a son who disliked change felt strongly that the 'without walls' service would not suit him as he refused to go to some community activities. He was now one of 16 people left using the centre building, with hardly any activities or equipment. Another parent said that a chronic lack of centre staff meant community trips and activities were constantly cancelled and her son became:

*'... annoyed and frustrated at having to play carpet bowls or colouring ... if they all got what they are supposed on their timetables I'm sure it would lead to more harmony overall. He kept saying he wanted to leave, but as there is nothing else here he has to stay.'*

## Employment

A number of families were delighted with the changes in their son or daughter after having a job. There were no examples of open full-time employment, although there were several of non open employment. One man worked full-time for Remploy. Another family wrote:

*'The scheme is treated as a business – all have paid jobs. They make wooden garden furniture, ceramic figures, gifts, etc. B enjoys it and is trusted by staff ... It is most beneficial, giving B a sense of working and being useful. We see a difference in him since he went there.'*

Some schemes also offered part-time work:

*'The Centre runs a co-operative firm which operates from a building on a neighbouring industrial estate. She is a member of the co-operative and works there 2 half days and 1 full day per week.'*

Part-time work offers many people with learning disabilities a significant boost to skills, confidence and enjoyment of life. One young woman worked two days a week in a print shop, with two days with a local service provider, her mother said:

*'I am now looking after a happier person with more interests to talk about. I am also feeling happier too.'*

However, her daughter now had a 4-day week, rather than a full 5-day week. The temporary nature of some jobs was a serious problem. Several families said that their relative had loved a short-term job, but could not find anything else afterwards:

*'Our son spent 3½ years working full time in a bakery. He really enjoyed this and got a lot out of the experience. Unfortunately this was only a training placement and no more permanent employment could be found.'*

Others had received training, short-term work experience or employment, but no further work. As day service places were no longer available, families had to provide activities themselves – if being bored at home all day was to be avoided. People had had their expectations raised, only to be very disappointed.

Families' experiences highlight the value of employment schemes, the difficulties of finding permanent jobs and the need to find alternatives to stop people with learning disabilities being left without either a day service or a job.

## Reliability and routine

Families wanted complex packages to be reliable and well-planned as well as flexible. There were some real success stories:

*'I can plan for my son's hours each week from Monday-Saturday, mornings, afternoons and evenings. We are benefiting and he is really happy and much more relaxed. He has a weekly programme of activities with pickup and arriving home time.'*

Other packages seemed poorly thought out. Expectations could be raised only to be disappointed, confusion could occur and worst of all, people with learning disabilities could be left sitting at home bored and dejected. Their families had to provide care and amusement at short notice when activities were cancelled. Others might find themselves back in a centre building but with nothing to do.

*'The changes initially met her needs. Now there is a wide range of 'airy fairy' choices – difficult to pin down or achieve ... She needs routine and the changes make it difficult for her to know what is suppose to happen on a particular day. This makes commitment difficult for her.'*

*'She is now at home very much more, especially when the college course finishes for the holidays. She has no routine now which confuses her and she misses regular contact with friends. At home with me more than when she was a child at school – not healthy in my opinion.'*



Another young woman was timetabled for a wide range of activities which were constantly being altered or cancelled because of staffing problems:

*'Although it is helpful to be given the chances to try new things, it is also **very** disappointing and frustrating for her when she is looking forward to things that are not going to take place.'*

### **Case Study: Craig**

*Craig lives with his mum and dad. Craig has severe learning disabilities and complex uncontrolled epilepsy. He requires one-to-one support wherever he goes and also needs lots of help in explaining tasks or new situations.*

*In 2002 Craig's mum found out about the option of direct payments while attending a conference on The same as you? They started using a direct payment to pay for support for Craig in the evenings and at week-ends. He now uses a direct payment to pursue his daytime interests as well. Craig likes animals, being outside, working hard, doing some sport and socialising with peers. The family knew it would be a challenge to achieve an interesting programme and meet his particular needs. Craig currently has a full week, having three jobs – on a farm, a garden project and a supermarket. He also goes riding, swimming and attends college, all with a personal assistant.*

*The family had initial help in setting up the direct payment from their local user led support organisation. They have ongoing help from a payroll service. They found a way round concerns about recruiting staff by employing people they knew or who worked for a local organisation.*

*Craig has four staff working for him on a part-time basis, and they have proved to be a great team. He hopes that direct payments will help him live a more fulfilled and independent life.*

### **Social opportunities, interaction and friendships**

A good social life, both within centres and outside, was very important:

*'Particular attention is taken to any friendships between centre members and built upon. My daughter cannot speak but has good eye contact and another young woman with similar difficulties gets on well and enjoys the same interests, so a good friendship is building up.'*

The size of social groups was important. Many people preferred smaller groups, especially people with autism who reacted badly to crowds. One mother felt that her son was losing friends. She said that he had lost contact with other people with disabilities due to the closure of drop-in centres, but had not been given sufficient support to make his own life choices, find his own friends or the employment he wanted. Many parents were sensitive to the difference between real relationships within the community – and simply being out and about on the streets with a paid helper:

*‘The so-called community can be a very lonely (and artificial) place – please consider this ... We seriously believe that many people are being condemned to social isolation and exclusion within the community ... I have often seen people with disabilities being walked around the town in silence by a carer who is not even walking beside the person ... are we really thinking about/listening to people like our daughter?’*

## Overall planning for day services

### 1. Impact of changes in one service on other local services

One family carer was very angry about overcrowding in her son’s day centre, apparently caused by the closure of another. Her son now found it very noisy and difficult, and she felt misled by the social work department:

*‘We were promised that our centre was already full so there was no way we would be accommodating the others, so when we were informed that this would now happen, to say the least we were very angry.’*

### 2. People who receive no day opportunities at all

Unfortunately some people with learning disabilities still had little or no day opportunities.

One man with challenging behaviour and complex needs had lived in a residential home for 4 years. His family said that support from outside the house amounted to a meagre 2 hours a week with a ‘recreational person’. Two others with very significant care needs had no day services at all and no social worker, nor did another person in a remote rural area.

## Practicalities

### 1. Buildings and bases

Almost all services the families described operated from a building base. A number of families had concerns about local plans for 'without walls' services, especially those caring for adults with either autism spectrum disorder or complex health needs.

*'Around 100 other previous day centre clients have moved on to a project 'without walls' i.e. without a day centre which makes total use of community activities and therefore does not care 09-09:30-15:30, 5 days per week. This would not have suited B (young adult with autistic tendencies) or us, being too haphazard to allow any sort of regular routine to develop.'*

*'I endorse social inclusion, but believe that people with PMLD [Profound and multiple learning disabilities] need a base. Profound physical impairments and complex health needs require specialist, often individualised equipment and a safe quiet environment where they can relax and "chill out".'*

Others had more general worries about safety, structured activities and the loss of friendships, where there was no base to return to.

By contrast, one mother of a son with profound learning disabilities had a very positive experience of a 'without walls' service:

*'It was very stressful at the start not having a "building" and if he could manage to be out in the community every day. Our concerns were: was the community really accessible for those with complex needs, also personal care, continuous learning, dietary requirements, keeping healthy and safe, risk assessments, trying new things, trust, the weather and transport. But thanks to the service provider our fears and anxieties are long gone.'*

## 2. Transport

Transport is essential if people with learning disabilities are to take part in a range of community activities. It was mentioned by many families.

Several said that they had to provide transport themselves, for example to sporting activities. There were particular problems for those in rural or remote areas. An older carer expressed worries about what would happen when she could no longer drive her daughter to her activities. Funding for transport was a common problem, for example for college attendance.

## 3. Access, equipment and barriers

Despite the Disability Discrimination Act 1995, families said many community venues still had poor physical access. Risk assessments, shortage of staff and/or equipment also prevented people going horse-riding or swimming, for example.

## Conclusion

Families taking part in this survey have made their views clear that day opportunities should offer people with learning disabilities the best possible chance of leading fulfilling lives. They want people with learning disabilities to be at the centre of careful, *individual* planning, with family carers as full partners in this process.

Consultation is a core principle of *The same as you?* The broad picture from this survey is that services succeed best when managers have actually been influenced by the views of people with disabilities and family carers, rather than '*listening with closed ears*'.

Some families described exciting developments in community inclusion since *The same as you?* Others said that little had changed locally, or that the changes made had not been helpful. Many said that day opportunities should be structured, reliable and purposive – hanging around shopping centres was not enough. Packages had to be practical and sustainable.

Families gave many examples of excellent developing practice. Good, committed staff – and enough of them – are needed, in order to make sure that the package is right for the individual person with learning disabilities and their family.

### Case Study: A Carer's Story

*'I am a carer who has sat on special needs committees of the Scottish Executive. I have also attended a Partners in Policy Course and sat on local Children with Disabilities Committees with health and social services representatives.*

*'I have a profoundly disabled son who has complex physical and behavioural problems but is generally of easy disposition. Until the age of 18 he attended a local school for children with special needs. He was happy and well cared for both emotionally and educationally. Prior to leaving school he had regular future needs meetings from age 14. These were arranged by the school and fairly well attended by relevant staff. If staff could not attend they sent a report. However, no-one took responsibility for moving things on between meetings. I suggested lots of things my son may like to be involved in, recognising he could never take on employment but although these were minuted no-one did anything about taking them forward.*

*'I found out my son had to leave school at Christmas in August when he had just turned 18. There was no choice in the matter and no explanation given except that he was 18 and had to leave. Child social services passed his case to an adult services social worker who was off sick and then on compassionate leave. No one else took up the case and as a result there was no communication between people. The school eventually contacted the local adult resource centre and my son left school one day and started there after the holidays with no lead-in period.*

*'The service provider at the resource centre went down the route of trying to take my son out into the community every day. This was against both my advice and the advice from the school. However, after a very unsettled six months they employed a full-time support worker for my son on a one-to-one basis. They also changed his programme to a building base with occasional forays into the community. This has been successful.*

*'Adult respite services are scarce; there is one service, take it or leave it. None of the ideas I had for my son regarding social and educational opportunities have been acted upon by anyone else other than the service provider. We now have a good relationship with them after a sticky start because of lack of information.'*







## CHAPTER 4

# What providers of day services told us



## Introduction

Local authorities and independent sector providers were asked to send information about developing practice in their day services. Rather than completing a mapping exercise, the intention was to give some practical examples about how day services have been developing across Scotland since *The same as you?*. We wanted to know what providers were doing, what was working well, and what providing good outcomes for people with learning disabilities.

A questionnaire was circulated to all 32 local authorities and all major independent providers.

## The survey of service providers

The questionnaire asked for:

- A summary of service provided
- Financial information
- Information about staffing levels and training
- Evaluation of practice outcomes
- Involvement of people with learning disabilities and their families in service planning
- Barriers experienced in developing the service
- Consultation with service users and carers
- Plans for further expansion of service.

25 responses were received from local authorities and eight from independent providers. Some were able to tell us about a number of new developments in their local area, and others gave only one or two examples.

Following analysis of the submissions, four key themes emerged:

1. Social inclusion
2. Employment and education
3. Complex needs
4. Organisational change

Given the large number of responses received, it would be difficult to list every initiative. We have therefore selected examples that best highlight the above themes. We would like to thank all the organisations that responded to the questionnaire.

## 1. Social inclusion

Many of the submissions told us about developments which enhanced people's social and leisure activities. Nearly all of these activities took place in community-based settings such as community and sports centres. Some activities were integrated with the wider community. Others were designed for a specific group but taking place in a community setting.

### Expressive arts

Dance and drama are a good way for people with learning disabilities to display their talents.

In **Glasgow**, the Independance Group has performed at various venues across Britain, with favourable press reviews. Paragon's *Moving Waters* piece was performed at the West End Festival and the Special Olympics.

Mask and puppet theatre work in the North-east of **Glasgow**. They have also showcased the contribution people with learning disabilities can make to the arts. Financial support came from the Council's Cultural and Leisure Services.

In **Highland**, a successful 3-month art project is now included in a centre programme. It is a course based at Art T.M, an independent printing and art studio. Thirty people attend over 3 days a week and attendance is flexible. It is a mainstream facility which helps integration with other artists. Five people are undertaking a SQA cluster of 3 units.

Feedback from people with learning disabilities has been very good and family and carers have been surprised and delighted at the quality of work displayed at exhibitions. Some artworks have been purchased and a lending scheme for paintings is also operated. Plans for the future include increasing the number of days, building individual portfolios, seeking access to open college course, inclusion in evening classes at Art T.M. It is planned to link with the access course offered by the Tate in London.

The Traveller Dance Company, with **Midlothian Council**, has been developed for people interested in working towards performance, gaining skills in movement and developing creativity. Eight people with learning disabilities use the service which operates within usual working hours and at weekend and evenings for performance and festivals. The project is financed from within existing day service funds, from community arts grants, and from reallocating day service staff to work in collaboration with a community arts organisation.

Traveller requires the help of two day service support staff and one to two dancers. Support staff training is both on the job and through working with professional artists and dancers as well as occasional workshop days. Outcomes for individuals are evaluated after each session and at the end of a block of sessions. Dancers have taken part in the recent Edinburgh Festivals and members and their families are involved in the regular performances. The outcomes for the people with learning disabilities who are involved are positive.

The AccessArt Project run by Turning Point in **Dumfries and Galloway**, provides one-to-one art and craft sessions for adults with learning disabilities. They pay £3 per session to cover cost of materials. The project organises exhibitions of people's work at public galleries and any profits from sales go to the artist. Members also visit local galleries and have entered national competitions. Forty people use AccessArt. 62% of sessions are at Dumfries Train Station Studio with the remainder using a variety of locations including people's own homes.

Review questionnaires have been sent to properties and staff and a pictorial/visual version to the users of the service. There have been 5 exhibitions of work and also some commissions. Initially some staff were unsure of the value of art to people with learning disabilities. However, feedback has been very positive with people who use the service being extremely pleased to see their finished work hanging in a gallery.

AccessArt are aiming to recruit 2 part-time members of staff to cover sickness and leave and help with sourcing galleries and finding new members. They would also like to find more volunteer artists, enter more work in national competitions, and form partnership with other organisations to bring the work of AccessArt to a wider audience

The Community Opportunities Service, in **Dumfries and Galloway**, supports people with learning disabilities to use mainstream community resources instead of day centres. Support is given with educational and recreational needs. Two people are supported in voluntary employment. Altogether 15 people are supported. The users have allocated hours every week, at evenings and weekends as well as in the day. The service is setting up a community based music group. There are 4 weekly support meetings which discuss how individuals are using the service and what activities they may be interested in. Individuals and their families are also involved in person centred P.A.T.H meetings.

## Health and leisure

Improving the health of people with learning disabilities was another aspect that emerged. This reflects heightened awareness resulting from the Health Needs Assessment (PHIS) Report<sup>3</sup> which highlighted a number of areas where there are poor health outcomes for this group. A number of submissions described how health and leisure activities can be combined to make improvements in people's lives.

In **Glasgow**, the Pedal in the Park scheme shows how people's health and wellbeing is a corporate responsibility for local authority and health services. Adapted tricycles that have two riders side by side are used so people with complex needs can take part in mainstream activities. Additional benefits of improved cardiovascular fitness, limb strength, confidence and well-being are a positive side-effect of the activity.

**Highland Council** has developed Club M.E.D., a men's group set up to address the health and social needs of men with a disability. About 12-15 people are involved. The members run the group, helped by two members of staff. It is up to the club members to decide whether they involve family members, the group meets every week to play football. It also offers swimming, sauna, racquet ball and weight training.

Experience in horse management and care, is something that has also been supported by **Highland Council**. This project is in association with a local riding instructor who assists by providing support and expertise. The 4 people taking part organise the project themselves although guidance and advice are available from staff.

As part of the re-provisioning of day centres to new integrated facilities, **South Lanarkshire Council** opened Lifestyle in 2004. This is a purpose built building which integrates social work and leisure services by combining a day centre with a fully equipped community based leisure centre housing a pool, gym, dance studio and five-a-side pitches. People can attend classes and activities on their own or with support. There have been significant benefits for the people with learning disabilities who take part, from increased fitness levels to natural opportunities for mixing with the wider community.

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<sup>3</sup> Health Needs Assessment Report: People with Learning Disabilities (2004) NHS Health Scotland

Inverclyde based Parklea Association 'Branching Out' is a horticultural project. People with learning disabilities take part in stimulating and productive activities that interest them. There are 10 people registered at the project with an average of six people attending the project each day, five days a week. Three people from the local authority day centres also attend the project for half-day visits, five days per week. There is also attendance from a local special needs school. Around 70 people a week use the project. The current unit cost is estimated to be £3.18 per hour.

Heart Matters is a healthy eating and health living initiative at Whitehaugh, **West Lothian**. It provides employment and training opportunities for people with learning disabilities and links in with local health initiative. The benefits of the project are two fold – offering health and employment. 56 people attend this service for 3 days a week on average. Centre hours are flexible. There is also support in employment. Originally this service was funded by 'Have a Heart, Paisley' but has become self financing. The service is monitored and evaluated by funders and has been inspected by the Care Commission. It has full service user and family involvement and feedback has been enthusiastic.

There are plans to develop the project further by running a mobile fruit and vegetable shop.

Turning Point Scotland have developed a dog walking project with the intention of some people taking this up both as a hobby and an option for potential employment, there are also the additional health benefits of increased activity. Three men have benefited so far. The hours are flexible and this is a low cost, easy way for people to get involved in the community and possibly earn some money.

## 2. Employment and education

We received many examples of day services which were developing good links and new ideas to support people in employment and education. This report is not about employment, as this area has been addressed by *Working for a change?* but it is a very important aspect of people's experiences within day services, and we wanted to reflect the many examples that people sent to us that brought day service and employment together.

At the Unity Enterprise catering project in the **Inverclyde Council** Buildings two members of staff work alongside three adults with learning disabilities. There are three places from Monday to Friday. The intention is that individuals move to real jobs. Similarly, The Unity Enterprise at Fitzgerald Centre is another catering project providing training and work experience. Results are evaluated by people with learning disabilities getting a recognised qualification and jobs.

The Boyndie Visitor Centre in **Aberdeenshire** opened in May 2004, the Centre is managed by the Boyndie Trust and was part of Aberdeenshire's day service provision. The staff continue to be employed by Aberdeenshire Council.

The Centre is made up of:

- Six acres of gardens, ponds, woodland paths, complete with plant sales area.
- Café, gift shop and gallery displaying and selling local art, crafts and other produce.
- Supported workshop accommodation for small art, crafts and giftware manufacturing businesses.
- Display material highlighting other attractions and quality businesses in the area.

Over 50 unemployed adults, most of whom have a disability learn new work skills through individual work-training programmes. 35 people attend from Monday to Friday and there are opportunities to work with the Trust at weekends.

In **Angus Council**, The Supported Employment Team supports users into paid employment. The team work with local schools, colleges and Future Need Co-ordinators. The team also works closely with Job Centre Plus and other employment agencies so that the project is as mainstream as possible. Service users have a vocational profile. Ten people are currently in paid employment. 28 are in profiling, gaining qualifications, or in a placement There is still doubt amongst some employers, families and carers that people with learning disabilities can work. To counter this a marketing project has been developed, run by people with learning disabilities. The people who have found employment are very positive about their experiences.

**Aberdeen**-based Aye-Can is an aluminium can recycling project, which collects cans from schools, offices and supermarkets and operates from a 'mainstream' industrial unit. 20 one-day a week placements are offered and four people attend at any one time. Two members of staff support them and most people still attend a day centre some of the time. Costs are high, as they have taken on new premises which are not yet fully used. The unit cost is about £60.00 per person per day.

**Dumfries and Galloway Council** is developing interlinked pilot employment projects across the region. These comprise of:

- 2 cafés
- a bookshop
- a commercial forestry business partnership
- a nursery
- art gallery and workshop
- an picture framing workshop
- a print workshop

Some of these projects are at the planning and development stage and others are operational.

The projects could eventually provide for 40 people, working an average of 3 days per week. Daily operational times may be standardised but with flexible individual attendance. The projects are supported by £90,000 from the Change Fund<sup>4</sup>, with additional Council finding for administrative and planning costs. Recruitment can be a problem in the area so most of the posts in the projects are seconded existing staff, with relief staff to cover their posts.

Feedback about the services has been generally positive but with some anxiety about change.

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<sup>4</sup> The Change Fund was set up in response to recommendation 4 of *The same as you?* to assist local authorities put in place the recommendations of the review. (*The same as you?* 2004, pp 22-23)



Staff and service users from Beachview Lodge in **Highland Council** are planning to create an aesthetically pleasing and educational arts installation in woodland Dunrobin Castle. They hope to employ adults with learning disabilities in upgrading the nearby woodland paths. A nearby donated building will be used as a classroom. Accommodation that could be used for respite could also be developed in the longer term, which would also bring in revenue. Local businesses and colleges have been enthusiastic and have offered funding and specialist help. This project would offer opportunities to 20 people. The views of users and carers have been sought through review notes, consultation groups and reports from advocates.

**Highland Council** are also intending to establish a bookshop at Caberfeidh House. It will have a small hospitality area for customers. People of all abilities can work at the shop thus enabling them to experience many aspects of employment. The shop will offer flexible schedules for all seven people at the centre and will also provide work placements for pupils with learning disabilities from the High School.

Carers are pleased with the aims and progress of the project.

In **Orkney** an employment co-ordinator arranges work experience placements for service users attending the day centre and for others outwith. Arrangements have been made for users of the day centre to go on short-term work experience placements as hospital porter assistants. One service user has secured seasonal paid employment, working during the summer and attending the day centre when not at work.

About half of the service users benefit from the services for between one or two days, with flexibility being a priority. The employment co-ordinator costs are met by the day centre budget, . Orkney has found that employers resist giving placements to services users. Feedback from users and carers has been broadly positive. The Council hopes to establish an employment network co-ordinator post.

CAN-ABLE in **Perth and Kinross** is a service in Blairgowrie which gives people with learning disabilities the opportunity to experience work and training for work. Approximately 10 people per day use the project, 30 in total. The service is five days a week. Weekly cost of running the project is around £1346.

The Council held a development day with service users, workers and other agencies. We evaluate the project by feedback from people who attend their carers and staff. Information has also been gathered from employers and volunteers.

**Shetland Islands**-based COPE (Community Opportunities for Participation in Enterprise) is a social firm providing employment and volunteering opportunities for people with a wide range of different needs and learning disabilities. COPE forms partnerships and develops niche business, such as the Shetland Soap Company, so as not to impact on other local businesses. COPE employs 22 full time and 32 volunteer staff. The enterprises are open 6 days a week and hours of attendance are flexible. All staff and volunteers receive ongoing training. And COPE also provides training for other social firms from all over the country. There has been no formal evaluation but there is ongoing feedback between participants, staff and managers. Families and carers are invited to reviews.

COPE is unique as it provides more than one enterprise and offers an expanding range of activities that benefit the community as a whole. It is expected that COPE will grow in the future because of the increasing numbers of school leavers with learning disabilities.

Café Connect is a new employment project for people attending day services in **West Dunbartonshire Council** with eight people with learning disabilities employed on part-time contracts working over a period of 6 days a week. A café manager and support worker are also employed. The objective of this project is to become self-sustaining and provide secure employment.

In **West Lothian Council**, Café Mistura is a training provision for adults with learning disabilities. The café operates in the new Strathbrock Partnership Centre which houses NHS resources and various Council and other services. The café provides a catering service to the general public and staff within the building. Trainees gain experience in food hygiene, literacy and numeracy, communication and general food and hospitality skills. They can work for an SQA Level 1 qualification. The Café is supported by West Lothian Council and Capability Scotland.

Trainees are initially referred from another agency. The present contract is for up to 20 placements and there are now 11 people. The Café is open Monday to Friday, 08:00-16:00. Attendance is flexible. Feedback from both trainees and carers has been very positive.

## Further education

Links to Further Education are an important part of the day service experience, and the examples below describe how people with learning disabilities have been integrated into colleges. This enhances the personal development opportunities available to people, and helps people gain confidence and increases aspirations towards employment.

**Shetland Island Council** has made use of ASDAN, a curriculum-based learning programme aimed at promoting the personal and social development of learners. It is based at the Eric Grey Centre for adults with learning disabilities. 35 people attend this centre. ASDAN is a five days a week flexible programme. The programme receives £1,000 per year for equipment from Shetland Islands Council.

A local school has been using a similar scheme for children with learning disabilities and it has been proving successful and effective.

The OFTTI Project, managed by Lewis Castle College and **Comhairle nan Eilean Siar** (Western Isles Council) integrates people with learning disabilities into all aspects of college life. 69 people use the Project, based at the three sites in Stornoway, Benbecula and Barra. Students are aged between 16 and 60 and the project is open 5 days a week (Monday to Friday) between 09:00 and 16:00 but attendance is flexible. The project is jointly funded by the social work department and European Social Fund money. The budget covers all staff costs and other expenditure including consumables, site services and beneficiary travel.

The project hopes to expand the Barra site in conjunction with the building of new College premises on the island.

### 3. Day services and people with complex needs

With the increasing demand for day services to cater for a range of needs, we felt that it would be important to highlight some of the service developments in this area.

Kantersted Development for Adults with Learning Disabilities in Shetland provides short breaks and day services. The day service is for older people who find existing facilities too busy and noisy. A maximum of 5 older people can use this facility which operates flexibly within daytime hours. The day care element requires 80 staff hours a week and staff need training on

dementia and care of the elderly. This facility has come about because of pressure from parents and families, as well as from groups such as Special Needs Action Group.

**Renfrewshire Council** are developing services for adults with profound learning disabilities by creating a unit for a small number service users. There is a working partnership with Have a Heart Paisley to develop a physical fun and exercise group. The Council is also participating in a new exercise group which is run and evaluated by physiotherapists. Parents and carers had some concerns about the changes arising from this reorganisation and these were overcome through mutual discussion.

Seven adults receive services 5 days a week during current working hours. There is some flexibility depending on individual needs. 8 people receive services at specific times for 1 session per week. A further 20 adults from a variety of agencies receive services for 1 session per week. These services have no cost implications as they are being funded through current budgets.

Sense Scotland in the **Glasgow** Resource Centre supports more than 30 individuals and offers a range of community and centre based activities. Resource Centre-based care is necessary for people with complex needs. Plans are being made to relocate due to shortage of space. The new resource centre will be fully accessible to the local community and it is hoped that local groups will use the centre and mix with and work alongside service users. The services at the centre aim to be flexible and operate when the users need them. Support is provided during the week, evenings and weekends. Evaluation of the service is conducted through service reviews and family carer feedback.

In 2000 six young people in **North Lanarkshire** were either looking for adult day services or about to leave school. They all had complex learning and physical disabilities with no verbal communication. The families of the young people, ENABLE Scotland, social work staff and teachers and health staff all worked together to develop new day opportunities, using person centred techniques. How people communicated and their abilities and wishes were given a lot of attention. An ideal day, week and month were considered and a tailor made, flexible service was designed for each young person so he or she could be an active part of their community. The Independent Living Fund helped with funding.

The development of the service has been in full partnership with families and people with learning disabilities. Because the service is provided from and to the person's own home there is ongoing contact with families. Photographs, videos and a communication passport help the individuals to communicate the detail of their day to their families.

There are regular reviews of individuals, quality assurance systems, monitoring of service through council staff, and the development of an outcomes framework. The six young people have acted as ambassadors, showing that day opportunities do not have to be restricted.

#### 4. Organisational change

A number of submissions described substantial restructuring of services in order to meet the recommendations of *The same as you?*. In all of the examples given, service user and carer consultation played an important role. Involvement in the early planning stages helped to allay fears associated with change, thus being a necessary prerequisite to any service development.

In November 2003, **Fife Council** closed Woodlands Day Centre in Dunfermline, replacing it with 9 small bases in the West Fife area. This new West Fife Community Support Service uses a person centred approach to offer individual support to help people get the lives they want. The 9 adapted bases are housed in community centres, but are mainly used as back-up facilities. Over a hundred people use this service on a flexible basis with some being supported at evenings and weekends. Through negotiations with the trade unions, staff terms and conditions have been altered to suit.

An independent evaluation by Scottish Human Services (SHS) concluded that significant results had been achieved. People have more opportunities within the community, get more jobs and training, build stronger relationships and feel very positive. Regular meeting kept all stakeholders informed and involved. There are 6 day centres remaining in Fife and the Council are consulting with service users and carers about developing future services.

**West Dunbartonshire Council** established a service user reference group in September 2003 to involve individuals in service redesign and to inform the Partnership in Practice (PiP) Agreement<sup>5</sup>. 10 people are involved and have produced a shadow PIP. A number of new services have been developed:

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<sup>5</sup> Partnership in Practice Agreements or PiPs were developed as a result of recommendation 1 of *The same as you?* (2000) pp 15-18.

- A community inclusion service started in April 2004. Three voluntary organisations provide individual day supports for people attending traditional day service. People with complex needs are included in the project. Phase one will provide 360 hours a week flexible support. The first ten service users have been referred to the providers.
- Social Work Day Services Alternatives is a new service for 14 people who use traditional day services, including those with complex needs. It will provide flexible support packages.
- 2 part-time posts have been commissioned through the independent advocacy project for people attending traditional day services.
- A full-time post has been commissioned through the local advocacy service to support people with learning disabilities and carers.

In the **Scottish Borders**, Brothers of Charity has reviewed its day services and is moving towards providing more support for employment for people with learning disabilities, including more job coaching, skills training and the development of social firms. A project called *Connections* has been established to help individuals with high support needs; this will include use of a community based resources. Day services for older people with learning disabilities have also been reviewed. 71 individuals use the work-related services and demand is growing. 20 people are using *Connections* and 41 are using two other day resource bases. The majority of users are over 60. Most people are using the services part-time basis.

Evaluation is through the person's individual service review. The organisation has links with Glasgow University and hopes to participate in a research study that will help to establish and evaluate social firms.

**Clackmannanshire Council** has begun to move away from a building based service. Support staffing levels have been reviewed using money from the Change Fund for additional staff. The Council has implemented person-centred planning training. There is an integrated support employment project within day support services. The recent appointment of a local area co-ordinator (LAC)<sup>6</sup> is related to changes in day services, the role of this LAC is to try to divert new service users from day centres. The LAC helps service users to get day opportunities in the community. Around 80 service users use this service in a typical week and the service is trying move to more flexible opening hours.

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<sup>6</sup> Local Area Co-ordinators (LACs) were established as a result of recommendation 2 of *The same as you?* (2000), pp 18-20



Evaluation is by questionnaires and evaluation of person-centred plans. Advocacy support is also available for evaluations. Users and carers are involved in the planning process through user committees, local planning groups, advocacy organisations and carers' centre input. They indicate that things are getting better. There is some fear of change as this can be seen as a reduction in service.

**Dundee City Council** is developing new day opportunities by moving from traditional day centres to supporting individuals into mainstream activities. For those with complex needs there will continue to be some centre-based provision. This new service has meant that staff from the day centres have been transferred. New posts have been established with new job descriptions. All day staff have also had training on person-centred planning. Service users attend services 3½ days on average. The service is open Monday to Friday and it is hoped it can be extended to evenings and weekends.

Service user consultation groups were set up. Five people were employed by an independent voluntary organisation to get the views of service users. There are plans to keep the existing 2 projects and introduce a third team. Additional teams will be developed from 2005-07 to benefit 115 individuals. The evaluation has shown an enthusiastic and positive response from the users and carers. They do not wish to return to the previous day service model.

Community Network in **East Ayrshire** was established in August 2003 and provides care and support to people with learning disabilities living throughout East Ayrshire, including those with high support needs. The network helps them to access resources within the community, such as employment, education, volunteering and social and recreational activities. Links with local services mean that people can access mainstream health or learning related groups. The Gateway Community Centre operates in normal day centre hours but acts as more of a drop-in centre or base. 85% of people attend day support 5 days a week, with 15% receiving services 2 to 3 days a week; 8% of people receive their entire service outwith the centre. On average people spend half their time being supported outwith the centre.

The aim of the network is to develop day services in a more flexible and person centred manner. Groups are smaller and staffing has increased. Independent support providers are funded to help individuals pursue their own day activities. Those who have experienced the new day services do not wish to go back to traditional day services. User involvement is high with



various groups meeting on a regular basis and contributing to the redesigning of services. Carers are encouraged to visit the centres as well as attending regular carers' meetings. There are plans to expand the support given beyond usual day centre times. There are also plans to include children's services to improve transitional difficulties.

Since 2003 **Edinburgh City Council** has been modernising its day services through the appointment of a Change Manager and Change Teams. One day centre officer with responsibility for change has been placed in every day service. The aim is to move away from centre based services to community bases and to design services around person centred plans and individual choice. The staff are also working in partnership with other agencies to achieve more opportunities in employment, education, volunteering and leisure. All 720 people with learning disabilities who use services are benefiting. Attendance at services varies and flexibility is evolving.

**North Lanarkshire** carried out a review of day opportunity services during 2002-03. The Review involved wide consultation with all key stakeholders. A set of essential characteristics was agreed ensuring that services for people with a learning disabilities would be person-centred, integrated, flexible and delivered around the person's needs. People with learning disabilities, carers and representatives from social work, health, community services and the trade unions have all worked together to implement the recommendations.

One of the most significant and overarching changes has been to ensure a co-ordinated approach to developments within a locality-based model of support. The change has involved a complete redesign of job description and regrading for staff. More flexible working approaches mean that staff support people where they live to be part of their local community. Training and development opportunities have focused on being person-centred, understanding communities, community mapping and organisational change. Locality planning forms the basis of joint approaches between social work and health colleagues. By working well together, a more co-ordinated approach to supports is developing, thus saving duplication of contact for people and their families.

Whilst the existing day centre buildings still remain, people are increasingly supported to access local resources, activities and integrated groups which best meet their needs based on person centred planning. The wider community are being encouraged to make use of those existing buildings.

A programme of joint capital work has developed a range of provision of accessible community facilities across the authority. The joint work has not only meant compliance with the Disability Discrimination Act 1995, but provides adult care and change facilities way beyond the basic minimum. Increasingly libraries, museums and community centres across the authority have tracking, hoists and plinths available for the dignified care of people with the most complex needs in community settings. It is anticipated that by the end of the process each township in North Lanarkshire will have an accessible personal care and change area to supplement the existing range of adapted toilets.

At a locality level, work is progressing in implementing individualised care and support services which best meet peoples' needs in flexible and responsive ways. Within the context of the ongoing organisational and systems change, localities are gradually developing person-centred supports which:

- are delivered at times which best meet individual and families needs
- provide appropriate support to enable individuals to access community resources
- explore transport options available which best suit individualised needs.

**South Lanarkshire** social work resources has 25 staff providing service users with day opportunities that are alternative to day centres. These include support to access college, work experience and training and paid employment. The Council did a Best Value Review in 1999 in which there was some strong support for centre based support to continue. The Council is also developing 5 new integrated facilities, two are now open (see below). These facilities will allow some centre-based activity to be retained but will also provide the opportunity for increased social integration.

- The Lifestyle Centre in Cambuslang is one example. Opened in June 2004, this facility has state-of-the art furnishing. The building provides a day service and is integrated with a leisure complex. This includes a full sized swimming pool, a fully equipped fitness suite, dance studio and five aside football pitches. There is also a café which offers employment opportunities for service users.

- The Murray Owen Centre in East Kilbride is another example of a resource for the local community. The building houses a large function hall, internet café (run by service users), a dining area, meeting and group-work rooms, a dance studio, art room, training kitchen, 2 fully equipped personal care rooms and a state-of-the-art multi-sensory room.

Some carers have been fearful of the move from traditional day centre support but with the success of 2 new centres they are now seeing the advantages. There have been some difficulties getting partner agencies on board and it is a challenge to integrate fully new facilities still in their infancy. Employment opportunities need to be improved and money has been invested from the Change Fund to create an employment post.

Following another Best Value Review, Glasgow Learning Disability Partnership decided to co-locate Area Learning Disability Teams with social work field-work staff, nurses, allied health professionals and medical staff, within day services premises. These 'hubs' are the focus for all learning disability service activity in each locality, with one phone number providing a contact for all health and social work services needs for people.

This programme, involving a £3 million capital investment, is nearing completion, with only one locality still to be co-located. As day services developed, and people spend more and more time outwith the building, there was space in buildings for re-configuration into office accommodation, although some buildings required extension.

There have been many local initiatives developed through this co-location of staff, with lots of issues faced by day service staff being resolved at a very early stage due to consultation with colleagues. Overall, the programme has been a resounding success.

In **Glasgow**, a day service depute manager worked as a care manager for part of the week to help school leavers develop opportunities outwith day services. There were remarkable personal and organisational spin offs from this work and good outcomes for service users.

## Summary

Our analysis of the submissions from local authorities and Independent providers highlighted a number of developments in the way that day services are changing and evolving across Scotland:

- Clearly there is greater emphasis on developing services that are linked to employment training and work experience. A considerable number of submissions described changes to daily activities within centres that created opportunities for individuals to gain experience in this area.
- Quite a number of submissions reflected the increasing trend to a more person-centred approach with more emphasis on individualised packages. Whilst it is apparent that in many local authorities centres and buildings still play a feature in the support that is on offer, what happens within them and, more importantly, outside them is changing in an attempt to offer more choice and greater opportunities for social inclusion. In some areas this has resulted in quite significant change; the centre being viewed much more as an administrative base, with the emphasis on developing facilities across the local area.

### Case Study: Derek

*My name is Derek, I live on my own now but used to live in a hostel. I'm happy with my house, I'm quite a busy person and very independent. I like to make up my own mind about what to do with my time. I started attending a day centre in 1985 and did that for 18 years. The centre bus collected me and took me home every day.*

*The day centre was quite good sometimes because there were things I liked doing like woodwork; but as I got older I wanted to do other things and I was interested in getting a job. I'm really interested in politics too. The people who went to the centre were encouraged to start having committees a few years ago and I was on the committee. I felt that I had a lot to say about the kinds of things I wanted to do with my life and what the Council could do to help me. I told them what I thought a new centre should be like and what I'd like to do there.*

*When I moved away from living with my mum, she was more worried than me about how I would manage; I knew that there were people to help me though. Now that I live in my own house I still need help from my support workers but need less help. I learned how to travel about on my own on public transport and do this every day. I travel to different colleges and I work one day a week in a café. The café is part of the new type day services that started in 2003 and I get a training allowance whilst I work there. I am doing an SVQ in customer care services. I think my job at the café has been really good at helping my confidence with meeting other people and using money. It's a good step towards getting a full time paid job which is what I'm going to do in the future*

*I'm not a user at the new centre now but I sometimes use the drop-in service there and join in with a community activity or use the internet computers or something.*

*Lots of different community groups use the building and I've met a lot of different people. I know that there are staff there who can help me out if I have a problem but I don't have to follow any kind of programme because that's not what I need. I enjoy dropping into the Centre and like that I can do my own thing.*

*When I want things to change something in my life now I have a social worker and support workers who listen and help me to change things. I go shopping, visit friends, chat on the phone and look after my house now. I have more choices about what to do.*





## CHAPTER 5

# Key themes

Some important key themes emerged from the information gathered from the service users, family carers and service providers who contributed to this report. These are familiar and embedded in *The same as you?*. They should help guide the development of day services over the next decade.

1. Users, carers and staff want varied and flexible services offering a mix of opportunities.
2. They want people with learning disabilities to be included in, and to make valued contributions to, their local communities.
3. People with learning disabilities want to be involved in purposeful activity, leading to employment that suits the individual.
4. A person centred approach is the ideal.
5. Service user and family carer involvement in running services is vital.
6. Partnership working with a broad range of stakeholders is essential.
7. Aspirations are greater than available resources.

## **1. Varied and flexible services**

The report described a wide range of services 'with and without walls'. Increasingly buildings are seen as a base from which people go out into the community or as places offering a range of options, some of which have a general community use. Such places can be seen as centres for social inclusion, very different from the old 'day centres'. Their use by members of the public, including a large number of school children, means there are natural opportunities for adults with learning disabilities to participate in activities like any other member of the community. However, not all services achieve this and many people with learning disabilities said they did not want to be isolated in day centres and complained about boring routines and activities. There is increasing commitment to helping people with learning disabilities take part in mainstream activities and occupations. This is valued greatly but can make significant demands on staff time.

The report has identified flexibility and opening hours as key matters, with some organisations wanting services to be available in the evening and at weekends, but a number of service providers noted the intention to extend service opening hours but at present it seems that intention is more common than delivery. There are complex staff and human resource matters to be resolved when conditions and hours of employment have to change.



**Case study: Frank**

*My name is Frank and I live in Inverclyde. Until my move to the Outreach Programme I had spent 34 years in day centres. Most of the staff there were fine and very caring but there was not much choice of activities. Things did start to change during my last couple of years at the centre. We started to get out more but this was usually in groups and on the centre's bus.*

*In April 2000 I was given the chance to join the Programme which was a community inclusion pilot project. When my keyworker explained to me what it was all about it was a bit scary but he was moving to the Programme as well which made the decision a wee bit easier. Up until then I had never been given the chance to travel independently, find a job or voluntary work. Sometimes I wasn't even asked about activities I would like to try. I always had to do the things that were on offer at the centre.*

*At first my family were really worried about my safety because I would be out more and travelling on my own. That made me a wee bit nervy as well. The staff at the Programme were very helpful and once the bus drivers got to know me they would watch out for me and wait for me if they saw me coming. I have managed to get a voluntary job doing reception work at a local resource centre. The staff there have been very good to me and I can't fault them. They have made me feel very welcome as a team member. The biggest difference for me is the way staff work at Outreach Programme. I am asked what I would like to do not told. Sometimes they don't ask me, I tell them what I want and they support me if it's possible. They call it profiling. Now I feel that if I want something or make a decision people will listen to me.*

*I have never been so happy with the move; it has given me a real boost and a lot of confidence. I am becoming more independent and my dream for the future is to have my own flat. If this hadn't happened I might have spent the rest of my life in a day centre.*

**2. Inclusion in local communities**

People with learning disabilities are becoming more involved and included in their communities. There is still social exclusion for people who never leave their homes or whose only outside activity is the day centre. Traditional day centre based services are providing more opportunities for people to take part in community activities. New, alternative day opportunities are much more community based. We heard much about the involvement of people in the community; both in mainstream activities and those designed for people with learning disabilities.

This is a key objective of *The same as you?*. It is not easy to achieve and there is a mixed picture across Scotland.

Local area co-ordinators (LACs) can help people build community networks. They should have strong links with community groups and natural communities, as well as links across the professional boundaries of health, education, social work and the voluntary sector. LACs are in a good position to act as a bridge linking individuals with a variety of opportunities. When people have these connections their circles of acquaintances, colleagues and friends grow and develop, making a difference to them and to the community. However, LACs are only part of the picture, they do not replace the need for all services to be working towards community inclusion.

There are a number of initiatives where people with learning disabilities are making an important contribution to their local community. For example, there are projects where people with learning disabilities are improving the local environment and helping people to have access to the countryside. Recycling projects are making communities aware of important environmental issues and are providing some employment opportunities. Such positive contributions help the rest of the community to see people with learning disabilities as equal and valued citizens.

Risk Assessment is an important factor when considering community involvement. Being involved in community activities or employment can, on occasion, lead to problems of bullying, abuse or exploitation which can happen to anyone. Family carers can worry about the risks which will confront their relatives when they have more independence. Risks need to be assessed and managed on an individual basis. The principles of the Adults with Incapacity (Scotland) Act 2000 can help with decisions about risk. These principles require intervention to:

- benefit the individual;
- be the least restrictive option compatible with a person's safety; and
- decisions should take account of the views of the individual and of family carers.

Managing risk can be very difficult for staff. They need proper supports in working with people with learning disabilities and family carers, and with other organisations.

### 3. Meaningful activities

People with learning disabilities, like all other citizens, want to choose what they do during the day. They want to take part in valued activities which contribute to a sense of wellbeing and belonging. There are some reports of dull and repetitive activities giving a poor quality of experience. People with learning disabilities should have a personal life plan which includes their hopes and dreams and ways of achieving them.

Research shows that people with learning disabilities can spend a lot of time disengaged from the activities around them. Service providers should review whether this is happening and, if so, make the appropriate changes. People should not just be fitted into activities which they do not like and which do not meet their needs.

The biggest desire we heard about was for real jobs with real pay. More people with learning disabilities are in employment. But many are not paid a real wage. The *Working for a Change?* and *Go for it!* reports provide more detail about how to help people with learning disabilities to get real jobs.

### 4. A person-centred approach and personal life planning

Not surprisingly users of services and family carers preferred a person-centred approach, with services revolving around an individual's needs, rather than requiring people to fit in with the provision available. Many of the submissions describe personal life planning with people with learning disabilities. This helps them identify their needs and aspirations and then to design the appropriate services. However, only a fifth of people with learning disabilities in Scotland have a personal life plan.

Personal life plans do not have to take lots of time to complete. What is important is that the plan is fit for purpose and, above all, puts the person with learning disabilities at the centre of things. Plans should start with what people with learning disabilities can do rather than what they cannot. It may not be possible to implement the entire plan right away but the person with learning disabilities needs to see that some things in the plan are actually happening. People may need support to understand that it may take some time to make elements of their plan happen.

People with learning disabilities sometimes complain that their personal life plans sit on the shelf with nothing done to implement them. Plans should therefore be reviewed regularly to see if changes are needed and to check that at least some elements of the plans are actually being implemented. Plans should have both quick wins and longer term goals.

### **Case Study: Susan**

*Susan is 30 years old with a beautiful open smile and long brown curly hair. She loves music, bowling, shopping, socialising, aromatherapy and all things feminine, from clothes to nail varnish.*

*Susan has profound and multiple learning disabilities, with complex health needs. Her chronic chest problems mean that she requires chest physiotherapy and postural drainage when secretions gather. She has asthma, (treated by nebulisation), and epilepsy. All her food, drink and medication is taken via gastrostomy tube. As she has no balance or head control, Susan wears a body brace and neck collar. She is quadriplegic and wheelchair-bound. She needs to lie down for periods of the day in order to change position and also must have daily physiotherapy to her limbs.*

*Susan goes to the centre run by her local Council, which offers day opportunities to people with physical disabilities. Her mother says that Susan is very happy there. The family are kept in close touch with staff and think highly of the service:*

*The centre uses a key worker system, and staff respond sensitively to day-to-day changes in Susan's health and energy levels:*

*'My daughter enjoys getting out and about. However, her health very much dictates how much this is possible. A very good mix has been established at the centre: on her good health days, going out is no problem, but on days when she isn't up to going out, a wide and varied programme of activities is on offer within the centre.'*

*This programme includes music, boccia, indoor curling, art, craft, baking and beauty therapy. The staff's ability to meet and work around Susan's health needs is essential if she is to take part in activities, both community and indoor. A physiotherapist based within the centre provides direct therapy herself and also gives staff ongoing support with health care tasks, so building their confidence. Susan's mother says:*

*'Medical procedures can be barriers to people as care staff in some centres are not allowed to do certain tasks. I believe that, with correct training and supervision, many can be carried out by care staff, and not always by nurses. However, guidelines should be clearer on who can do what.'*

## **5. Involving people with learning disabilities and family carers**

All the submissions from the local authorities and the independent sector report that people with learning disabilities and family carers are involved in the planning and delivery of day services. Some organisations do not say a great deal about how this is actually done or about how people with learning disabilities and family carers are given support to become involved. We know this is crucial in determining whether involvement is successful.

The surveys of people with learning disabilities and family carers showed that some people with learning disabilities and family carers do not feel they are consulted. Generally people tend to be satisfied with what is being done to modernise day services, provided they feel they have been consulted from the outset, and that their views have been taken into account.

There can be tensions between what people with learning disabilities want from day services and what family carers want. Family carers often stress the respite element of day services, their routine and security. People with learning disabilities stress the need for choice and inclusion.

People with learning disabilities and family carers are now more involved in the planning and delivery of their services than ever before. *The same as you?* says services should be person centred, this cannot be achieved if people with learning disabilities and family carers are not fully involved as contributors to the planning and delivery of services.

## 6. Stakeholder involvement

It is widely recognised that implementing *The same as you?* should not just be the responsibility of social work services but should be a corporate agenda for local authorities, and their partners, and for society as a whole. There are examples in this report of project partners collaborating to deliver good outcomes for people with learning disabilities and family carers. As people with learning disabilities become more visible and included in their communities more agencies should develop their interest in them to help make *The same as you?* a reality for people with learning disabilities across Scotland. Partnerships should be real and not just people from different agencies coming together for the sake of appearances. Although some partners will be more active than others they all need to share the goals of *The same as you?*

## 7. Aspirations and affordability

People with learning disabilities and family carers want, and increasingly demand, a good quality of life and the services to help them achieve this. This is the goal of *The same as you?* Local authorities and other service providers have to deliver services for the money available. Helping people with learning disabilities to get a good quality of life is not just about money. One of the themes emerging from consulting with people with learning disabilities is that they want to spend time with people who are not paid to be with them. Local area co-ordination can be a way of helping people with learning disabilities identify their needs and meet some of them by mobilising community resources rather than using paid support workers. Local area co-ordinators (LACs) across Scotland are working to help people with learning disabilities to be included in their communities. Often this inclusion is achieved without the involvement of paid support workers.

Lack of resources has been identified as a major issue by people with learning disabilities, family carers, local authorities and independent care providers. Whilst some support needs can be met by maximising use of community resources and nurturing positive relationships with members of the local community, there is a vital need for the creative use of available resources to provide the right paid support.

Direct Payments can be beneficial in improving an individual's access to a wider variety of activities and services. Some case studies show a few people with learning disabilities benefiting from Direct Payments used to pay for day services which have been arranged by the individual or their family. One of the barriers to the increasing use of direct payments is that funding is often tied up in existing day services, their staffing and buildings. More work needs to be done to see how people with learning disabilities and their families can use Direct Payments to buy good quality services.







## CHAPTER 6

# Opportunities and obstacles in modernising day services



This review has highlighted the desires and needs of people with learning disabilities, providers' aspirations and some encouraging developments in practice. It is clear that in the next decade there will be opportunities to grasp and obstacles to overcome. The main challenges are:

1. Staffing
2. Education and Employment
3. Transport

## 1. Staffing

Not surprisingly the responses emphasised over and over again the crucial contribution of staff in achieving the goals of *The same as you?*. The number of staff, their quality and attitudes, their training and support and their ability to work with a new agenda are priority matters for the development of day services.

### Staff ratios

There were many comments about the importance of staff resources and their influence on the delivery of a quality service. We were often told how providing a 1 to 1 service, which has great benefits for the individual concerned, can adversely affect the rest of the group.

It is clear that users appreciate 1 to 1 support and benefit from it. Family carers are also positive about 1 to 1 support. Many people struggled to find new and imaginative ways of increasing 1 to 1 working with people whilst still running an acceptable group based service.

We were told that the problem of providing support to a group of people as well as 1 to 1 day service can sometimes be overcome, in part, by the use of community service or local volunteers. The ILF has also been used to help people develop more individualised community-based services. These are welcome developments which show how services and resources are being used to complement one another.

The kind of activities that people with learning disabilities are involved in also affect the number of staff required. Some activities require two members of staff to support one person. The variety and creativity demonstrated in the responses to the questionnaires is testament to the considerable efforts made by staff to develop new ways of working.

However, not all changes have been for the better and some service users indicated that some elements of their day service, such as outings to other places and access to activities based in day centres, such as art, pottery and computing had declined.

Day Services are inspected by the Care Commission who set minimum numbers of staff that should be on duty. However, the model used to determine the number of staff can vary across the country and specific services. The changing nature of day services requires that a new way of assessment of the needs and number of service users is required.

### **Staff training**

Day service staff are subject to registration by the Scottish Social Services Council. At present managers must hold, or be working towards, an SVQ level 4 or equivalent qualification as well as a management qualification. Basic grade day services staff will become subject to registration in April 2006 and will be required to hold a level 3 qualification in social care or the equivalent. These requirements are welcome and help to enhance the professional nature of the job being undertaken. They also help to reassure people with learning disabilities and their families and carers of the suitability of staff working with them.

Job definition becomes increasingly complex when the method of working becomes more individualised. Skills which were very well suited to people working within traditional day centres are not always easily transferable to working in community based individualised services. Staff development is critical if people are to understand the changing nature of their role and feel confident in their abilities to deliver a new service. It is the responsibility of employers to ensure their staff get the appropriate training and development.

There are several examples of staff being supported to undertake both formal and informal training. For example, Glasgow invested heavily in an SVQ programme to assess people working for SVQ Level 3 in care, SVQ Level 4 and the registered manager award. Over 100 people gained qualifications within 18 months, thus confirming people's abilities and providing a platform for further development opportunities. One of the biggest challenges was persuading staff this programme would be achievable. There was tremendous mutual support and a great sense of achievement when the programme was completed.

There were also good examples of service users influencing the training needs of staff.

## Recruitment and selection

The involvement of service users in the recruitment of staff was noted in a few of the comments from people with learning disabilities. Some people had been involved in the recruitment of staff who would work with them and their peers. This was a feature of successful projects where people with learning disabilities were very much at the centre of service development. However, overall such involvement did not seem common and it is important that it should develop. A common theme was lack of choice over staff and key workers.

Everyone involved in the recruitment and selection of staff requires training for this important area of work. This of course includes people with learning disabilities who need appropriate preparation and support to ensure that their involvement is not simply tokenism.

## The supervision and management of dispersed services

Some submissions described the changing nature of the supervisory relationship between staff and managers. In building based day services managers can actually see staff's work with service users and so can form a judgement about its quality. In dispersed, community-based services the chances of this happening are less likely. Managers must therefore develop different ways of assessing the quality of services received by people with learning disabilities. These should include normal supervision requirements, the auditing of case records and occasional joint visits to service users. Systems are also needed to ensure that those who receive services are involved in assessing their quality and any developments needed to improve service provision.

## Absence management

A number of submissions commented on the difficulties that people with learning disabilities face when staff are unable to provide a service when they are on sick leave. A carer commented that there was a need for set routines so that when activities get cancelled because of staff sickness people do not just sit around. We were also told that staff ratios should take account of annual leave and staff sickness.

We do not have the information which would make it possible to compare sickness rates in learning disability services across Scotland, or between the more traditional day centre based services and those in the community. It would be useful for local services to collect this information and make comparisons between various services. Staff absences are less likely when people are well motivated and enjoying their work. Changes in service delivery can bring changes in staff roles. It is important to ensure that people have responsibilities for which they are suited and which they enjoy.

## 2. Education and employment

People with learning disabilities, like all other citizens, need to develop their potential throughout their lives through a variety of education and training opportunities. It is clear from the submissions that these are some of the most valued activities. For some people they are also a starting point for employment which is an important goal for increasing numbers of people. The report *Working for a change?* shows that many people have achieved far more than carers or staff thought possible.

The number of submissions focussing on education and employment is encouraging. There are many examples of innovative employment projects. Both those which provide employment just for groups of people with learning disabilities (non-open employment) and those which help people with learning disabilities get work on the open market. Much of this would have been thought impossible a decade ago. However, developing employment opportunities requires knowledge of current government employment policy and benefit implications. Persistence is needed in the face of employer resistance, sensitivity to any concerns family carers may have and ingenuity in obtaining the resources, especially staff time, for development work and individual support.

The submissions relating to employment and education describe how these matters have been tackled. Information and help can also be provided by a number of government initiatives. The current policy context for employability is positive. The Scottish Executive is developing an Employability Framework for Scotland which will provide a strategy for handling employability development for all groups. In addition, there are various relevant pilot employment projects supported by the Department for Work and Pensions. These include:

- Pathways to Work
- New Deal changes

## Pathways to Work

These projects focus on people receiving incapacity benefit, recognising that some of these recipients would like to work. Assessment is based on what people can do, rather than what they cannot. The implication for a person's benefits are also examined.

These pilots provide:

- Early support from skilled personal advisers, including work-focused interviews and action plans;
- Access to a range of specialist programmes, including new rehabilitation services provided jointly by Jobcentre Plus and the NHS;
- Greater financial incentives to work, including a Return to Work Credit of £40 a week for 52 weeks for those finding a job that pays less than £15,000 per year and access to a discretionary fund of up to £300 to help find a job;
- More support for people with health problems who move from an incapacity benefit to Job Seekers Allowance (JSA).

(More information is available at the DWP Website:

[www.dwp.gov.uk/publications/dwp/2003/pathways2work.pdf](http://www.dwp.gov.uk/publications/dwp/2003/pathways2work.pdf))

## Building on New Deal: Local Solutions meeting individuals' needs

This government paper shifts the emphasis from a top down programme to a person centred one focussed on the specific needs of individuals and employers. It emphasises flexibility, devolution and local discretion.

(More information is available at the DWP Website:

[www.dwp.gov.uk/publications/dwp/2004/buildingonnewdeal/index.asp](http://www.dwp.gov.uk/publications/dwp/2004/buildingonnewdeal/index.asp))

## The New Futures Fund (NFF) Initiative

The introduction of the NFF initiative anticipated many of the issues that are now at the heart of the policy agenda. The fund was initiated by the Scottish Executive in 1998 and managed by Scottish Enterprise. It takes a holistic approach to employability enhancement and aims to assist the most disadvantaged target client groups to develop the skills, knowledge, attitudes and attributes they need to be more employable. The target group was people aged 16-34 who wished to move into the labour market and for whom there was no existing suitable employment and training provision.



Although NFF ended in March 2005 it has produced a range of case studies and valuable information and guidance on how to deliver employability support. This could be directly relevant to the development of this part of a day service. The Scottish Enterprise website, [www.scottish-enterprise.com/newfuturesfund](http://www.scottish-enterprise.com/newfuturesfund) has a number of useful documents including:

- The Evaluation Report for Phase Two
- The Employability Framework and Employability model
- Case studies

The framework and model are practical guides on how to set up or change a service. They also identify what is needed to help service users' progress towards employment, training or education.

Networking with the right agencies is crucial. The range of stakeholders needs to be broad to maximise opportunities and ensure all aspects of delivery are covered. In some areas small changes could impact significantly on services for users. One of the key lessons learned from the New Futures Fund projects is that there are other organisations who can offer specialist employment support.

### 3. Transport

There are many problems in ensuring reliable, comfortable transport for people with learning disabilities some of whom travel for 2 to 3 hours a day between their homes and centre or project destinations. The special buses common in many parts of Scotland are uncomfortable and differ from other forms of transport and which can contribute to a sense of stigma. Responses from the majority of people with learning disabilities were they would like to use public transport.

In cities and large towns accessible buses and taxis are becoming common and drivers have had training in disability awareness. This has still to be replicated throughout the country.

The very provision of special transport has contributed to a dependency on it by service users who could readily use, or learn to use public transport. However, knowing that transport is provided door to door gives some service users and family carers a sense of security. They are concerned about the potential risks in using public transport. For public transport to be a real option for many service users its accessibility, safety and availability has to be

tackled. There are special problems in rural Scotland where there is very little public transport.

The move to more localised community-based services has had a positive impact and people are spending less time each day travelling. When people are out and about in their communities the opportunity to develop confidence in using public transport is enhanced. Where people can use public transport regularly they increase their network of acquaintances – drivers or people they meet at the bus stop or who travel the same route. Through such networks they may make lasting friendships.

## Conclusion

*The same as you?* set out to improve the lives of people with learning disabilities and their families. It recognised that this would need considerable change, and involve a more person-centred approach that would allow people with learning disabilities to realise their potential and achieve their ambitions. Leading a full life and being included is important for everyone living in Scotland. The delivery of day services is changing across Scotland and there are many examples of more choice, more freedom and more independence for people with learning disabilities.

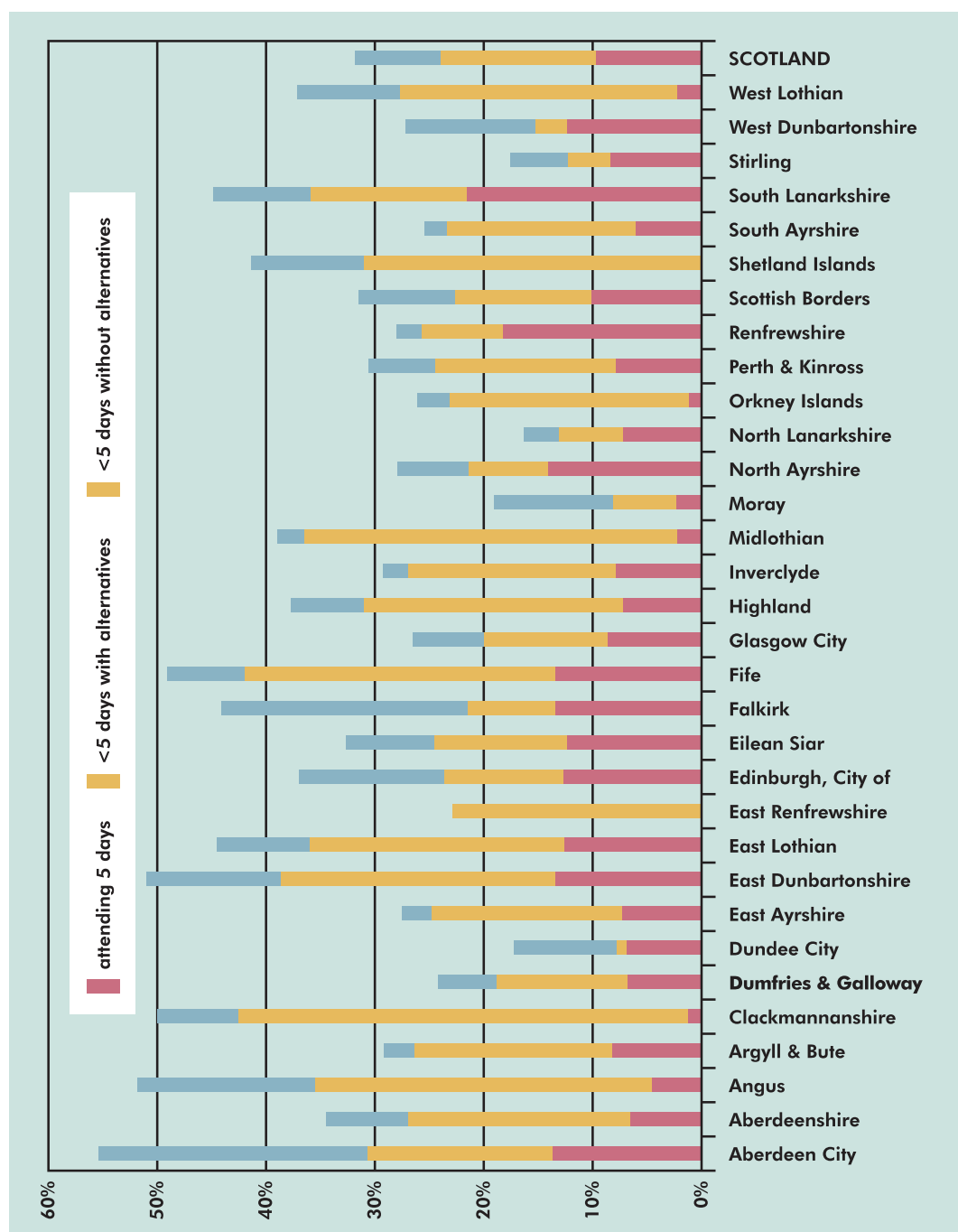
It is clear from the evidence collected for this report that many people with learning disabilities and their family carers have positive experiences of the changes that have been made to day services. It is also clear that some people have not had a completely positive experience and feel let down by the lack of consultation, and involvement, of service users and family carers in deciding how new services will operate. In order to ensure that service users and family carers influence the development of new services it is important to give opportunities to both of these groups to be involved and to ensure that re-designed day services meet their different needs. The process of involvement should also continue as part of the person-centred planning of the individual.

It is clear that there has been significant progress in the last five years and it is encouraging to see the progress being made in Scotland to develop better, more flexible and individualised day opportunities for people with learning disabilities. This report aims to inspire those responsible for the development of day opportunities; to be more aware of the needs of service users and family carers and to involve them in the development of services that fulfil the recommendations of *The same as you?*



## ANNEXES

## Annex 1: Proportion of adults with learning disabilities visiting a day centre by local authority, typical week September 2004



The chart shows the percentage of all adults known to be attending day centres on a full time basis, on a part time basis with alternative opportunities and on a part time basis without alternative opportunities. So, for example, in Aberdeen City 14% of adults known to the social work department attended 5 days a week, 17% attended for less than 5 days a week and had alternative opportunities and 25% attended for less than 5 days a week and didn't have alternative opportunities.

## Annex 2

### Membership of the Day Services Sub Group

Maria Brown	Inverclyde Council
Yvonne Cavanagh	Scottish Enterprise
Ursula Corker	Family Carer/Carers' Scotland
Julia Cowie	Values into Action
Camilla Fowler	Scottish Borders Council
Lorraine Kennedy	Scottish Consortium for Learning Disability
Ian Kerr	Scottish Executive/Social Work Inspection Agency
Stuart Landels	Clackmannanshire Council
Rhoda MacLeod	South Lanarkshire Council
Colin Meehan	West Dunbartonshire Council (co-chair)
Joe McGeady	Renfrewshire Council
Jessie Roberts	PAMIS
Steven Robertson	People First (Scotland) (co-chair)
Linda Sheridan	Advocating Together, Dundee
Amanda Taylor	Glasgow Learning Disability Partnership
Polly Wright	East Lothian Council

Professor Juliet Cheetham and Anne Dagg (the Scottish Executive) assisted the Group in preparing the report.

## Annex 3

### Glossary

The following glossary explains the meaning of words that appear in the text.

<b>Advocate/ Advocacy</b>	Someone who helps people with learning disabilities to say what it is they need and to make their own decisions. See citizen advocate and self-advocate.
<b>Allied Health Professionals or Professions Allied to Medicine (PAMs)</b>	These are physiotherapy, occupational therapy, chiropody, radiography, dietetics, remedial gymnastics, orthoptics, art, music and drama therapies.
<b>Asperger's syndrome</b>	This is a type of autism (see below) that some people of average intelligence and language ability have. They find it particularly difficult to understand what other people think and this makes it hard for them to communicate and act appropriately.
<b>Autism spectrum disorder (ASD)</b>	A lifelong, complex condition resulting in mild to severe social, language and communication, and thought and behavioural impairments.
<b>Behaviour analysis</b>	Looking into the cause and effect of behaviour based on what has happened in the past.
<b>Brokerage service</b>	Somewhere people with learning disabilities can go to get independent help in deciding on and buying the services they need.
<b>Capital</b>	Money spent on buying things that will last longer than a year, for example, land, buildings, equipment.
<b>Care Programme Approach</b>	A way of making sure that all those with serious mental health problems and complex needs have an assessment and care plan that all the different professionals agree on (for example, social workers and doctors). This is checked regularly to see how well the person is doing.
<b>Challenging behaviour</b>	A term used to describe when someone is acting in a way that might do themselves or others harm. People who care for these people are 'challenged' to stop the harm. That is why we call it 'challenging behaviour'.

<b>Citizen advocate</b>	An 'unpaid' volunteer who is independent of the services, a person with learning disabilities receives. This advocate represents the needs of the person and supports them to make sure they get their rights.
<b>Cognitive behavioural approaches</b>	Ways of understanding and changing what people do and feel – mostly used by psychologists and psychiatrists.
<b>Commissioning</b>	Deciding what services are needed and then getting someone to provide these by signing a contract.
<b>Complex needs</b>	This describes the needs a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour.
<b>Continence management</b>	Trying to help people who have problems with bladder and bowel control.
<b>Continuing care</b>	Nursing or medical help or both of a level that cannot be provided in a care or nursing home.
<b>Direct Payments</b>	Local authorities giving people money to buy their own social care services so that they have more say in how their needs are met.
<b>Domiciliary services</b>	Care services provided to a person in their own home.
<b>Dual diagnosis</b>	Where someone has both a learning disability and mental health problems.
<b>Early onset dementia</b>	A term used to describe people who get dementia at an earlier age than might be expected. This leads to a variety of problems, including difficulties in remembering, making decisions, and learning new skills. These difficulties get worse as time passes.
<b>Learning difficulty</b>	Pre-school and school-age children are usually described as having a learning difficulty rather than a disability when they have special educational needs that need extra or different approaches to the way they are taught.
<b>Mainstream</b>	Generally available to all members of the community.



<b>Managed clinical network</b>	Where healthcare professionals who have an interest in the same area of work share their knowledge and resources to get the best care for patients. A network can be local, regional or national depending on what the work is.
<b>Mapping of services</b>	Finding out what services there are and what they are like.
<b>Mobility</b>	Being able to move from one place to another with or without help.
<b>Multiple disability needs</b>	Where someone needs help with several aspects of life which may include health, education, leisure, financial or housing support and being part of the community.
<b>Natural supports</b>	People who help those with learning disabilities like family and friends and are not paid to do this.
<b>Palliative care</b>	Managing care for someone who is not going to get better.
<b>Peripatetic support staff</b>	Staff who go from place to place to do their work rather than staying in a single centre.
<b>Post school education</b>	The range of education that takes place after school leaving age. It may include further education, community education, higher education, adults going back to school, other kinds of informal education and vocational training.
<b>Prevalence data</b>	A way of working out how many people in a population are likely to have a learning disability.
<b>Profound disability needs/ Profound and Multiple Learning Disability (PMLD)</b>	A term used to describe someone who has a very severe degree of learning disability which may be associated with complex needs. For example, this could include feeding difficulties, physical disabilities or sensory impairment.
<b>Psychotherapy</b>	A psychological treatment based on talking and usually designed to help the person understand what is happening now and how to change it.

<b>Record of Needs</b>	A document opened by an education authority for a child with pronounced, specific or complex educational needs which will lead to regular review and which helps to fund the best way of providing what is needed.
<b>Rectal diazepam</b>	This is a drug inserted up a person's bottom to stop severe epileptic fits.
<b>Revenue</b>	Money spent on day-to-day costs like paying for staff and services.
<b>Self-advocacy</b>	Where people with learning disabilities promote their needs and wishes for themselves.
<b>Sensory impairment</b>	A loss of sight or hearing or both.
<b>Social inclusion</b>	Helping people to feel and be part of the society in which they live. They are 'socially included'.
<b>Therapeutic interventions</b>	Giving treatment of any kind – drugs, physical or psychological therapy – to promote a person's well-being.

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