How is it Going?

A survey of what matters most to people with learning disabilities in Scotland today

By Lisa Curtice

scottish consortium for learning disability
Building respect in the Scottish community

ENABLE Scotland
LEADING THE WAY IN LEARNING DISABILITY

Contents

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Thanks

Our thanks to ENABLE Scotland for commissioning this research. The Board members of ENABLE Scotland kindly provided comments on a draft of the report and Norman Dunning and the communications team at ENABLE Scotland played a valuable role in drawing out the main messages.

We would like to take this opportunity to thank all those involved with this report. Especially to everyone who returned a questionnaire, over 600 of you. Also thanks to those who distributed the questionnaire – advocacy groups, local area co-ordinators, colleges, providers, day services and others. If you supported one or more individuals to fill in the questionnaire we are very grateful to you also. Without you all this report would not have been possible.

Thanks to all members of the SCLD team who worked so hard and enthusiastically to ensure that the study was completed, especially Claire McCue who made the questionnaire user-friendly and took responsibility for all the coding and the data management. Thanks also to Trish Dunlop for helping to finish the report.

We would like to thank those whose photographs are used throughout this report.

This is the first major survey into what people with learning disabilities in Scotland really think about their lives today.

Lisa Curtice

Director, Scottish Consortium for Learning Disability

Foreword

Norman Dunning Chief Executive of ENABLE Scotland

“The same as you?” – published in 2000 - marked a step change not only in policy for children and adults with learning disabilities but also in the way that the policy was devised, involving extensive engagement with those who use services and their carers. The policy was seen as long term – a 10 year programme – in recognition that many of the changes needed were fundamental, requiring not just a dismantling of some institutions but changes in attitude and approach, putting the person with a learning disability at the centre of their own planning process. The policy was widely welcomed as the right way forward at the time and, 6 years on, this study gives a clear indication that confidence in the policy was right.

People who have been affected by the changes of “The same as you?” have a lot of positive things to say. Real changes are happening. There are some concerns as to whether this will continue which may reflect uncertainties about continuing funding or commitment or just a response to change. Those living at home with their families need a fairer share of support. There is also some way to go in some areas such as ensuring that we create social and community links for people to establish friendships and participate. This reinforces the value of local area co-ordination as envisaged by “The same as you?” which is still in need of greater investment and expansion. It also gives importance to ENABLE Scotland’s own ENABLElink scheme which focuses on helping people to get in touch with others with similar interests and active work in the community to try to gain more acceptance and accommodation for those with disabilities. We should also listen to the clear message that people wish to maintain contacts and friendships which may be threatened by some of the changes, however welcome these changes might be in themselves.

This study is very impressive in its scope reaching 1 in 200 people with learning disabilities in Scotland. We are extremely grateful to all those who have so enthusiastically and fully assisted by giving us their accounts and stories. Not everyone could be included and further work to follow up the experience of young people and those with complex needs is needed. But there is more than enough in this study to reinforce the main messages of “The same as you?”, and give good indications of things which can be changed and further pursued.

But perhaps the clearest message of all is that the central concept of “The same as you?” - that people with learning disabilities want to be seen like everyone else – is clearly shown here too. Who would not share the priorities which emerge from the opinion of people in this report – home, family, friends and independence? This study should lead to a reinforcement, a redoubling of efforts to reach all children and adults with learning disability, and a clear determination to succeed – because we are beginning to see what success looks like.

Summary

This report is about what matters most to people with learning disabilities and autistic spectrum disorders in Scotland today.

Who replied?

In total, 605 people replied to a postal questionnaire about their lives and what is important to them. This represents about 1 in 200 of the population of people with learning disabilities in Scotland (120,000) as estimated in "The same as you?" (Scottish Executive 2000) and 1 in 40 (2.7%) of the 22,500 adults with learning disabilities aged over 16 in Scotland who are known to local authority services (Scottish Executive 2006). A third of the people in this survey still live with parents, a third are "in their own place" and a third in supported living. Three people are still living in a long-stay hospital. There are more women than men in this survey and the young and older age groups are under-represented when compared to national statistics as are people with profound and multiple disabilities.

What matters most?

What matters most to people with learning disabilities is getting their own home, having friends and being able to go out more. They also want to make sure they stay in contact with family and they keep the support that is essential to their independence. They enjoy socialising more than anything else and next to that, sport. They hope for new experiences.

These findings reinforce the policy direction set by the Scottish Executive's review "The same as you?" published in May 2000 to ensure that people with learning disabilities have as full and independent a life as possible. They also show that there is still more to do.

A home with access to support represents the most fundamental security for people with learning disabilities. It is important to change stereotypes of people with learning disabilities in the housing market and to look at a wide range of options to fit people's personal circumstances.

The biggest worry that people have for the future is the death of their parents, showing that individuals need to be involved with their families in planning for the future. People with learning disabilities can now expect to live to an older age and they do not expect to see their hard-won independence disappear.

Choice and independence

Support to make choices and to have a say is part of the principles of "The same as you?"

Three quarters of respondents say they are living where they want to live but a quarter think they would not be able to move if they wanted to. People living with parents are less likely to feel they could move than people living "in their own place". It is essential that this choice is available to more people and that proper planning is in place for those living at home with parents.

Over half think that they have the chance to live the life they want all the time but this was less so for people living with parents than for those living in their own home. This may be because of the level of support. Overall 469 people have some paid support, although 110 have none. Most think the amount of support they receive is about right and trust those who support them. Those living at home with parents are less likely to think they get enough support. Over a third of the respondents have not had a say in the appointment of people who support them. There is room for people with learning disabilities to have more choice and control over their lives, for example in choosing who is paid to support them and many of those living with parents need more support to live a life of their choosing.

Friends and relationships

Whereas 462 respondents (81%) say they have all the opportunities they need to make friends only 173 (30%) have a boyfriend or girlfriend and only 11 people (2%) are married. There are obstacles at every stage for people with learning disabilities forming relationships. People with learning disabilities say they need more opportunities to meet and spend time with people with similar interests in groups and other social activities, to go to more places to meet new people and to have time to get to know people and talk to them. Some people need help with arrangements and others lack opportunities to meet people their own age or go out at night.

These findings show that more priority needs to be given to enabling people with learning disabilities to have opportunities to socialise and meet others through developments such as local area co-ordination and befriending. There are initiatives that demonstrate the value of supporting people with learning disabilities to form friendships. ENABLElink though in its infancy, is already supporting people with learning disabilities to form what is expected to be lasting and meaningful friendships based on common interests – the type of friendships most people have.

Leisure

People with learning disabilities must represent an important part of the leisure market. Access to mainstream (open to everyone) leisure opportunities is very important for them to meet friends and lead a full life. Therefore it is essential that their needs are taken on board with respect to information, access and transport. TV, sport and socialising are the most popular activities.

389 respondents say they have all the leisure opportunities they want compared with 144 who do not. They identify some 724 places that they like to go locally. Top of the list are shops, sports and leisure centres and restaurants. Groups and clubs form an important part of people's social experience. People belong to a mixture of disability-specific groups, including advocacy groups and mainstream groups.

Work

Only 1 in 3 respondents (34%) are working and, of those working, the vast majority (76%) are working for less than 16 hours a week. Only 3 people are working 35 hours a week or more. Those working are making a wide variety of contributions with the greatest proportion (20%) employed in catering. A further 172 people are doing voluntary work.

Of those not working 125 people (35%) want to work although 174 (48%) do not and 60 people (17%) are unsure. Mainstream employment is not yet the experience of most people with learning disabilities. Barriers to work include problems related to health or disability, not being able to find a suitable job and the benefits trap. In order to overcome these there is a need for more information and support to help people with learning disabilities get a job and keep it. More employers need to be made aware of what people with learning disabilities can offer and be encouraged to create appropriate positions. The perverse incentive of the benefits system is probably affecting the willingness of people with learning disabilities to work.

Education and training

Over one-third of people are in some form of education and training and the vast majority feel that they are learning what they want to.

Individuals and citizens

This research gives a unique snapshot of the lives and feelings of people with learning disabilities in Scotland today.

- 62% report that they have overcome big difficulties in their lives including living independently, the effects of poor health or impairment, the death of parents, moving house and travelling by themselves.
- 57% report achievements including awards for sport (22%).
- 75% identify responsibilities they are proud of including looking after their home and paid and voluntary work.

People with learning disabilities in Scotland today are both survivors and contributors and have many things to be proud of.

Changing lives?

So are things changing? 391 people (66%) believe that their lives have got better in the last few years, compared with only 34 (6%) who think that their lives have got worse. However for 166 people (27%) things seem to have stayed the same. This shows that, for many, "The same as you?" policy is working. The things that have made life better are a new home, more freedom and more friends. The main thing that has made things worse is a reduction in support.

It is essential that everyone now works together to maintain the gains in independence that have been made and to extend these benefits to more people with learning disabilities. Their views, captured in this unique snapshot of the lives of people with learning disabilities in Scotland today, show why this is so important.

We aim to repeat this survey in 2009.

How this research was done

This research was commissioned by ENABLE Scotland to find out what people with learning disabilities and autistic spectrum disorders feel about their lives just now. Have things changed for them over the last few years? If so, has this been for better or worse? What do they hope for in the years to come and what would help to make this happen? ENABLE Scotland want to see what people's lives are like 6 years on from the publication by the Scottish Executive of "The same as you?" review of services for people with learning disabilities and to help set the agenda for the next five years.

A questionnaire called "How is it going?" was designed to explore these issues. It asked about people's achievements as well as their needs. The questionnaire had 7 sections:

- About you
- About your home
- About your life and the support you get
- About the people that matter to you
- About the things you do
- About the area where you live
- About your hopes, plans and fears.

The questionnaire was designed to be completed by people with learning disabilities with support from a family member, advocate or paid supporter. If the person could not fill it in themselves we asked the supporter to talk to them and fill in the answers they wanted to give. A freepost service was provided for the return of the questionnaires.

It was decided, on this occasion, not to issue a separate questionnaire for family carers because of the volume of work involved and also because there had been a very good response to a recent survey conducted on unpaid carers (Care 21 2005). However a discussion was held with a group of parents from PAMIS who care for a son or daughter with profound and multiple learning disabilities and with members of ENABLE Scotland's Parents' and Carers' Committee.

Around 3000 questionnaires were distributed through the SCLD Bulletin and website, self advocacy groups, provider organisations including ENABLE Scotland, local area co-ordinators and some day services. A preparatory meeting was held with representatives of some of these groups to explain the purpose of the questionnaire.

Originally we asked for questionnaires to be completed during the week beginning March 27th 2006 so that the results could be ready for an event organised by the Cross-Party Group on Learning Disability to be held in the Scottish Parliament on 24th April. When this had to be postponed because the Chamber was unsafe the deadline was extended and questionnaires continued to flood in during the rest of April.

Preliminary findings were discussed with the Council of ENABLE Scotland on 12th May and a number of individual self advocates told us their stories in more detail.

The questionnaire comprised 35 tick box questions and space for comments in 38 places. All the comments were typed up and then coded into categories so that we could include them in the analysis. The data was analysed using the Statistical Package for the Social Sciences. The numbers of people answering each question varied so there are different bases for the percentages given in the report. This base number is shown after each table or chart in the report as 'number ='

Where we report that a difference is significant this means that we have used a test of significance called a t-test and we can be almost (95%) sure that the difference is not due to chance.

The findings tell political representatives, policy makers, service providers and others what people with learning disabilities and autistic spectrum disorders and some family members think about their lives. These are the voices that count in monitoring the impact of policy and practice.

Whose lives are we talking about?

Introduction

This section gives some facts about the people who replied to the survey. In this report we often refer to them as 'the respondents'. This information is relevant when considering the findings and recommendations. It is important to know if any sections of the population have been left out or any others over-represented.

How representative is the sample?

In total, 605 people replied to the postal questionnaire about their lives and what is important to them. This represents about 1 in 200 of the population of people with learning disabilities in Scotland (120,000) as estimated in "The same as you?" (Scottish Executive 2000) and 1 in 40 (2.7%) of the 22,500 adults with learning disabilities aged over 16 in Scotland who are known to local authority services (Scottish Executive 2006).

	People who took part in this survey		Scottish statistics for people with learning disabilities	
	How many	Percentage	How many	Percentage
Men	262	48%	12,568	56%
Women	286	52%	9,905	44%
All	548		22,473	

In our survey there are more women than men with learning disabilities which is different from the national statistics for people with learning disabilities in Scotland. This is shown in the table below for the 548 respondents for whom the gender is known. However gender did not prove to be an influence on the results we found.

There were 5 questionnaires completed for young people aged under 16. Of the 549 adults aged 16 or over who completed the questionnaire and told us their age there are 15 young people aged between 16 and 19 (gender is unknown for one of these) and 29 aged over 65. These 2 age groups are under-represented in our survey compared with the population of people with learning disabilities who are known to local authority services in Scotland.

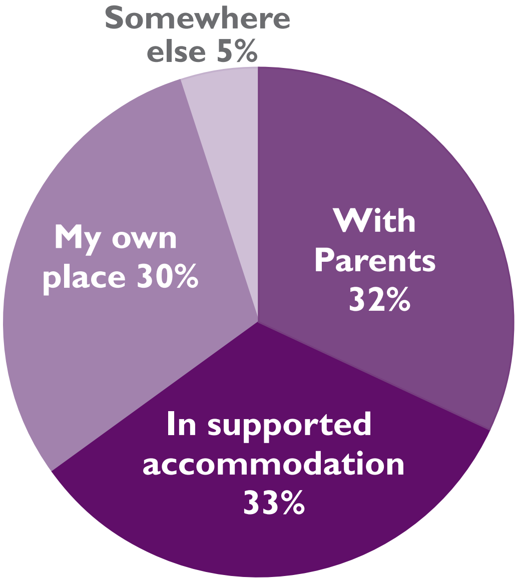
	People who took part in this survey				
Age	**Under 16**	**16-20**	**21-64**	**65+**	**All**
Men	4	11	239	12	266
Women	1	13	256	17	287
All (%)	5	24 (4.3)	495 (89.5)	29 (5.2)	553

	Scottish statistics for people with learning disabilities				
Age	**Under 16**	**16-20**	**21-64**	**65+**	**All**
Men		1,421	10,061	1,086	12,568
Women		845	7,961	1,099	9,905
All (%)		2,266 (10)	18,022 (80)	2,185 (9.7)	22,473

For reasons of confidentiality we were requested not to ask which area of Scotland people were from. We know from some of the answers that those who replied include people from remote rural areas, small towns and cities and from many different areas in Scotland. However we cannot say which areas are or are not represented.

Some people filled in the questionnaire by themselves, many completed it with support and a few parents and carers (9 that we can positively identify) completed it on behalf of the individual. Of these, 5 are the parent of a child under the age of 5. It is clear from the responses that some questionnaires had been completed on behalf of people with complex needs. 3 people have profound and multiple disability, a further 3 do not use speech and 2 (one a child) have complex needs. However we accept that a different sort of study or approach is required to find out more about people with profound and multiple disabilities.

Children and young people with learning disabilities are also under represented in this survey. Though some work has been done to gather the views of those with complex needs, children and young people with learning disabilities, we recognise that more research is needed to present their experience.



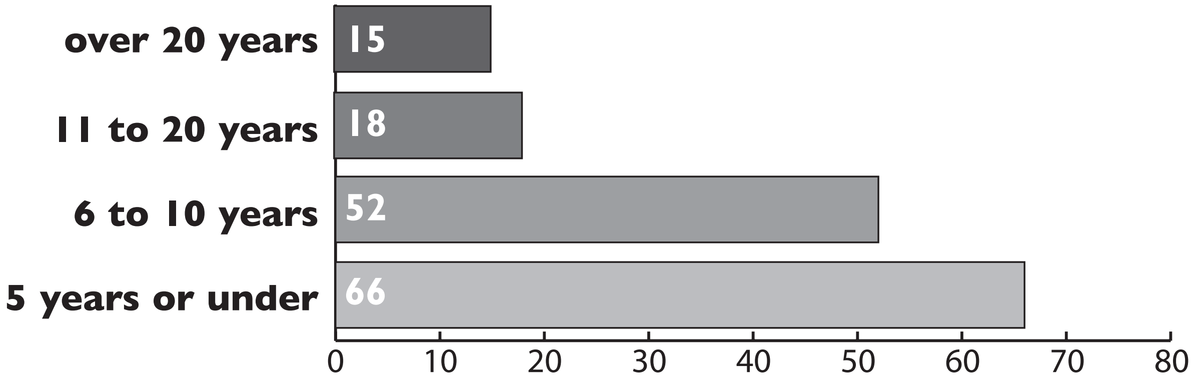
Where are you living?

Number=602

Where people were living

About a third of the respondents (193) live with parents, a third "in their own place" (178) and a third in supported accommodation (200) – the boundaries between these last 2 categories may be fluid. 31 people say they live somewhere else. Of these 4 live with other family members, 4 in residential care and 3 people are still living in a long-stay hospital.

How many years since you left hospital? Number=151



180 people have lived in a hospital or nursing/care home in the past. Just over three quarters of the 151 people who told us when they left hospital have left within the last 10 years.

Conclusion

It is not possible to give a response rate to this survey because we do not know how many people with learning disabilities received the questionnaire. However we can compare the number of questionnaires that were returned with estimates of the numbers of people with learning disabilities. The 605 respondents represent 1 in 200 of the estimated population of people with learning disabilities in Scotland and 1 in 40 of those known to services. This is a good response.

There are more women and fewer young people, older people and people with profound disability in the survey than in the population of people with learning disabilities in Scotland. The survey does not make it possible to compare experiences in different areas of Scotland, although this can be done to some extent from national statistics (Scottish Executive 2006).

There are enough people in the survey to compare the experiences of those living at home with parents with those living "in their own place" or living in supported accommodation. 30% of people in the survey have had experience of living in hospital or a care home which means that we can also look at their experience of changes over the last few years.

There are obvious limitations to using a self-complete questionnaire but supporters made it possible for over 600 people to participate. Inevitably those who completed the survey are much more likely to be connected to, and receiving, social work, health and voluntary sector services. Nevertheless the response to the survey was enthusiastic and we believe it is a good basis for considering people's views and experiences.

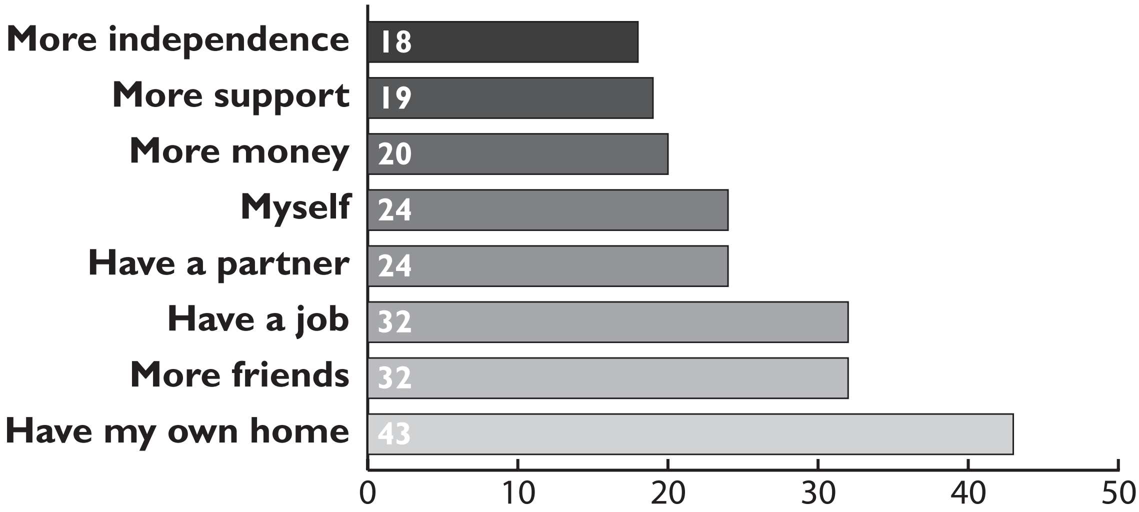
What matters most

I would like to be seen as any other person living in the community with all the same privileges as anyone else in the community.

Introduction

This survey provided a lot of opportunities for people to say what is important to them. In this section we bring together the responses to a number of questions to answer the big question: what matters most to people with learning disabilities?

If you could change one thing about your life what would it be? Number=300



If you could change one thing about your life, what would it be? Winning the lottery? Finding a partner? In response to an open question the most popular choice in this survey was having your own home or a new house (43 out of 300 responses). In second place, friends and getting out more was given equal importance with work..

Independence is an underlying theme of many of the comments. For example, 5 people want more chances to be with their partner. Other desired changes are improved health, more family contact, opportunities to learn and moving to a quieter area. One person wants support to keep her children.

If I could change one thing, I would...

Housing

Have my own place

Move into a flat with friends

Move into supported living like some of the people I know

Social

Go to the football with friends instead of support workers

Have more freedom to meet my pals

Work

Be in paid employment

Be a cashier at work instead of tidying up

Partner

Be able to marry

Move in with my boyfriend

Self

Lose weight

Stop being so bad tempered

Money

Have my own money

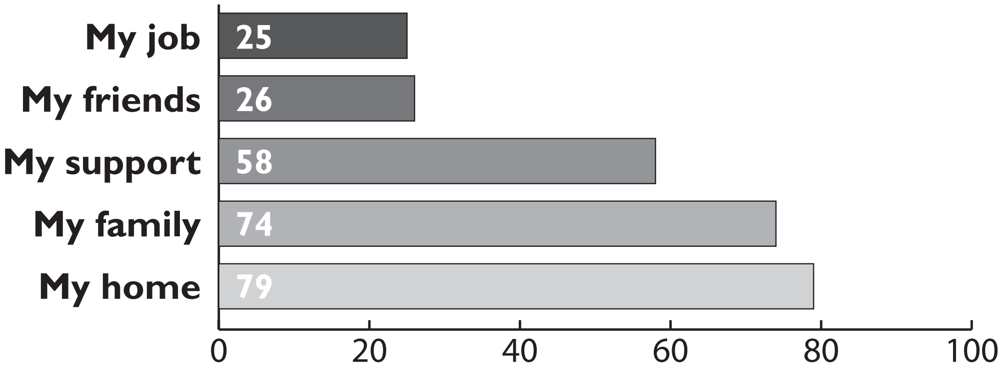
Support

Have support and not rely on mum

Independence

Be able to control my own finances

What do you want to stay the same? Number=430



We also asked people if there was anything they want to make sure stays the same. Home again clearly topped the chart with 79 responses, but family contact also emerged as something very important. 45 people want to make sure they stay in contact with their families and 29 want to continue living with their parents. Next most important is making sure you still get support (58 responses). Of these, 20 want to keep the same support staff. Keeping in contact with friends is mentioned 26 times and keeping a job 25 times.

Other issues that people think it matters to keep the same are particular activities, the day centre, living in the same area and a relationship. 23 people say they want 'everything' to stay the same! (Only the top 5 responses are shown in the chart.)

If I could keep one thing the same, it would be…

Home

To continue staying in my own flat

Staying myself in my mother s house

Remain staying in my own house and being as independent as I can with support

Staying in this house because it is the best house I ve ever lived in

Support

My support hours

That the care co-ordinator does not leave

To carry on with current support staff

Friends

Keep the bond with my friends

Always having friends

Family

Being able to see my mum

Living close to my grandparents and phoning them every night

Staying with my dad

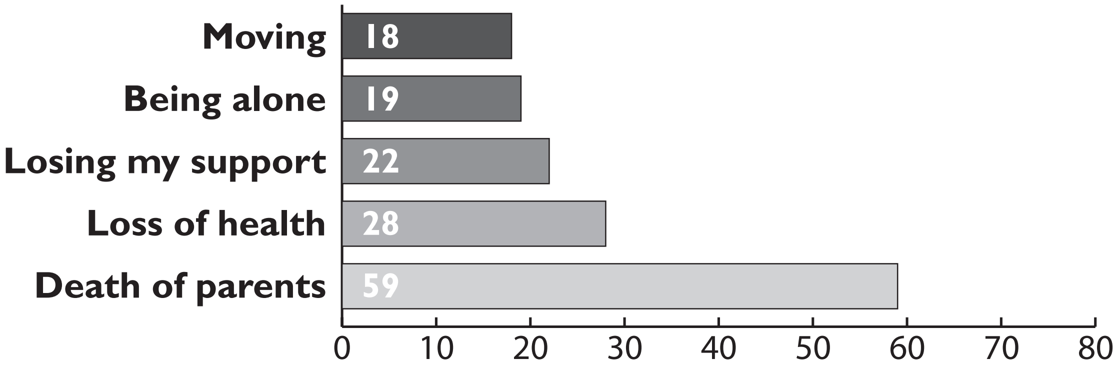
My mum and sister to be with me for ever

Job

My work that I really enjoy and would like to do more

What is your biggest worry for the future?

Number=274



My biggest worry for the future is…

Death of someone close

"If anything should happen to mum and dad"

"My mum's failing health"

Loss of own health/ independence with age

"Being too old and unwell to get out of the house"

"Getting old, losing my independence"

"I don't want to get dementia"

"I don't want to live in an old folks' home"

Change in support/funding

"Changing my day centre as the one I attend at present is closing down in June '06"

Being alone

"To be lonely. No family, friends or girlfriend for support"

Moving/Leaving home

"Moving is a big step"

There are lots of individual concerns including, "not having enough money to pay bills", "splitting up with my girlfriend", concerns for other people and "people dying in the world". These days, people with learning disabilities are living longer and many have experienced independence. One person sums up an underlying concern "losing the things I have already achieved".

Hopes for the future reinforce earlier comments about what matters most and also show that people with learning disabilities want "the same as you". Top of the list is being happy or having a good life, closely followed by their own or a new house, work and relationships and family. Desires to travel and have holidays and be independent show a wish to extend experiences and control.

- 46 people think being happy/having a good life matters most

  "Just to be happy"

- 44 people answer having their own or even just a new house

  "To be settled in my own home"

- 41 people say having a job makes life better

  "Getting my job and keeping it"

- 41 people say that relationships and family matter most

  "To get married to my partner"

- 37 people want more travel and holidays

  "Travel and see the world"

- 32 people think being independent is what is important

  "To be able to do more for myself"

What do you enjoy most?

When asked what they enjoy best in the entire world the people who answered the questionnaire say:

92 people say socialising/friends/relationships

Conferences, groups, retreats, social nights, neighbourhood networks

Having new friends to socialise with

Being married and happy

Being with friends and having fun

45 people prefer music

Singing and playing guitar

Listening to music

78 people prefer sport

Playing basketball

- indoor bowling
- football
  — watching and playing (22),
- swimming

53 people say holidays and travel

Going places - to different parts of Scotland

I like to go away for a far away day out

Going to nice holidays (hot)

73 people like going out

Going out with my pal

Going out for a drink

Going out with the pipe band

50 people say their family

Family visits

Some people also prefer quiet pursuits such as the TV and radio (22). 23 people mention attending their day centre.

Conclusion

What matters most to people with learning disabilities is getting their own home, having friends and being able to go out more. They also want to make sure that they stay in contact with family and that they keep the support that is essential to their independence.

Those who first promoted ordinary living for people with learning disabilities were therefore right to focus on the home as the first step. In discussion, members of ENABLE Scotland's Council came up with the following reasons why your home is so important.

Security

- A home gives you safety, security and shelter.
- A home is the basis for all our lives.

Rights

- A home is everyone's human right.
- Ownership, possession, and being like everyone else are important for most people.

Independence

- Independence and something you have decided for yourself.
- Having a home increases your choices, such as being able to choose to have pets and the freedom to live the way you want. You do not have to ask for anyone's permission to do things.
- Your confidence and self-esteem grow when you live independently from your parents.
- It teaches you responsibilities, for example paying bills.

Just as the significance of a home has many dimensions, so also do many different organisations and professionals need to take responsibility for making independent living a realistic possibility for more people with learning disabilities. As the recent report - Changing Childhoods? from the Children's "Same as you?" sub-group emphasises, ordinary lives start with ordinary childhoods when so many expectations are set (Scottish Executive 2006b). Adults with learning disabilities may choose different housing options, but planning, advice and support are very important to help them achieve their goal. And income and wages matter if you are trying to take responsibility for a home. Mortgage lenders and housing associations need to be just as aware of the needs of people with learning disabilities as do social workers. This research suggests that it is important to challenge the stereotypes of people with learning disabilities in the housing market as only individuals living alone and remember that increasingly they may be looking for homes in which to bring up their families.

People with learning disabilities in Scotland today see supported living as very important for their independence. However this is not to the exclusion of staying in touch with their families and some want to continue living with their families. The death of parents looms large as a concern for many whose life and wellbeing are so closely connected with family support. Planning for the future is therefore an issue for individuals as well as for parent carers. Moreover the needs of people with learning disabilities to have their emotional and spiritual wellbeing nourished are often overlooked. The very high prominence given to concerns about death and dying in this survey show that this is a mistake. People's feelings matter.

"The same as you?" was right to say that people want a full life and many now have friends and activities in their life that they want to keep. Support services are essential to enable people to live "the same as you". People with learning disabilities can now expect to get older and they do not want to lose the independence that some have gained.

ENABLE Scotland Scottish Council's thoughts on how to achieve better housing

Plan

- Develop a plan for independent living during transition planning or when leaving school.
- Better assessments and the right support.
- You need to have money and/or a good wage.
- It is important to choose the type of housing you want - maybe through tasters like training flats.

Think of alternatives

- Funding and lenders need to be more creative about how housing can be paid for.
- Local councils and the Scottish Executive need to promote appropriate choices and services.
- Houses should be in 'clusters' as one option.
- Houses should not be on the fringe of a place or a "less desirable" area.
- People should be able to live near family and friends.
- People can be lonely living on their own. Some people want more privacy than others.
- More people need to be trained as support workers to support people in their homes.

Suitable housing

- More houses need to be made available and existing houses adapted for individuals' needs.
- Houses need to have the right accessible facilities.
- Family homes with gardens for parents with learning disabilities.

Advice and support

- Support to make a good choice, find a good location and support to get to know the area.
- Money advice and help for people to buy houses.
- Advocacy and support before, during and after your move makes you feel better.
- Support to live alone and to cope with things like bills and cooking.

Attitudes

- We need to get rid of myths about people not being able to cope in their own home.
- Parents need to share and support these dreams.

Choice and Independence

I d like to continue to become more independent.

I m happy as I am at the moment, more wheelchair accessible buildings and transport would be good, eventually I would like my own motorised transport.

Introduction

Two of the fundamental principles of "The same as you?" are that people should be asked what they want and be supported to live the fullest life possible:

People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.

People with learning disabilities should be helped and supported to do everything they are able to do (Scottish Executive 2000).

This section explores whether people feel that they have choices and a say in decisions, what they feel about the level of support they are getting and whether any people seem to be getting a better or a worse deal than others.

Can you choose where you live?

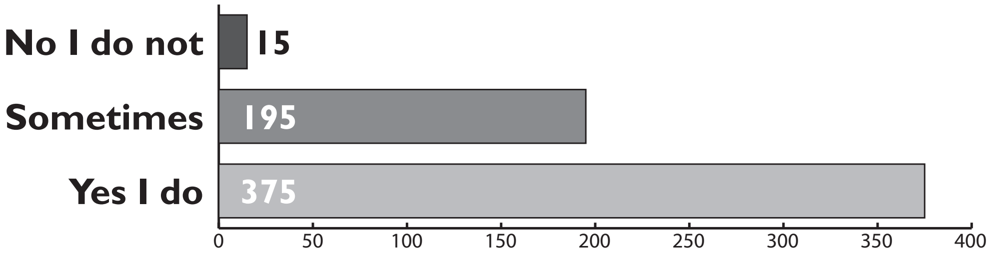
Three quarters of the people who replied (450 out of 577) say they are living where they want to live but 99 (17%) are not and 28 (5%) are not sure. 351 out of 530 (66%) think they would be able to move if they wanted to but 165 (28%) would not. The most common reason for not being able to move is waiting for a suitable property or support.

People living "in their own place" are more likely to feel able to move (73%) than people living with parents (55%). The difference is statistically significant. People in supported living (69%) are also significantly more likely to expect that they could move than those living with parents.

You cannot enjoy the benefits of home if you feel insecure there. In the survey the overwhelming majority of people 487 out of 585 (83%) say they feel safe at home all the time and 91 (16%) some of the time. What makes people feel secure is having staff there or nearby (105 responses), having family nearby (96 responses) and being able to lock doors and windows (57 responses).

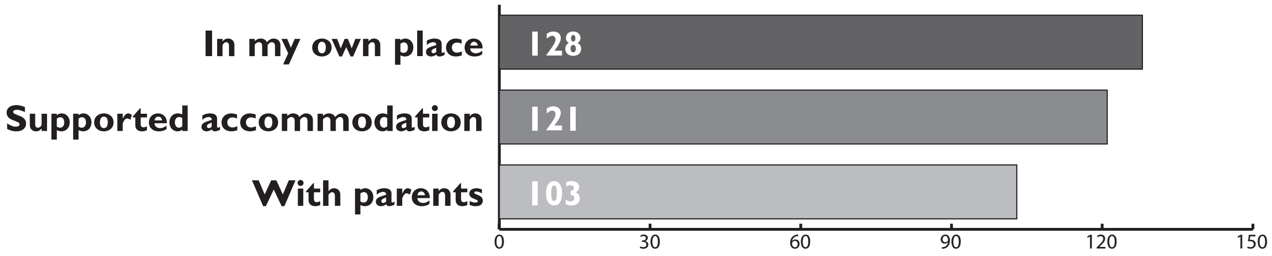
Do you always get the chance to live the life you want?

Number=585



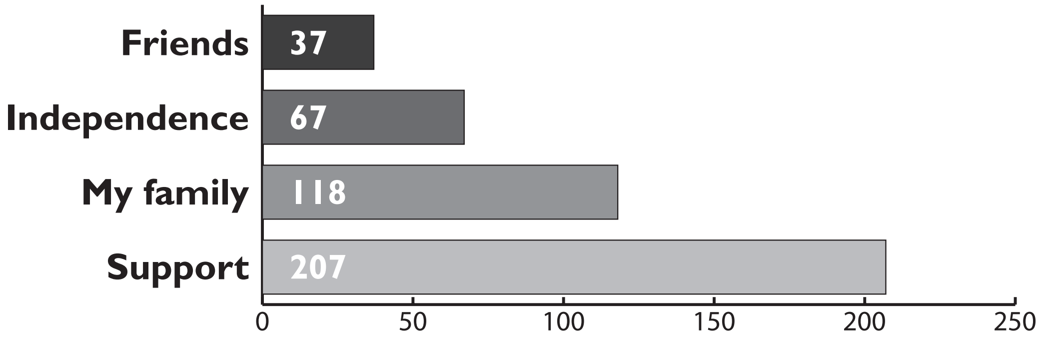
Choice and control are very important to wellbeing. Over half feel that they are getting the chance to lead the life they want all the time and 33% some of the time.

Does your chance to live the life you want vary by where you live?



Significantly more people living "in their own place" feel that they always have a chance to live the life they want compared with people living with their parents (72% compared with 57%). There is also a significant difference for people living "in their own place" compared with people living in supported accommodation (62%).

What helps you live the life you want? Number=362



Flexible support, family and having independence are the three things that most help people to live the lives they want. Friends are top of all the other things mentioned.

I feel staff around me help me to live my life the way I want to. I do all my activities and really enjoy and follow my daily plan.

I have been encouraged to be independent by my parents.

My work placement has helped me to be more confident.

Yes I can do what I want in my own home.

Yes, having friends and enough support.

What makes it hard to live the life you want?

Lack of staff

Myself and my partner rely on worker support in order to meet up. It doesn't happen often enough.

Family restrictions

I would like to get out more without my parents.

Inflexible/ poor support

At the day centre it's not always what I want to do and I have to go and do what the group is doing.

The other side of the coin is that, out of 107 responses, a lack of staff (21), family restraints (15) and inflexible or poor support (13) are the main things people identify as making it hard for them to live the life they want.

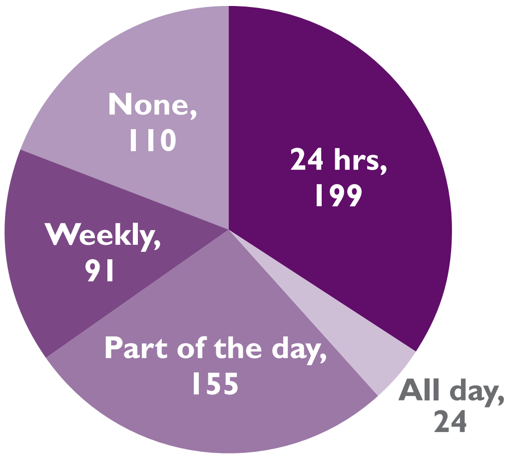
Other barriers to living a life of one's choosing include lack of confidence, not enough money, no privacy and bullying by other people, for example "having kids kicking me".

How much paid support do you get?

Number=579

469 people say they are getting some paid support although 110 (19%) are getting none. 385 people (64%) think that the support they are getting is "about right" but 88 (18%) think it is not enough. 14 people think that they are getting too much support.

Significantly more people living at home with their parents think that the support they are getting is "not enough" compared with people in supported accommodation (33% compared with 11%) and also with people living in their own place (18%).



The great majority of people, 477 out of 496, (96%) trust the people who support them but over a third, 182 out of 492, (37%) do not have a say in who supports them. People who report themselves as living in their own place are more likely to have a say in who supports them than people living with their parents (69% compared with 52%). The difference is statistically significant.

Conclusion

Most people say that they do feel they have a choice in where they live and what life they lead. However the "The same as you?" principles that everyone should have a say and be supported to live their life to the full have yet to be fulfilled for some. Those living with family carers are less likely to have so much choice or a say in the staff who support them. This seems linked to the fact that they are more likely to feel that they do not get enough support, an interpretation reinforced by the fact that respondents identify flexible support and family as important in either enabling or restricting their freedom to live their life as they choose.

The need for more support for older families caring for people with learning disabilities has been highlighted in South Lanarkshire (Johnston and Martin 2005), while the situation of unpaid carers nationally has been comprehensively reviewed (Care 21 2005). This survey adds the perspectives of people with learning disabilities living in the family home. It suggests that more support is needed for them to increase their chances of living an independent life.

That over a third of people surveyed say that they have no say in who supports them shows that there is considerable room for improvement in the control that people have over their own support. There are many examples across Scotland of people being successfully involved in recruiting their own staff. However it is possible to go much further than that. "Changing Lives", the report of the 21st Century Social Work Review says that services should be personalised, that is, arranged around the individual (Scottish Executive 2006d). Person-centred services were pioneered with people with learning disabilities and for "The same as you?" to become a reality there is a need for more radical change in the way that many support services are delivered so that the individual is not only at the centre but is also "calling the shots". In-Control is the name of an approach that is seeking to ensure that people who use support services have more control over their budget and support, as befits people who are citizens. There is a need to make such innovative practice widespread in order to make a real difference to the lives of people with learning disabilities and their families.

Friends and relationships

I have made lots of friends since I moved to my own house.

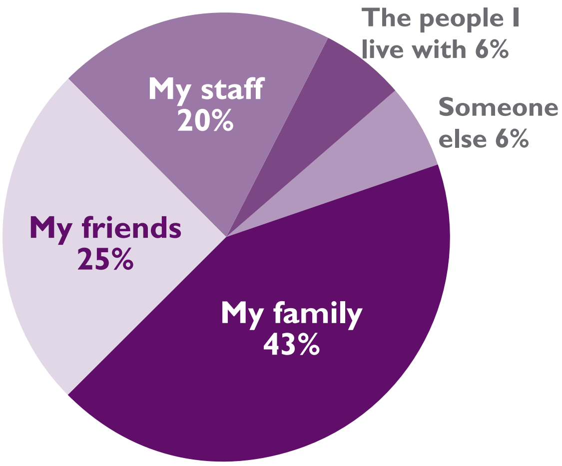
Need a long time and regular, planned meetings to get to know people.

Not getting out there but learning.

- 540 (95%) say that there are people in their lives that they can share things with.
- 503 (82%) are friendly with someone who is not one of their support staff.
- 462 (81%) think they get all the opportunities they want to make friends and 371 (66%) do not have problems with being able to see friends.
- 173 (30%) have a boyfriend or girlfriend but only 11 (2%) are married.

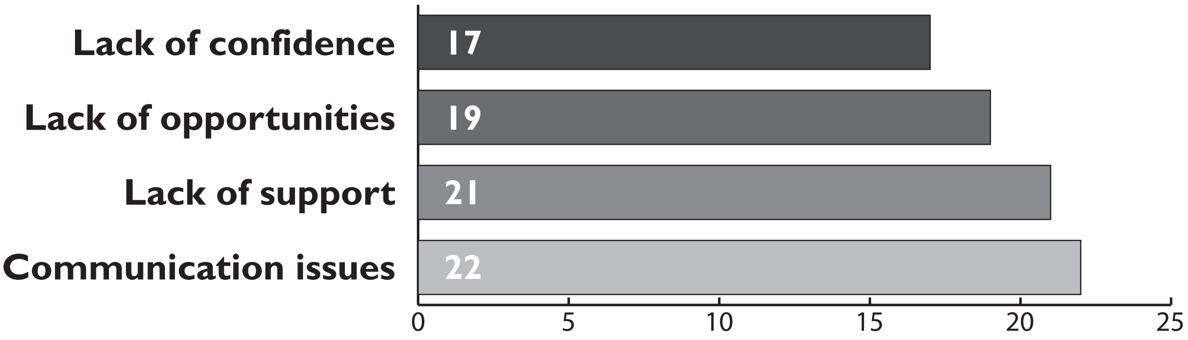
Our survey shows that at every stage of intimacy it becomes harder for people with learning disabilities to make and maintain relationships.

Who can you share things with? Number=153



Family members are mentioned most often (66 times) by people who comment on whom they are most likely to share things with. Friends (38 mentions) and support staff (31 mentions) are also important.

What gets in the way of you making friends? Number=141



Being unable to arrange things spontaneously, having to arrange support to do things, support not being available, people thinking I don t need friends because I have paid supporters.

Lost touch because I don t have their telephone numbers.

Answers to 3 of the survey questions provide some insight into the difficulties people with learning disabilities encounter in making friends as well as how these could be overcome. The questions were about what stopped people staying in touch with friends, what got in the way of them making friends and what would make it easier to get to know people.

190 respondents say they have friends they no longer get to see and 150 people give reasons. Distance (49%) is by far the most common reason for loss of contact. Services closing or not being available (9%) is also a reason people no longer see their friends. An interesting finding is that some people do not have the means to contact a former friend, for example their phone number.

141 respondents identify at least one thing that gets in the way of their making friends. Top of the list are communication issues (16%), lack of support (15%) and lack of opportunities or places to go (13%). Others highlight their shyness or other aspects of themselves.

What gets in the way of you making friends?

22 people said communication difficulties make things hard

My speech is not very clear so some folk shy away

21 people thought a lack of support is the problem

I need someone to take me to make friends

Getting support services to make arrangements at good places

Just arranging things. I m not good at doing this myself

19 people said there is a lack of opportunities and places to go

I would like more opportunities to go out in the evenings

Not enough opportunities to get out and meet people

Go to the same places all the time

Availability of suitable clubs

17 people thought it is their own shyness and lack of confidence

A bit shy meeting people

Feel like I hold back in case people think I m being nosy

I find it hard to speak to people

13 people say they aren't allowed to go out/don't get a chance to go out

Not allowed out, don t get taken out

I don t get out at night much and when I do I m with my mum

12 people say transport/independent travel is their problem

I am not able to go out at night because of transport

Can t travel independently

12 people say they find it difficult to make friends because they have a disability

Asperger s syndrome

Misunderstanding people shouting

My sudden approach to people

7 people thought problems with trust and relationships made it hard

People need time to get to know me

I don t trust people because people let me down

5 people said it was because of their health/mobility

I m not well a lot of the time, can t get out and about

5 people said it was other peoples attitudes

Some people are wary of me having epilepsy

3 people thought it is to do with the people they live with/other service users

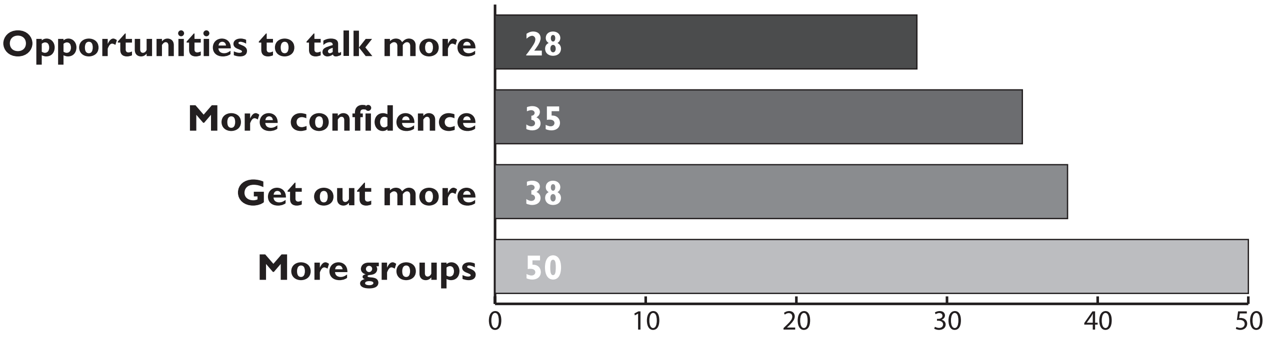
Folk in here

5 people said there was another reason

I stick to routines but could do with meeting new people if I joined clubs/leisure facility

Sometimes not motivated to go to groups etc when invited

What would make it easier to make friends? Number=255



Having a club where I could go to with or without support to meet people my age, 18-30s, who have the same interests.

When asked the question what would make it easier for you to get to know people better 18 people say 'nothing' but 241 people make a total of 255 suggestions. The most popular suggestion is more groups, clubs or social activities (50), followed by getting out more or going to new places (38), having more confidence to talk to people (35) and having more opportunities to talk to people (28).

These suggestions make a lot of sense when set against the issues that people identify as barriers to making friends.

People with learning disabilities know what helps anyone to make friends – opportunities to meet people with similar interests. Clubs and groups are a particularly important way for them to achieve this, and a good range of social activities is a precondition for getting the chance to know people. For example, peoples' comments include "joining new groups", "a group where we could do more for each other", "more activities, away football matches". Restrictions on being able to go out and in particular, a lack of opportunity to go to new places, means that it is much harder to meet people that you may have something in common with. For someone with complex needs, physical access can be a barrier to getting to places to meet people – "access to places can be restrictive, due to being wheelchair dependant". Suggestions for improvements include "going to places to meet people", "getting out to different places", "going to ordinary places", "being allowed to get out on my own a bit more".

The respondents' analysis of the problems they face reveals that they particularly need time to talk in order to get to know people. Many respondents highlight "talking to people" as the first step but some lack confidence and many lack opportunities. So chances just to meet up and talk to people are very important. For example, "getting the chance to speak to people", "meet up more often". This can often be through informal opportunities such as "inviting people to the house for tea", "meet for coffee with friends more". It is also important for maintaining, as well as making relationships, for example "if I saw them more than twice a week".

It is often said that no one can make a friend for you but some people do need support with the practicalities of making arrangements to meet. 19 people identify the need for support in order to meet people, 9 say they need someone to organise meetings and 7 suggest a befriender or buddy. This is how people think these things would help:

someone to support me and enable me to do this

a support worker type of co-ordinator or facilitator just to give a little start to this

a support type person just to introduce new folk

an organiser or someone to co-ordinate outings/meetings .

There are 4 people who make the very simple point that they do not have the contact details or telephone numbers of people they meet, perhaps in other services such as respite, for example "I would write if I knew the address".

For the 3 people still "stuck in hospital" (their words) the issues are not having enough staff and not getting enough telephone calls.

There are several ways in which people with learning disabilities want to be part of more mainstream activities in order to get to know people better. These include being able to go out more at night, access to transport or going out alone, experiencing friendlier communities and meeting people their own age. People say:

more activities at night time in the community

being able to travel further afield

if people were more tolerant

staff to think of ideas to include me in the community

mixing with young ones .

It would be wrong to conclude that people with learning disabilities all have problems making friends. 18 people (7%) stress this is not the case. "I have no problems making friends" says one and another explains "I am very outgoing and will talk to anyone and make friends with people I like. I get lots of chances to meet people and make new friends. I belong to lots of social groups."

Conclusion

Family members represent the most important circle of support for people with learning disabilities, followed by friends and staff. People with communication difficulties are particularly disadvantaged in making friends. There has been a big focus in service development on how to support people with learning disabilities to be part of mainstream social activities. These findings support that direction – people want to go out more at night and do ordinary things. However people told us a lot more about what they need to be able to make and keep friends – to go to more groups and new places, to have more opportunities to meet and talk and, for some, to have someone actively organise these opportunities. In recent years there have been some changes to make these things happen more including local area co-ordination, circles of support and peer mentoring. People with learning disabilities want these things to happen much more.

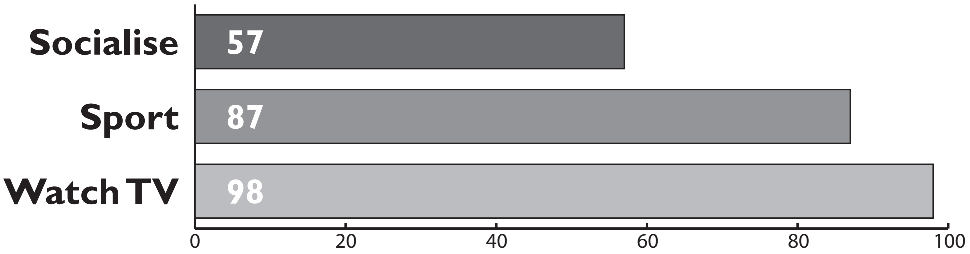
A major survey in England of the lives of nearly 3,000 adults with learning disabilities also found that more contact with family and friends was a big priority. Just under 1 in 5 of the people they interviewed never saw members of their family and nearly 1 in 3 (31%) said that they did not have any contact with friends (Emerson, Malam, Davies and Spencer 2005).

The barriers that disabled people face are often thought of in physical terms. However what people with learning disabilities say about what helps and hinders them from making relationships shows that time and opportunity are important barriers in this case. It is striking that so few people with learning disabilities actually marry. This chapter has set out how it may be systematically more difficult for people with learning disabilities to form and maintain relationships from first having the chance to get out and meet people, to staying in touch and finally (as we have seen earlier) to finding a place to live with a partner. These barriers can be hidden. However relationships are a big priority for many people with learning disabilities and supporters need to assist them to overcome the barriers to making and keeping their friends.

Leisure

What do you like to do in your spare time? Number=546

Go down to our caravan and chill out



Asking what people do in their spare time was a popular question which 546 people answered. Many listed lots of things but we recorded just one for each person. We chose the one that seemed most significant or that they mentioned first. The most popular activities turn out to be watching TV, DVDs or videos (18%), followed by sport and games (16%) and socialising (10%).

There are lots of other things that people do with their spare time including listening to music, other creative activities, going out to cafes, pubs and restaurants, using computers or playing computer games, shopping, going to clubs and centres, walking, going on trips and holidays, writing, going to the cinema or theatre, baking, housework – and sleeping!

Watch TV, listen to music, go for coffee

Swimming, horse riding, walking, badminton, cooking, listening to music, gardening, going out for meals, going on holiday

Eating out, spending time with partner, watching sports

Meet friend, watch TV, go to old folks centre

Bowling, knitting, going for a drink down town and seeing boyfriend

Chat on phone and visit friends .

Nearly three quarters (389 out of 533 who answered the question) think that they get all the opportunities they need to pursue their interests, compared with 144 (27%) who do not. Even more (444 out of 556) think that there are places that they really like they can go to in their area. People list 724 places they like to go to in their local area. Shops were top of the list, followed by sports and leisure centres and restaurants. The majority appear to be mainstream settings in the community.

Are there places you really like that you can go to in your area?

Place	Number who like to go there
Shops	118
Sports/leisure centre	102
Swimming	57
Restaurants	53
Cinema	50
Cafes	48
Parks	39
Walks/bikes	33
Bowling	28
Club	26

Place	Number who like to go there
Trips	22
Church	19
Library	16
Club for people with learning disabilities	12
Community centre	12
Out with friends	12
Football	11
See family	6
Other	60
All	724

A small number of people comment on the leisure opportunities available to them. 23 identify lack of support as the reason that they do not get all the opportunities that they want, for example "I need staff or special transport".

Just under a quarter (116 out of 540) say there are places they would really like to go to in their area but that they cannot. The main reason given is staff shortages (31) followed by problems with access and transport (17 each).

Groups and clubs form an important part of people's social experience. 403 respondents identify at least 1 group or club that they belong to. Sports clubs are top of the list (64). Some of the clubs seem to be 'mainstream' and many specifically for people with disabilities. There are a range of disability-specific groups including social and advocacy. 53 people report attending ENABLE Scotland clubs and 36 identify self advocacy groups.

A very striking finding is that many people seemed to engage in both disability groups and other activities.

60% feel it is safe to go out and about in the area where they live and a further 30% think it is sometimes safe. People think that having someone with them and more police (43 responses each) would make the area safer. The other main things that would make people with learning disabilities feel safer in their area are increased road safety, fewer drunks and hooligans, fewer young people and more street lighting. The biggest threats to feeling safe is people coming to the door (23) and noisy neighbours (20).

For the most part the present experiences of people who have lived in hospital in the past do not seem to differ from those of other respondents to the survey. However their experience of neighbours is significantly less positive. 75% describe their neighbours as "mostly friendly" compared to 82% of those who have never lived in hospital.

Conclusion

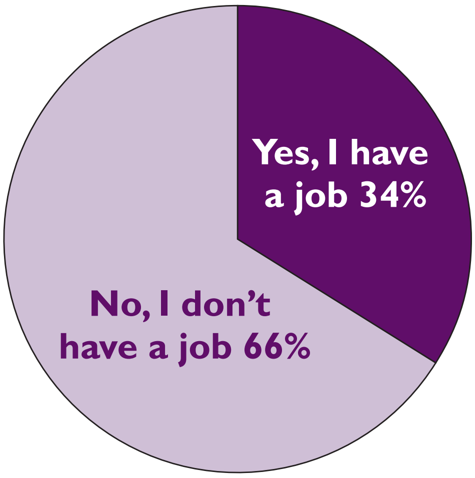
People with learning disabilities must represent an important part of the leisure market. Access to mainstream leisure opportunities is very important for them to meet friends and lead a full life. Therefore it is essential their needs are taken on board with respect to information, access and transport. Support is as important for people being able to access leisure opportunities as it is for other parts of their lives and it needs to be flexible so that people can pursue their own interests.

Belonging to groups and clubs is also important to people's experience. This extends from social groups to collective advocacy. Such groups can be an important way to meet people, get and give support and campaign. Many people attend disability-specific groups and also engage in mainstream activities. Both perform a role and whilst it is very important that everyone with a learning disability has all the opportunities they want to take part in mainstream groups they may also wish to be a member of a disability group and/or advocacy organisation. When speaking about making friends, people with learning disabilities have emphasised the importance of just being able to get together with other people of similar interests and having time to socialise.

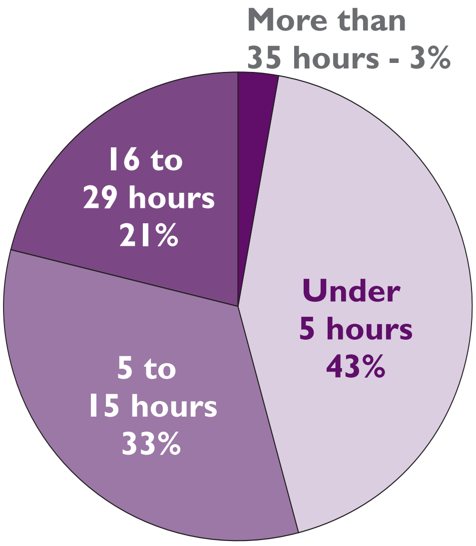
Work

Not enough opportunities, the right job hasn t come along

I d lose my benefits.



Do you have a job?
Number=585



How many hours do you work? Number=172

199 (34%) of the 585 people who replied to this question have a job, but 386 (66%) do not. Of those working who told us how many hours a week they work, 131 (76%) are working less than 16 hours (this may be related to benefit regulations) and only 3% are working 35 hours or more. 74 are working for fewer than 5 hours a week.

The Scottish Executive statistical returns for 2005, report that 60% of people with learning disabilities work less than 16 hours a week, 26% between 16 and 30 hours and 14% over 30 hours. However broadly this finding is the same - very few people work full-time. It is likely that people have reported more voluntary or sheltered jobs here which may account for the even higher proportion of those working under 16 hours. In work commissioned by the Scottish Executive, Ridley et al (2005) found that 75% of those in unpaid or voluntary work worked under 10 hours per week and half of those in paid jobs worked fewer than 16 hours.

The jobs people are most likely to have are catering (20%), retail (15%) and jobs in gardening or recycling (15%). It is clear that not all the jobs are in open employment and some people describe voluntary work or even going to their day centre as their job. 16 people have roles advocating for themselves or others or training staff.

A few examples of the roles people perform show the range of contributions that people with learning disabilities are making in the world of work.

What is your job?

Job	**Number with this job**	**Percent**	**Example**
Café/catering	36	20	*"Restaurant – I set tables, dust down and take care of customers"*
Retail	27	15	*"Body Shop – bring in deliveries and put out stock"* *"volunteer at college stationery shop – serve customers, tidy up and count money (day's takings)"*
Gardening/ recycling	26	15	*"Helping on a croft"*
Office/clerical	22	13	*"Office assistant – do office duties within a busy office"*
Cleaning	17	10	*"Cleaning a book shop"* *"working at a racing stables, cleaning stables and tack"*
Advocacy	12	7	*"SAY rep at Advocating Together"*
Caring (Elderly children)	12	7	*"volunteer at centre for elderly people"* *"nursery assistant"*
Day centre	6	3	*"He sees going to the centre as his job"*
Co-Trainer	4	2	*"Co-trainer Scottish Borders Council"*
Other	14	8	*"Postman"* *"I work in a hairdresser's salon"*
All	**176**		

135 are paid for the work they do and 120 of these are satisfied with the pay they receive. 184 (93%) out of 198 people who are working and answered the question are happy with their work.

A further 172 say they do voluntary work. Working in a charity shop is the most common contribution (29), followed by café and catering work (23) and advocacy (13) but there is a wide range of examples of how people contribute and help others.

Lay Assessor with the Care Commission

I m a peer advocate and work in sheltered housing

I run a football team

Help out in community centre

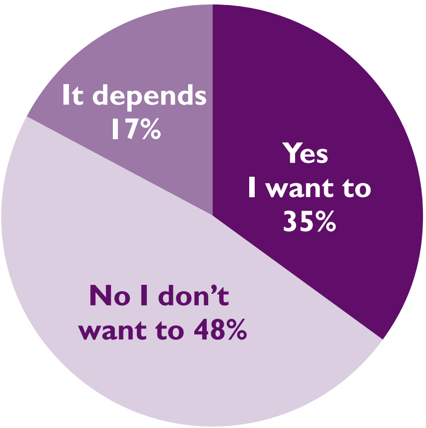
Help the volunteers at ENABLE when there are fundraising events. Also help at my church

I befriend an elderly lady one to one and another via phone

What are the barriers to you working?

I did have a job where I worked on a voluntary basis, organised by my Care Manager, however I did not receive any support i.e. a job coach and I found it difficult.

Did you want to work? Number=359



359 answered a question about whether they want to work. 125 (35%) say they want to work but 174 (48%) do not and for 60 (17%) it depends. People who have lived in hospital are less likely to say they want to work (26%) than people who have not (40%).

When asked "what gets in the way of you getting a job or keeping it?" people identify the biggest barriers as: the impact of their disability or health problems, not being able to find or knowing about a job that is suitable, lack of support and the benefits trap - feeling that they cannot afford to work without losing the income to pay for their support.

Conclusion

The proportion of people who say they are working (34%) is higher than that (14%) reported by local authorities to the Scottish Executive, probably because individuals in the survey are using a wider definition of work. Both this survey and official statistics agree that very few people with learning disabilities are experiencing full-time work. The pattern of employment reported here reflects that identified by Ridley et al (2005) who surveyed 200 providers of employment support and examined the experiences of 15 people in supported employment. They concluded that the best practice of supported employment is not widespread and that the mainstream, open employment opportunities expected by the Short-life working group in "Working for a Change" (2003) are far from a reality for most people with learning disabilities.

However this survey shows the potential of people with learning disabilities to contribute to the labour market. While most are employed in sectors that might be expected (catering and retail) their individual accounts show that the third of people who have a job are contributing in a wide variety of ways.

What gets in the way of you getting a job or keeping it?

What gets in the way	**Number who said this**	**Percent of those who replied**	**Comment**
Disability/health	56	35	*"I'm too slow and can't keep up"* *"My learning disability, poor concentration"* *"Visual impairment and epilepsy"*
No suitable job	26	16	*"Lack of supported employers – 3 year waiting list"* *"Availability of suitable jobs I can do"* *"Hard to get a job that's suitable"* *"Nothing available for someone like me"*
Lack of support	13	8	*"Possibly voluntary work – not got help to find one"* *"I need support shadowing most of the time"* *"I need help to get there and back. I can't do independent travel."*
Benefits trap	13	8	*"Benefit worries"* *"Loss of benefits" "Benefits trap"*
Don t want job	12	8	*"Don't want one"* *"I do not feel I am ready for a job"*
Lack of confidence	8	5	*"Filling forms in and confidence"* *"Lack of confidence. I feel I could do a job but would need help with it first."*
Nothing	8	5	*"Nothing gets in the way of getting a job"*
Lack of education/training	5	3	*"I need support to get qualifications"*
Lack of experience	4	3	*"No experience - need to find Company to gove first job"*
Other	13	8	*"Transport" "Being in hospital"* *"Mum would not allow anything"* *"Because of people. I used to have job but people sat back and let me do all the work"*
All	**158**		

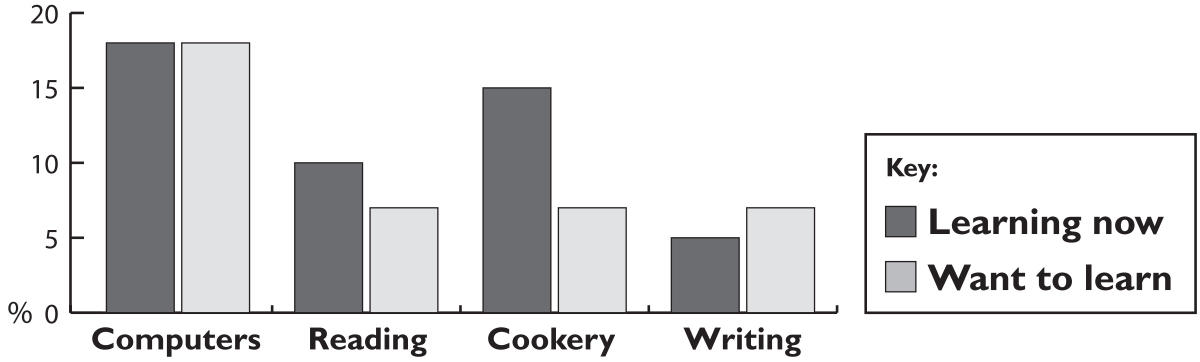
At least as many again as are working want to work. In order to overcome the barriers they face there is a need for more information and support to get a job and keep it and for more employers to be aware of what people with learning disabilities can offer and create appropriate positions. The perverse incentive of the benefits system is affecting the willingness of people with learning disabilities to work. The current proposals to reform incapacity and other benefits, together with the system of tax credits, should seek to ensure that people with learning disabilities who can work are supported to do so and those who cannot work receive sufficient benefits to enable them to lead a reasonable quality of life.

Education and training

I have applied for 2 courses at college and am waiting to hear if I have been accepted.

I d like to learn about the things I didn t get a chance to do at school.

What are you learning and what would you like to learn?



240 people (42%) are undertaking some form of education or training and of these 220 (92%) say they are learning what they want to learn. Out of a list of some 300 courses or subjects that people are currently undertaking the most common are computers, cookery or catering and reading. 19 report that they are learning work skills. People give an equally long list of other things they would like to learn about. However the most popular choices are very similar to what people are currently learning.

One parent of a child in primary school feels there is a long way to go before inclusion, which this family supports, becomes a reality for many children.

Offering mainstream education to children is the way forward, but it needs more support within the schools to ensure that these children can properly access the education on offer. The children with special needs are expected to do all the adapting

Conclusion

It is likely that the training reported here includes training in day centres or elsewhere and not only in colleges. It seems as though people's expectations may be being formed by what they know to be on offer and so there may be room to explore a wider range of learning opportunities. However it is positive that people are reporting learning skills that have relevance to possible employment and to living independent lives. The low level of open employment demonstrated in this and other surveys may therefore not be due to a lack of educational and training opportunities. Our survey did not ask how many of the learning opportunities provided were in mainstream classes. We know this to be an issue still for many people with learning disabilities. The comment received from a parent indicates that there is also more work to do to make inclusion a reality in schools.

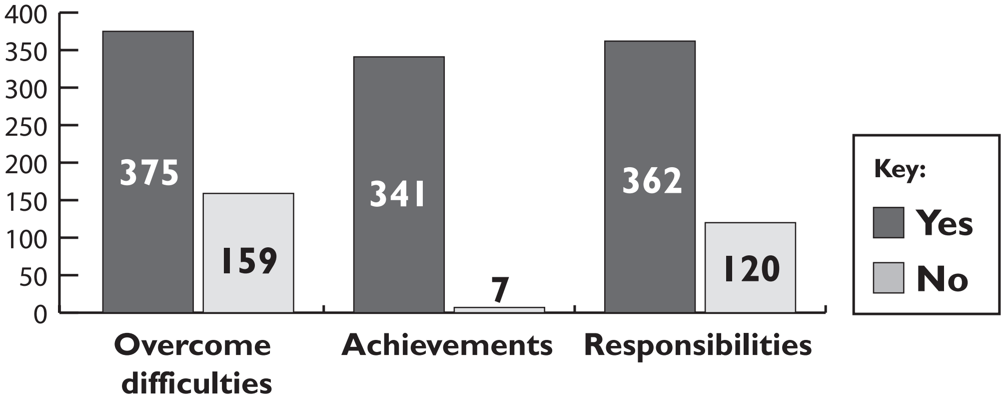
Individuals and Citizens

The teacher at college asks me to help other people because I can do things others need help with.

Have you overcome difficulties?

Do you have achievements you are proud of?

Do you have responsibilities?



What difficulties have you overcome?

When doctors told me I wouldn t be able to walk, I worked hard and managed.

The majority of respondents, 375 (62%), report that they have succeeded in overcoming big difficulties or obstacles in their life.

The top 5 of these are living independently, overcoming a health problem or impairment, the death of parents, moving (house or area) and travelling independently.

Trying to convince mum and dad that moving into my own home was best for me

I have neurofibromatosis and have managed to learn things and get speech therapy

Bereavement (pets and family)

I moved to my own flat

Using public transport on my own

There is also a wide range of other difficulties, both personal and social, overcome by individuals. For example,

I found working in an office a challenge as I didn t know what to expect when I began there

Becoming more confident and accepting who I am

Consistent with other findings from this survey the most common ways given for overcoming these are support staff (or provider organisations) (114) and family (71). However in third place (65 out of a total of 451 factors mentioned) is the self-confidence or positive approach of the individual themselves.

I can stick up for myself

I decided life must go on

Decided that it wasn t going to stop me

Perseverance, having a go and seeing how it goes

What achievements are you proud of?

Last year I flew for the first time, I was so proud of myself

Replying to an open question, 341 people report some 413 achievements. 74 people (22%) have achieved sporting awards, 59 have certificates, 34 have made strides in independence, 34 have been successful in creative activities such as art and drama and 32 have other sporting achievements that they are proud of.

What responsibilities do you have?

I own my own home so I have a mortgage

362 people (75%) say they have some responsibilities they are proud of, compared to 120 (25%) who do not.

By far the most common of the 362 responsibilities that people identify are responsibilities in the home (135), followed by being in a voluntary organisation (69) and paid work (40). It is striking how many people hold roles such as secretary of a local group.

Clean the house, make my own dinner

Managing own home and life

Getting my own automatic key to open my house door and keeping this myself

My work with ENABLE gets me talking to people from different countries

Becoming an office worker, member of People First and Calling the Shots group.
Member of Quality Network team .

People also reveal their personal qualities and tell of individual responsibilities showing they have trusted and valued roles.

In charge of honesty box

Have keys to the office where I work

Very proud of the fact that I am helping to train staff

I am proud of my interest in politics

Conclusion

This section shows the range of achievements that people with learning disabilities have to be proud of and how much they contribute to society in Scotland as individuals and citizens. Life has thrown some major challenges at many of the individuals who replied to the questionnaire. Yet they have faced and overcome these with determination.

The second key message here is that people with learning disabilities are not only relying on networks of support themselves but are giving back support to others, particularly in the voluntary sector. In the jargon, many are creators of "social capital", given the opportunity to exercise responsibility and make links. 'Changing Lives' (Scottish Executive 2006d) expects public services to pay much more attention in future to the development of communities, so that people who use services can be part of wider networks. This will require many agencies and services that are not presently aware of the needs of people with learning disabilities to take account of them as customers and citizens. For many, this "mainstreaming" agenda is seen as the next step to ensure that the goals of "The same as you?" - for people to have an ordinary life in the community - are achieved. This survey supports this direction but also shows that some people with learning disabilities are already citizen leaders within their own communities and networks.

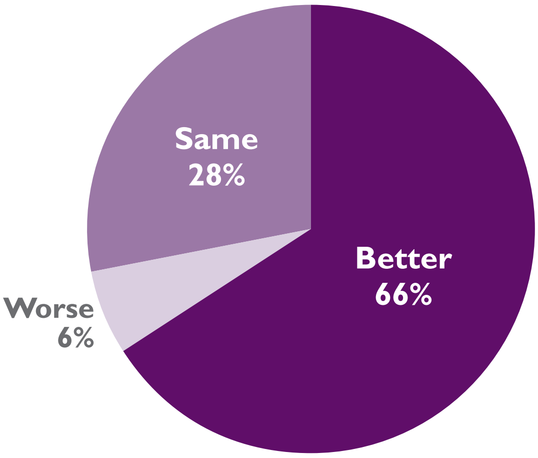
Yet more are achieving personal milestones and exercising responsibilities in their everyday lives, as sons and daughters, colleagues, friends and partners. People should be able to use their support to enable them to fulfil these roles and services should never be a barrier to their fulfilling them. This was a key message of the User and Carer Panel of the 21st Century Social Work Review and people with learning disabilities will be among those who expect to see more flexible support as a result.

Changing Lives

"I moved into a new house and made some friends."

"Some things like bullying have made it worse."

In the last few years has life been better, worse or the same? Number=591



Do people with learning disabilities feel that their lives have changed? The majority (66%) think that "in the past few years" things have got better for them. Only 6% think that things have got worse. However 166 (28%) feel as though things have stayed the same.

Only a few people comment on why they feel their lives have got better but these reasons reflect what people say about what matters most to them – having a new home (10), more freedom and more friends (9 each). The main reason for feeling things are worse or have stayed the same is a reduction in support (6).

What do you hope to achieve?

I would like to live a normal life and have a family.

Looking to the future, we asked people if there was something they would like to achieve for themselves. The most common response is work (37) followed by holidays and travel (36). People who have been in hospital say that the thing they still want to happen to make their life better is to move into their own home.

Conclusion

"The same as you?" is working, at least for the majority of people who replied to this survey. It is essential that the gains made in independence and quality of life are maintained in the next five years and extended to build an even fuller life for people with learning disabilities throughout Scotland.

Afterword - Listen to people with learning disabilities!

This survey has shown that people with learning disabilities are keen to provide their views and share their experiences. We think that they should be included in any important surveys about public opinion in Scotland. For this to happen many people would need to have support. Of course surveys are not the only, or even the best way, for people to have their voices heard. Self advocacy groups enable people to express their views independently on issues that matter to them. When people get together they can develop their views and it is important that self advocacy groups are regularly consulted. It is also very important that different approaches are used to ensure that the needs of people with profound and multiple learning disabilities and communication difficulties are included when considering issues that affect people with learning disabilities. When services can get it right for them they will probably get it right for everyone!

Some people told us that they enjoyed completing the questionnaire and would like to do it again in the future. We have learned that we should make it shorter and allow organisations and groups more time to get it out to people and get it filled in. In the future we would also like to target younger and older people better and include parents of people with profound and multiple learning disabilities. Here are some of the comments we received about the questionnaire:

> *Our members enjoyed the task and worked well at it. However they were hampered by the short time scale and the timing However we feel it is imperative that this kind of information is collected regularly and noted. (advocacy group)*

> *I like all the post you send me as it makes me feel involved in making things better. I like to help out by answering the questions. I like it when you take an interest in my life. (individual respondent)*

We propose that, with the changes we have mentioned, we should repeat this survey in 2009 so that we can see how much has changed.

Documents to look up

Care 21 (2005) "The future of unpaid care in Scotland", London, OPM.
http://www.care21scotland.com/care21/files/Headline%20Report.pdf

Emerson E, Malam S, Davies I and Spencer K (2005) "Adults with Learning Difficulties in England 2003/4", NHS Health and Social Care Information Centre
http://www.icservices.nhs.uk/documents/LearningDifficultiesSurveyMainReport.pdf

Johnston L and Martin M (2005) "Older family carers and learning disabled adults cared for at home: their views, experiences and thoughts on future care" A report for South Lanarkshire Council, Social Work Resources, Adult Services, Hamilton, South Lanarkshire Council

Ridley, J, Hunter S and Infusion Co-operative (2005) "'Go for it' Supporting people with learning disabilities and/or autistic spectrum disorder in employment", Edinburgh, Scottish Executive

Scottish Executive (2006) "Adults with Learning Disabilities: Implementation of "The same as you?", Scotland 2005", Statistics Release,
http://www.scotland.gov.uk/Publications/2006/05/22101802/0

Scottish Executive (2006a) "Make my Day, The same as you? National Implementation Group Report of the Day Services Sub Group", Edinburgh, Blackwell's Bookshop
http://www.scotland.gov.uk/Publications/2006/04/24103440/0

Scottish Executive (2006b) "Changing childhoods?: The same as you?: National Implementation Group: Report of the Children's Sub Group", Edinburgh, Blackwell's Bookshop
http://www.scotland.gov.uk/Publications/2006/04/24104745/0

Scottish Executive (2006c) "Having Your Say? The same as you? National Implementation Group: Report of the Advocacy Sub Group", Edinburgh, Blackwell's Bookshop
http://www.scotland.gov.uk/Publications/2006/04/13144910/0

Scottish Executive (2006d) "Changing Lives: report of the 21st Century Social Work Review", Edinburgh, Blackwell's Bookshop.
http://www.scotland.gov.uk/Publications/2006/02/02094408/0

Scottish Executive (2003) "Working for a Change? The same as you? National Implementation Group Short-Life Working Group on Employment", Edinburgh, The Stationery Office
http://www.scotland.gov.uk/Publications/2003/12/18575/29596

Scottish Executive (2004) "Home at last? The same as you? National Implementation Group Report of the short-life working group on Hospital Closure and Service Reprovision", Edinburgh, The Stationery Office
http://www.scotland.gov.uk/Publications/2004/01/18741/31584

Scottish Executive (2000) "The same as you?, a review of services for people with learning disabilities", Edinburgh, The Stationery Office
http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp

Valuing People Support Team (2005) "The Story So Far: Valuing People - a new strategy for learning disability for the 21st century", Bristol, Valuing People.
http://www.valuingpeople.gov.uk/documents/VPReviewReportLong.pdf

Where to get advice and help

Some of the SCLD partner organisations provide information and advice services and welcome enquiries from individuals, families, staff and other organisations.

ENABLE Scotland Information Service

ENABLE Scotland
6th Floor, 7 Buchanan Street
Glasgow G1 3HL

Tel. 0141 226 4541

Enquiry line open Mon-Fri 1pm-4pm

E-mail: info@enable.org.uk

http://www.enable.org.uk

ENABLE Scotland Information Service provides information on learning disability issues, particularly rights and services.

ASCS (Advice Service Capability Scotland)

Capability Scotland
11 Ellersly Road
Edinburgh EH12 6HY

Tel. 0131 313 5510

Textphone. 0131 346 2529

e-mail: ascs@capability-scotland.org.uk

http://www.capability-scotland.org.uk

ASCS offers information on Capability Scotland services, specialist advice on cerebral palsy and general advice on disability issues.

Down’s Syndrome Scotland

158-160 Balgreen Road
Edinburgh EH11 3AU

Tel. 0131 313 4225

e-mail. info@dsscotland.org.uk

http://www.dsscotland.org.uk/

Down's Syndrome Scotland provides support, advice and information to people with Down's syndrome, parents, carers and professionals.

PAMIS

Springfield House
15/16 Springfield
University of Dundee
Dundee DD1 4JE

Tel. 01382 34 4953

e-mail. j.t.taylor@dundee.ac.uk

http://www.dundee.ac.uk/pamis/

PAMIS offers a comprehensive information service on all matters concerning people with profound and multiple learning disabilities and their carers.

PAMIS also runs the Profound and Multiple Learning Disability (PMLD) Network and Online Forum on behalf of SCLD

http://www.dundee.ac.uk/pamis/pmldintro.htm

SCLD Library partnership

The above 4 organisations, together with SCLD, also provide the SCLD Library service. Between them, the libraries have over 10,000 books, videos and reports available for loan to anyone in Scotland. You can search the library catalogue at www.scld.org.uk or contact one of the library partners if you are looking for materials to borrow.

What matters most

Planning for the future

ENABLE Scotland Legal Service

ENABLE Scotland Legal Service can help individuals and families to make wills and set up discretionary trusts to benefit people with learning disabilities.

ENABLE Trustee Service Ltd

ENABLE Trustee Service provides a professional trustee management service and can act as a trustee in trusts created for the benefit of people with learning disabilities.

Both services are based at:

ENABLE Scotland
6th Floor, 7 Buchanan Street
Glasgow G1 3HL

Tel. 0141 226 4541

E-mail: legal@enable.org.uk

E-mail: trustee@enable.org.uk

http://www.enable.org.uk

For general information about wills and trusts for people with learning disabilities contact the ENABLE Scotland Information Service in first instance.

Thinking Ahead

A handbook to help families of people with learning difficulties think about planning for the future and keeping control when circumstances change.

Thinking ahead in Glasgow available from
Quarriers Head Office
Quarriers Village
Bridge of Weir
Renfrewshire PA11 3SX

Tel. 01505 612224

http://www.quarriers.org.uk/documents/user/ThinkingAhead.pdf

Thinking ahead in Fife available from
Joyce McDonald
Fife Council
Q10 Social Work Office
Flemington Road
Queensway Industrial Estate
Glenrothes KY7 5QF

Tel. 01592 415 185

Choice and independence

National Centre for Independent Living

4th Floor, Hampton House
20 Albert Embankment
London SE1 7TJ

Tel. 0207 587 1663

http://www.ncil.org.uk/sslocalarea.asp?id=Scotland

NCIL can provide information about personal assistance and personal assistance support schemes.

Ownership Options

The John Cotton Centre
10 Sunnyside
Edinburgh EH7 5RA

Tel. 0131 661 3400

http://www.oois.org.uk/

Ownership Options specialise in home ownership issues and can provide information, training and consultancy about home buying for disabled people in Scotland.

In Control

This is a new way of helping people with learning disabilities achieve Self-Directed Support which means an individual budget and more control over their lives and services. SCLD and ALTRUM are developing In Control in Scotland.

http://www.in-control.org.uk/

Update

27 Beaverhall Road
Edinburgh EH7 4JE

Tel. 0131 558 5200

e-mail. info@update.org.uk

http://www.update.org.uk

Update provides disability information resources for other organisations and general information to individuals. Its website contains a section on direct payments.

Friends and relationships

ENABLElink

ENABLE Scotland
6th Floor
7 Buchanan Street
Glasgow G1 3HL

Tel. 0141 226 4541

http://www.enable.org.uk

ENABLE Scotland is developing a network of local friendship support schemes.

Local Area Co-ordination

SCLD (2006) Making Connections: Stories about Local area co-ordination.

http://www.scld.org.uk

Local Area Co-ordinators work alongside people with disabilities and their families and support them to make positive changes in their lives.

Common Knowledge

Room 14, Adelphi Centre
12 Commercial Road
Glasgow G5 0PQ

Tel. 0141 429 4912

http://www.ckglasgow.org.uk

Common Knowledge provides an online community to help people with learning disabilities find and link to friends.

Befriending Network (Scotland)

45 Queensferry Street Lane
Edinburgh EH2 4PF

Tel. 0131 225 6156

http://www.befriending.co.uk

Befriending Network has a directory of befriending projects on its website.

Best Buddies

Best Buddies is an international programme that creates one-to-one friendships for people with and without intellectual disabilities. In Scotland, Best Buddies is being co-ordinated by ENABLE Scotland.

http://www.bestbuddies.org/

e-mail: Scotland@bestbuddies.org

Leisure

Scottish Disability Sport

Caledonia House
South Gyle
Edinburgh EH12 9DQ
Tel: 0131 317 1130

http://www.scottishdisabilitysport.com/

FAIR - Family Advice and Information Resource (Edinburgh)

95 Causewayside
Edinburgh EH9 1QG

Tel. 0131 662 1962

http://www.fairadvice.org.uk

FAIR can provide information on leisure activities in the Edinburgh area.

Local council websites also have information about local leisure activities.

Work

Careers Scotland

150 Broomielaw
Atlantic Quay
Glasgow G2 8LU

Tel. 0845 8 502 502

http://www.careers-scotland.org.uk

Careers Scotland has an online resource centre with information about applying for training, finding out about careers and going to college.

Scottish Union for Supported Employment (SUSE)

32 Redhall Crescent
Edinburgh EH14 2HU

Tel. 0131 539 4967

http://www.suse.org.uk/

SUSE has an online directory of organisations that provide supported employment across Scotland.

ENABLE Scotland
Employment Access Team

Fountainbridge Business Centre
Unit 46, Ellis Street
Coatbridge ML5 3AA

Tel. 01236 607 103

e-mail. eat.coatbridge@enable.org.uk

Education and Training

SKILL Scotland

Norton Park
57 Albion Road
Edinburgh EH7 5QY

Information line open Mon-Thurs 1.30pm-4.30pm

Freephone . 0800 328 5050

e-mail. admin@skillscotland.org.uk

Office Tel. 0131 475 2348

http://www.skill.org.uk

Skill promotes opportunities for disabled people in learning and employment.

LEAD (Linking Education and Disability)

Queen Margaret University College
36 Clerwood Terrace
Edinburgh EH12 8TS

Tel. 0131 317 3439

e-mail. enquiries@lead.org.uk

http://www.lead.org.uk

LEAD supports disabled young people and carers to access post-school education through volunteer support, loan of computers and literacy and numeracy projects.

Association of Scottish Colleges (ASCOL)

Argyll Court
The Castle Business Park
Stirling FK9 4TY
Tel. 01786 892100
e-mail. enquiries@ascol.org.uk
http://www.ascol.org.uk/index.asp
ASCOL can provide links to all of Scotland's 43 further education colleges.

Individuals and Citizens

Disability Rights Commission

DRC Helpline
FREEPOST MID02164
Stratford upon Avon CV37 9BR

Telephone: 08457 622 633

Textphone: 08457 622 644

DRC Helpline is open 8am - 8pm, Monday to Friday

http://www.drc.org.uk/

The DRC can advise about disability discrimination issues.

Scottish Independent Advocacy Alliance

138 Slateford Road
Edinburgh EH14 1LR

Tel. 0131 455 8183

http://www.siaa.org.uk

SIAA can signpost you to local advocacy organisations.

ACE (Advisory Committee of ENABLE Scotland)

ENABLE Scotland
6th Floor
7 Buchanan Street
Glasgow G1 3HL

Tel. 0141 226 4541

http://www.enable.org.uk

ENABLE Scotland has 13 local self advocacy groups across Scotland encouraging people to speak up for themselves as well as a national ACE Committee.

ACE Advocacy

6th Floor
7 Buchanan Street
Glasgow G1 3HL

e-mail. ace.advocacy@enable.org.uk

A network of independent citizen advocacy services managed by ACE.

People First Scotland

77-79 Easter Road
Edinburgh EH7 5PW

Tel. 0131 478 7707

http://www.peoplefirstscotland.com/

People First is an international self-advocacy movement of people with learning difficulties with a network of local groups across Scotland.

ix:seed (Glasgow Learning Disability Partnership)

http://www.ixseed.org.uk

This is a source of information for people with learning disabilities and their carers in Glasgow.

Calling The Shots (Interactive Learning Resource)

Scottish Consortium for Learning Disability
Room 16, Adelphi Centre
Glasgow G5 0PQ

Tel:0141 418 5420

http://www.scld.org.uk

This resource enables organisations to be more inclusive in all areas of their work.

ENABLE Scotland

ENABLE Scotland is the country's leading organisation of and for children, young people and adults with learning disabilities, their families and carers.

We provide innovative, community-based services that help those with learning disabilities to live, attend school, work and enjoy meaningful participation in their local community. We support people with learning disabilities and their families to campaign, lobby and fight for greater equality and better opportunities.

We also campaign for a socially inclusive society where people with learning disabilities are regarded and treated as full and equal citizens. An important part of our work is providing parents – who have just been told their child has a learning disability – with information and support.

Recently ENABLE Scotland celebrated 50 years of caring and campaigning for children and adults with learning disabilities. A lot of progress has been made to establish the human rights of children and adults with learning disabilities, to end segregation in long stay hospitals and to recognise that they, like all people, make a valuable contribution to our communities with the right help and support.

As an organisation ENABLE Scotland continues to expand. Currently we have 66 local branches across Scotland and around 4000 members and 1000 volunteers.

ENABLE Scotland is governed by Scottish Council — an elected group of members drawn from our branch networks who advise on what work ENABLE Scotland does and what members think. Members include parents, professionals and people with learning disabilities themselves. Scottish Council establishes specialist groups, whose participants are drawn from members of ENABLE Scotland, from all over the country, to assist with its work.

ENABLE Scotland has a wide experience of working with other statutory and voluntary organisations. These include the Scottish Council for Voluntary Organisations (SCVO), Learning Disability Alliance Scotland (LDAS), Cross Party Group on Learning Disability, Disability Rights Commission, Community Care Providers Scotland (CCPS), Apex Trust, Disability Agenda Scotland, Scottish Union for Supported Employment (SUSE), Carers Scotland, Supported Training and Action Group (STAG), Carers Alliance, Children in Scotland, Special Educational Needs Forum, Down's Syndrome Scotland, Capability Scotland and the Scottish Association for Mental Health. In the UK we work with MENCAP – our sister charity in England, Wales and Northern Ireland. We also work with Inclusion Europe and Inclusion International. ENABLE Scotland is a member of the Scottish Consortium for Learning Disability.

scottish
consortium
for learning
disability

Building respect in the
Scottish community

About SCLD

SCLD is a consortium of partner organisations who work together to encourage best practice in the support of people with learning disabilities through training, information, consultancy, research and public education.

All our work is carried out in partnership with people with learning disabilities and family carers.

Our goal is to make Scotland a country where people with learning disabilities belong as equal citizens - a place where people with learning disabilities are valued and respected, can carve out their own lives and make equal and unique contributions amongst everyone else in life, learning, work and leisure.

SCLD's 13 partner organisations are:

ARC, BILD, Bagaduish Outdoor Centre, Capability Scotland, Down's Syndrome Scotland, ENABLE Scotland, Key Housing, PAMIS, Quality Action Group, University of Abertay, University of Dundee, The Glasgow University Affiliated Programme, University of St Andrews.

We offer:

- Training opportunities – for people who support people with learning disabilities and for people with learning disabilities and family carers too.
- Consultancy on "The same as you?" – support to learn and change.
- Changing Hearts and Minds – telling peoples stories to help build communities in Scotland which respect and value people with learning disabilities.
- Research and Evaluation – researching issues that matter to individuals and families.
- Information – based on evidence and experience.
- Capacity Building – strengthening others to work in partnership.

With the User and Carer Forum SCLD is supporting citizen leadership in the design and delivery of services.

See www.socialworkscotland.org.uk/programme4d.php

Further copies are also available from:

ENABLE Scotland
6th Floor, 7 Buchanan Street, Glasgow G1 3HL
Telephone:0141 226 4541
www.enable.org.uk

The Scottish Consortium for Learning Disability
Adelphi Centre Room 16,
12 Commercial Road, Glasgow G5 0PQ
Telephone: 0141 418 5420
www.scld.org.uk

This document can also be downloaded from the following websites:

- www.enable.org.uk
- www.scld.org.uk

You can also get copies of the questionnaire from SCLD

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Building respect in the Scottish community

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