



The same as you? 2000-2012: Consultation Report

Easy Read

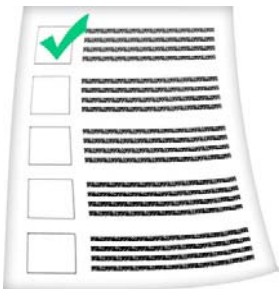
What is 'The same as you?' consultation report?



'The same as you?' was written by the Scottish Government in 2000. It looked at the services for people with learning disabilities and people on the autism spectrum.



'The same as you?' said that people with learning disabilities should have support to live the lives they want.



'The same as you?' made a list of 29 things that should be done to make the lives of people with learning disabilities better.



The Scottish Government want to know if the lives of people with learning disabilities have got better since 'The same as you?' They set up a research team to find out. Research is a way of finding out facts and opinions.

Who did we speak to?



The research team spoke to **49** adults with learning disabilities in Scotland. They spoke to **51** family carers in Scotland.



We wanted to talk to as many different people as we could. We spoke to people from **4** different parts of Scotland.



We spoke to adults who were younger and adults who were older. We spoke to people who needed only a little support. We spoke to people who needed more support.

Who did the research?



Each person with learning disabilities we spoke to was interviewed by 2 researchers. 1 of the researchers was always a person with a learning disability.

Consultation



To find out if people agree with what we have said or not the Scottish Government is holding a **consultation**. This means they want to know what people think about what we say in this easy read.



There are questions in the consultation. If you would like to answer the questions you can tell us as much or as little as you want to.



You will find a copy of the consultation questions on the Scottish Government website alongside this easy read.



The Scottish Government will look at what everybody says and write a report. The information people give us will help a group of people make a new **strategy** (big plan) for people with learning disabilities for the next few years. This group will have people with learning disabilities in it.

Housing

Leaving hospital and living in the community



'The same as you?' said that people with learning disabilities should not live in hospitals. It said that all long-stay hospitals should be closed by 2005.

What did we find out?



Some long-stay hospitals stayed open for longer than they should have done.



Since 'The same as you?' was launched over 1000 people have moved out of hospitals and into the community.

Where people live now



Over half of adults with learning disabilities lived in social housing. This means local authority and housing association housing.



Younger adults were usually living at home with their family.



People living independently were usually older than 35. People told us that they really liked having their own home.



We found out that not everybody is in the type of housing they need.

Services and support



'The same as you?' said there should be more services and support in the community. This included things like local area co-ordination.

What did we find out?



People with learning disabilities and their families really value local area co-ordination where it is available.



There has been an increase in supported living services. These services can support people with things like housing and managing money.

Care standards



‘The same as you?’ said there should be rules setting out the quality of care people using a service should get.

There are rules about what people who use a service should expect.



There are organisations that check the rules are being followed. One of these organisations is called the **Care Inspectorate**.



The Care Inspectorate says that services should make sure that people with learning disabilities have the things that matter to them. This includes having choice and independence.

Children and young people



We did not speak to children as part of the research.

The parents we spoke to thought these things were the most important for their children:

- communication support
- chances for their child to spend time with other young people
- short breaks for the parents to be able to spend time with their other children



Parents told us that at school their children need support from people like speech and language therapists.



Sometimes it is hard to get this help. Sometimes it is hard to keep this help once you have it.

School



'The same as you?' said that every child should have an education that meets their needs. If they need support to do this they should get it.



In the past some people with learning disabilities did not go to school. Most people with learning disabilities do go to school now.



Some people are still missing out on school if they cannot get the right support. The families of children with complex needs sometimes found that school services could not meet their needs.



Sometimes the planning around leaving school does not work well. Young people and their families need time, information and support from lots of different organisations to help them plan well.

College



'The same as you?' said that people with learning disabilities should carry on learning after they have left school. This will help to develop all of their skills and talents.

What did we find out?



Going to college to study is part of weekly life for many adults with learning disabilities. Most of the people we spoke to had been to college at some point.



College was a place to meet new friends.



We found that some college courses are not giving people the skills they are looking for. This includes skills to be ready for independent living and having a job.



Some people told us they were not able to get a college place for the coming year.

Work



'The same as you?' said that lots of people with learning disabilities wanted to work. It said that local authorities and health boards should help to make this happen.

What did we find out?



Not many people with learning disabilities are in paid work. Those who do have jobs often work 16 hours or less a week.



Not many people said there was a choice of job opportunities.



People often wanted to work more hours. Sometimes people were worried about changes to their benefits if they did this.



1 in 3 people with learning disabilities do **voluntary work** (help for free). People might do voluntary work because it is hard to get a paid job.



Work has lots of benefits for people. This includes things like:

- more confidence
- getting out into the community
- earning money
- getting new skills and making friends

Day opportunities



'The same as you?' said that nobody should go to a day centre full time. It said that people should have a mixture of different things to do including work and college.

What did we find out?



People have more access to different daytime opportunities now.



There is more available for people with complex needs now. But people with complex needs are less likely to have as many opportunities as other people.

Relationships



'The same as you?' said that people with learning disabilities should have the chance to make friends and have relationships.

What did we find out?



1 in 3 people with learning disabilities had at least 1 good friend.



About 1 in 4 people had a partner.



The places people said they could meet other people were day services, college, evening classes and at work. They could also meet other people while doing things in their free time.



The lack of accessible buildings in some areas made it hard for people to meet with friends. A lack of support and public transport can also make it hard to meet friends.

Transport

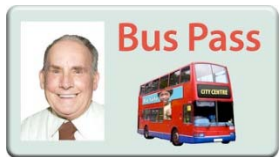


'The same as you?' said that people with learning disabilities should be able to use public transport.

What did we find out?



Public transport was important to a lot of people with learning disabilities as it helped them get to work and college. It also helps them have a social life.



Many people found a disabled person's bus pass very important to independent living.



People with complex needs were more limited in what public transport they could use.



Things that made using public transport hard were:

- noise
- getting on and off buses and trains
- knowing which bus or train to get on

Independence, choice and control



'The same as you?' said that people with learning disabilities should be supported to do everything they are able to.

What did we find out?



Most people with learning disabilities said they had been asked about what they wanted to happen in their lives.



About half of the people with learning disabilities we spoke to said they had a plan about what they wanted in life. Some people's plans had not been looked at again for a few years.



We found that people with learning disabilities sometimes could not do the things they wanted to do.

This might be because they do not have a support worker who would go with them. A lack of accessible places and transport sometimes meant they could not do the things they wanted to do.

Self-directed support



'The same as you?' said anyone who wanted direct payments should have them. There are now other ways to get self-directed support too.

What did we find out?



The number of people who get a direct payment has gone up since 2001. There are lots of people who still do not get direct payments though.



Not that many people with learning disabilities knew what a direct payment was.



Some people used their direct payment to pay for support workers. Some used it to go on days out and holidays.



Not everyone wanted to take more control over their support.

Advocacy



Advocacy can help people with learning disabilities say what they think.

'The same as you?' said people should have access to advocacy as it helps people to find the right answers to questions and problems.

What did we find out?



About 1 in 4 people with learning disabilities had used some type of advocacy.



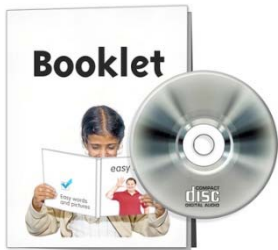
Some carers said there was a gap in advocacy for people who need support with communication and people with complex needs.

Information



'The same as you?' said that accessible information was very important. This is because it helps people choose and be in control.

What did we find out?



Almost everyone we spoke to said they got the information they needed to make choices.



People liked to have more than one type of information to help them understand. This might mean they would like someone to talk them through written information.



More than half of the people who answered this question said that someone talking to them was the best way of getting information.

Health



'The same as you?' said that people with learning disabilities should have good health services.

What did we find out?



People with learning disabilities have poorer health than people without learning disabilities. Since 'The same as you?' the Scottish Government and the NHS have tried to do things to change this.



People with learning disabilities often knew what to do to be healthy. Some found it hard to do these things in everyday life.



Some people took regular exercise.

Things that stopped people being healthy were:

- having enough time and support to cook a meal
- sometimes support workers did not want to support people with some types of exercise



Safety and risk



'The same as you?' said that people with learning disabilities should not be picked on. They should not be treated differently from others.

What did we find out?



A lot of people did not want to talk about bullying.

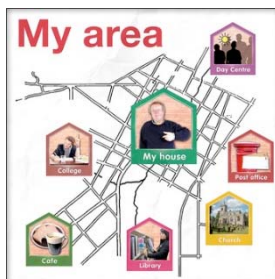
Almost 1 in 4 of the people we spoke to had been picked on or bullied in the past.



Most people felt safe in their homes. Some people who lived on their own worried at night.



Most people would not go out at night. This could be because they did not want to or were unable to.



More than 2 in 3 people said they felt safe in their local areas.

Criminal justice



The **criminal justice system** is a term used to mean the police, courts and prison.

'The same as you?' said that the needs of people with learning disabilities who come into contact with the criminal justice system should be met.

What did we find out?



People with learning disabilities come up against barriers to accessing the criminal justice system.



All of the 4 people with learning disabilities we spoke to who were in the criminal justice system had mental health needs.



We spoke to 1 person who was in prison. He did not know what services or support would be available for him when he left prison.

Parents with learning disabilities



'The same as you?' said that some people with learning disabilities may want to be parents. Training and support were needed to help them get parenting skills.



The number of parents with learning disabilities in the UK is going up. 4 out of 10 of these parents are not living with their children. Sometimes services do not give parents the chance to show they can look after their children.

Parents with learning disabilities who are in contact with social care often have these problems:

- poor housing
- living in tough neighbourhoods
- not much money
- no job
- lack of information



2 out of 3 people in some research in Scotland said that services did not meet the needs of pregnant women with a learning disability.

People with profound learning disabilities



'The same as you?' said that local authorities should work together with lots of organisations. This would help them look after the extra needs of people with profound learning and multiple disabilities.

What did we find out?



Most people with profound learning and multiple disabilities still go on to day centres after leaving school.



There are still gaps in services for people with profound learning and multiple disabilities. There are still problems with getting services to work together.

People with profound and multiple learning disabilities do not seem to get the same chances as other people. If services work with the people who know the person best this can help make sure they have a good life.



Black and minority ethnic (BME) communities



'The same as you?' said there was not enough information available in community languages.

What did we find out?



We spoke to 3 people with a learning disability from black and ethnic minority communities. We also spoke to 4 family carers from BME communities.



Many black and ethnic minority families feel alone. Some said they do not get support from their community. Some said they find it hard to access services.



People do not always know how to get access to information in their own language.

People with dementia



'The same as you?' said that local authorities and the NHS should make sure that staff are looking for the early signs of dementia. This will make sure people get the right treatment and services.

What did we find out?



Some adults with learning disabilities get dementia. People with learning disabilities who have dementia are living longer. This means they may need more service

like housing and health.



We found out that some family carers know about dementia. They understand that this might affect people with learning disabilities.



We found out that people needed more information about how they can get help as they come to the end of their life.

Family carers in Scotland



We found out that families give the most support to people with learning disabilities. People with learning disabilities need support with:

- personal care
- money
- travelling safely
- going to medical appointments



Lots of people with learning disabilities live with an older carer.

Carers said that bringing up a person with a learning disability had affected their lives. They said that:

- it can cause stress
- it can have an effect on the brothers and sisters of the person who has a learning disability
- it costs money





Carers also said that bringing up a person with learning disabilities brought positive things to their life as well.



We found out that the most difficult time for family carers was often when their child left school.

Support for carers



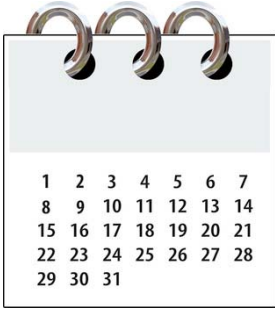
'The same as you?' said that families and carers should have help and support. Help and support means things like:

- giving training to help people look after someone with a learning disability
- access to short breaks
- access to people who can help with carer's needs



We found out that the main support given to family carers was:

- day centre places
- short breaks
- help to make their house more accessible.



Some carers found it was hard to get short breaks. Most families felt that they had to take dates that did not always suit them.



There were people with more complex needs who had good experiences with short breaks.

Access to services



‘The same as you?’ said that families had to fight to find out what services they could get. This is still the case for lots of families.

Life planning



The same as you? said that life plans need to say what people will do when their family carers can no longer care for them.



We found out that a lot of family carers have worries about this. Very few carers had a plan for what would happen.

Views on progress



People with learning disabilities and family carers said that the lives of people with learning disabilities have got better. This is because of having more opportunities.



Some things still need to get better though.

Most people with learning disabilities thought that people with learning disabilities were not treated fairly.



Most carers thought that people with learning disabilities should be seen more in the community.



They also said that there needs to be more work opportunities for people with learning disabilities.



Most of the carers we spoke to thought that people with learning disabilities were not valued in society.

Carers felt that:

- they were taken for granted
- they did not get enough support
- access to resources and services was not always equal
- support should be given without having to apply for it. This includes things like getting a bus pass



Future priorities

People with learning disabilities and carers said that these things need to happen in the future to make people's lives better:



- support to live independently
- access to homes with support
- more job opportunities
- better access to transport
- more chances to learn
- more things to do during the day
- good health care
- people with learning disabilities are more included in society
- carers felt that they should get more money to help them



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