

# ***The same as you?* 2000-2012: Consultation Report**

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## **Introduction**

*The same as you?* (SAY) (Scottish Executive, 2000) was launched by the Scottish Executive in May 2000 and reviewed the services then available to people with learning disabilities and people on the autism spectrum. It said that people with learning disabilities had the right to be included in, and contribute to, society, to have a voice, and to have access, with their families, to support to live the life of their choosing. It contained 29 recommendations intended to drive a change programme to improve services.

## **Note on language**

Throughout this report we use the term 'learning disability'. We recognise that some people prefer the term 'learning difficulty' and this is the term used by People First (Scotland), the national self-advocacy organisation.

We have used the term 'people on the autism spectrum' but recognise that some people will prefer a different term. Some people with learning disabilities are also on the autism spectrum. However, people on the autism spectrum do not necessarily have a learning disability.

## **Evidence**

In 2010 the Scottish Government set up an Evaluation Team to review the evidence on progress that had been made since *The same as you?* and the challenges that remain. It has produced 3 reports:

- an Evidence Scoping Paper (Trew, 2010) - summarises the published evidence on progress on the 29 SAY recommendations
- a Health Scoping Paper (Allan et al, 2012) - reviews the health needs of people with learning disabilities and developments to improve their health. It has an appendix about parents with learning disabilities (People First (Scotland) Parents Group, 2012)
- an Evaluation Report (Curtice and Trew, 2012) - reports the results of face-to-face interviews with people with learning disabilities and family carers.

This consultation report summarises the findings of all these reports. The full reports can be read at [www.sclid.org.uk/SAYevaluation](http://www.sclid.org.uk/SAYevaluation)

## **The consultation**

The purpose of this consultation report is to summarise the evidence which the Evaluation Team has gathered about the progress on *The same as you?* from published evidence and from face-to-face interviews with people with learning disabilities and family carers about their lives. This report summarises that evidence.

Through the consultation you now have an opportunity to comment on the findings and to share your own experiences and views. The Scottish Government wants to know if you agree with the findings from the evaluation, what your experience can tell us about how to improve the lives of people with learning disabilities and their families and what you think are the most important things that need to be done next. The accompanying consultation questionnaire explains how you can take part.

## **What will happen next**

The Scottish Government will analyse all the comments from the evaluation and publish a report on them. It will set up a National Strategy Group which will look at the findings from the evaluation and the comments made during the consultation. From these it will develop a new strategy and an action plan to show what needs to be done next to improve the lives of people with learning disabilities and their families.

## **Evaluation methods and sample**

The purpose of the evaluation was to find out whether people with learning disabilities and family carers were experiencing the changes that *The same as you?* had tried to bring about. It was decided to interview 50 people with learning disabilities and 50 family carers in 4 different areas of Scotland. The interview schedule for people with learning disabilities was based on *The same as you?* and focused primarily on people's lives. The carer's interview asked about the person they supported, their experiences of caring and finally, their views and opinions. The data was analysed both qualitatively and quantitatively.

eSAY, the national dataset on people with learning disabilities<sup>1</sup>, was used to define the sample characteristics. Local authorities then sent out invitations to people with learning disabilities using accessible information sheets. Only when someone agreed to take part were their details passed to the interview team. Family carers were identified largely through carer groups. Interviews took place where the person wished it, usually their own home. For the interviews with people with learning disabilities there were usually 2 interviewers, one of them a researcher with learning disabilities. Consent was obtained before any interview took place. Interviews took place in the 4 research areas between February and May 2011.

### **The people interviewed for the evaluation**

The sample of people for the evaluation was selected to represent a range of different situations, experiences and characteristics, including: age and gender, living situation (for example, living with a family member, living independently, living in a group home, living in restricted settings) and type of area (urban/rural, level of deprivation).

49 people with learning disabilities took part across 4 different local authority areas. 31 were men and 18 were women. The youngest person was in their 20s and the oldest person was in their 70s. The sample consisted of people with a range of support needs, from people who needed little or no support to people with very high support needs, including 2 people with profound learning and multiple disabilities. 12 people had complex needs, including sensory impairments, complex health needs, and mental health needs. 16 of the people in the sample had communication difficulties. 3 were from Black and Minority Ethnic Communities. More than a fifth of the sample were living in an area which fell into the 10% most deprived areas in Scotland. Their living situations are shown below. The term 'living independently' covers a wide range of support from none to 24 hour support.

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<sup>1</sup> <http://www.sclld.org.uk/sclld-projects/esay>

### **Living situation of the people with learning disabilities and/or on the autism spectrum interviewed**

<b>Living Situation</b>	<b>Number</b>
People who were living in the family home	18
People who were living independently	18
People who were living in a group home	8
People living in settings which restrict the person's liberty	4
Other	1
<b>Total</b>	<b>49</b>
People who had formerly lived in long-stay hospital	4

We spoke to 51 family carers in 40 interviews; sometimes we spoke to more than one family carer in the same interview. 42 of the carers were women and 9 were men. The carers were aged between their 30s and their 80s; 25 were aged over 60. 11 had postcodes which fell into the 20% most deprived areas in Scotland and 5 fell into the 20% least deprived. The family carers represented a range of caring experiences. 32 were caring for someone still living in their home and 19 had a relative who now lived elsewhere.

### **Family carers interviewed**

<b>Category</b>	<b>Number</b>
Older carers	19
Carers of people with complex needs	18
Carers of children and young people	11
Carers of people with profound learning and multiple disabilities	10
Single parent carers	9
Carers of people on the autism spectrum	5
Carers from Black and Minority Ethnic Communities	4
Sibling carers	4
People with learning disabilities who are carers	1
Other carers	3
<b>Total number of carers interviewed</b>	<b>51</b>
Some carers fell into more than one category.	

The carers supported a total of 40 people with learning disabilities. 8 of those cared for were children and young people aged 19 or younger, 20 were in their 20s and 30s and 12 were aged 40 or over.

### **Summary of key findings on progress and challenges since *The same as you?***

This section summarises the main findings which are then described in more detail in each section of the report which follows.

- the value and relevance of the principles set out in *The same as you?* are confirmed by all aspects of the evaluation; people with learning disabilities want support to live independent lives and an end to discrimination
- since 2000, more than 1,000 people have moved out of hospital into homes in the community. The closure of all the long-stay learning disability hospitals is a key achievement from *The same as you?* The overwhelming majority of adults with learning disabilities now live in the community. More people have experience of supported living, although some people are still in inappropriate placements and there is a wide variation in packages of support
- the education of people with learning disabilities is taken much more seriously. More people go on to college than in the past, but transition from school is still an issue, as is learning skills and moving into work
- those in work benefit economically and socially. Supported employment has been shown to be cheaper and more beneficial than day services. However, only a minority are in paid work
- people have access to a more varied and meaningful range of day opportunities that involve them in the community. Day services have diversified including for people with complex needs
- a majority of people have been asked about what they want to happen in their lives. Individual planning and flexible support has increased independence. People with access to flexible funding have used this to develop leisure and meaningful opportunities. Life Plans can be effective where followed up and reviewed
- improved access to meaningful activities and social relationships has benefitted people's wellbeing. Both people with learning disabilities

and family carers felt that greater social opportunities and inclusion have improved public attitudes

- people generally felt safe in their homes and out and about. However, bullying and harassment is still a serious concern
- being healthy underpins all other activities. Many people with learning disabilities are aware of healthy living messages, but encounter barriers to putting these into practice.

The evaluation also identified challenges which need to be addressed including:

- an end to parents being given negative messages on the birth of a disabled child
- timely information and support to individuals and families throughout life to assist in planning for the future and to prevent crises
- a much greater emphasis on support that builds people's capacity to lead independent, healthy lives
- local health and social work services commissioning appropriate local support to improve outcomes for people with learning disabilities whose behaviour challenges services
- opportunities for more adults with learning disabilities to have greater choice and control through employing their own staff and choosing meaningful activities
- young people with learning disabilities leaving school and college to have information about their options and the offer of further training or employment
- accessible information to be the norm for all public bodies
- the need for significant improvement in the numbers of people with learning disabilities in meaningful paid employment
- greater progress in making transport and mainstream services accessible to all
- use of the NHS Quality Strategy (Scottish Government, 2010b) to ensure the equal access of people with learning disabilities to effective healthcare and reduce health inequalities
- joint work with the police and others to ensure equality of treatment by the criminal justice system

- implementation of equalities legislation where people with learning disabilities are unduly disadvantaged
- strong responses to discrimination and abuse
- improved skills, information and joint working to support parents with learning disabilities, families from black and minority ethnic communities and individuals and families of people with complex and profound needs
- strategies to plan for the needs of increasing numbers of young people with complex needs and older people with increased health needs including dementia.

There is a fuller summary of priorities to be addressed at the end of this report.

### **How many people with learning disabilities are there in Scotland?**

*The same as you?* reported the following prevalence of learning disability in the general population in Scotland:

- 20 people in every 1,000 have a mild or moderate learning disability
- 3 or 4 people in every 1,000 have a profound or multiple disability.

The current data available points towards there being between 27,000 and 30,000 adults with learning disabilities in touch with health and social care services in Scotland. These figures are derived from the eSAY database and the GP Quality Outcomes Framework.

Data from the 2009 'Pupils in Scotland' (Scottish Government, 2009) survey shows that there are around 9,250 children with additional support needs due to learning disability. However, the number of children with learning disabilities is likely to be higher, since this figure does not account for children who are younger than school age or whose disability has not yet been recognised.

The population of people with learning disabilities is changing. This is due, in part, to an increase in life expectancy across all ages, even though people with learning disabilities generally die earlier than the general population. People who have very complex health needs are also living longer. There are growing numbers of children and young people with

more severe, profound and complex needs, as many more children born preterm are surviving into adulthood. Increasing life expectancy is also impacting on the number of people with learning disabilities surviving into older age.

### **Leaving hospital and living in the community**

*The same as you?* said that people with learning disabilities should not live in long-stay hospitals, but in the community with appropriate programmes of support. Recommendation 12 said that health boards should make plans straightaway so that all long-stay learning disability hospitals would close by 2005.

The closure of all the long-stay learning disability hospitals is a key achievement from *The same as you?* Since 2000, more than 1,000 people have moved out of hospital into homes in the community.

Some hospitals remained open for longer than they should have done. By 2005 11 long-stay hospitals had closed and 8 remained open and in December 2005 there were still 165 long term hospital places (NHS Quality Improvement Scotland, 2006b). Reasons for the delays in hospital closure included a lack of available housing provision and delays in setting up appropriate care packages for people with learning disabilities in the community (Short Life Working Group on Hospital Closure and Service Reprovision, 2004).

4 people interviewed for the SAY evaluation had lived in long-stay hospitals for periods of between 10 and 40 years. Some found it hard to talk about their experience there. One person who had moved from a long-stay hospital to a group home via a hostel simply said:

“I had a bad life, but it is better now”.

Other people concurred and were able to identify the independence of their current lives as the key difference between life in hospital and life now.

## **Where people live now**

eSAY data shows that more than half of adults with learning disabilities live in social housing. 60% live in mainstream rather than sheltered or adapted accommodation (Scottish Consortium for Learning Disability, 2011).

In 2010, 72% of adults with learning disabilities were the only person with a learning disability in their accommodation. Around 60% of these adults were not living with a family carer. A further 28% of adults with learning disabilities lived in accommodation with other adults with learning disabilities, of whom a third lived with more than 5 other adults with learning disabilities (Scottish Consortium for Learning Disability, 2011). According to Scottish Government data the number of adults with learning disabilities in care homes has fallen by nearly a third from around 3,100 in 2001 to around 2,100 in 2010<sup>2</sup>. Learning Disability Alliance Scotland has campaigned against younger people with learning disabilities being placed in care homes for older people (Learning Disability Alliance Scotland).

‘How is it going?’, a survey of people with learning disabilities in Scotland by SCLD and ENABLE Scotland, found that what mattered most to people with learning disabilities was having a house of their own and more independence (Curtice, 2006).

The Social Work Inspection Agency (SWIA) noted that the increase in the numbers of people with learning disabilities who live independently in their own homes was ‘partly attributable to the availability of Supporting People funding’. They also commented that there was variation between councils (Social Work Inspection Agency, 2010a).

The SAY evaluation found that:

- younger people were more likely to be living at home with their family than the rest of the people who were interviewed
- people living independently tended to be people over 35 with a few notable exceptions
- just over half of people aged 36-49 were living independently. Over a third (35%) were living with a family carer

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<sup>2</sup> <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/TrendLearningDisabilities>

- some people said that they liked to share accommodation, but living in group homes created all the challenges of sharing space and resources as well as restricting choices.

### **Assessment and treatment places**

SAY Recommendation 13 said that health boards should aim to reduce their assessment and treatment places for people with learning disabilities to 4 for every 100,000 population and plan for appropriate community services to avoid in-patient assessments and treatment. Recommendation 14 reinforced this stating that 'health boards with sites remaining after 2002 should develop, with their partners, other services in the community as a priority and set aside resources to meet these costs. This will feature in planning guidance and the boards' performance management arrangements.'

In 2007 there were 388 adults with learning disabilities within inpatient services in Scotland and of these 91 were under statutory orders (Perera et al, 2007). This is in line with the SAY estimates. eSAY data from 2010 reports 217 people living in NHS hospitals, 12 in specialist rehabilitation units and 13 in independent hospitals (Scottish Consortium for Learning Disability, 2011).

The available evidence suggests that more remains to be done. SWIA notes that the 'census data that records the number of people waiting in hospital for community care assessments and/or services does not cover people with complex disabilities and high support needs where there is no appropriate service available, or people subject to adults with incapacity provisions. Some people in these groups remain in hospital for long periods waiting for suitable community services to support their discharge' (Social Work Inspection Agency, 2010a).

Following an investigation into the care and treatment of Ms L, the Mental Welfare Commission (Mental Welfare Commission for Scotland, 2008a) recommended a national strategic approach to planning to ensure appropriate provision for people with ongoing high needs for care and support. In response to the abuse which took place in the Winterbourne View private hospital in England, a joint statement was issued by the Care Inspectorate, Mental Welfare Commission, Healthcare Improvement

Scotland and SCLD (2011) which stressed the importance of strong leadership in all sectors to promote a culture grounded in human rights. It said that services must be personalised and flexible enough to provide care and support for people with the highest level of need. It recommended that effective services for people with high support needs depend on:

- joint funding and commissioning of support packages
- close co-operation between different professions and agencies
- very detailed support plans which are consistently adhered to
- staff skilled in positive behaviour support
- access to independent advocacy and communication support
- safe recruitment practices.

The Joint Improvement Team (JIT, 2008) has produced an online workbook to inform the development of joint commissioning strategies and capacity planning for learning disability services by local partnerships.

### **Positive support for people with learning disabilities whose behaviour is perceived as challenging**

*The same as you?* recommended that 'health boards and local authorities should make sure that there is appropriate specialist support such as additional support teams to improve services for people with learning disabilities who have challenging behaviour. The aim of the specialist services should be to support mainstream services and to help people stay in their own homes as far as possible' (Recommendation 27).

There have been developments to improve the evidence-base for practice and to improve the skills of the workforce to support people whose behaviour is perceived as challenging. During 2008, the Scottish Government Health Department developed 'A guide to planning and delivering evidence based psychological therapies within NHS Boards in Scotland' (Scottish Government, 2008b). A sub group has been set up to develop the evidence base around psychological interventions and therapies for people with a learning disability.

In 2010, NHS Education for Scotland (NES) commissioned a training programme in Positive Behaviour principally for learning disability nurses and allied health professions. The Richmond Fellowship won a Care

Accolade in 2010 for embedding leadership for Positive Behaviour Support throughout the organisation. Its project reduced by 50% episodes of behaviour that challenged. NES has also commissioned a work-based educational resource to enhance workers' knowledge and skills in supporting people with a learning disability and complex needs, and their families and carers.

SWIA reported that its inspections found that amongst people with learning disabilities there were 'increasing numbers of people with complex disabilities and high support needs. This included people with complex physical disabilities, mental illness, challenging behaviour and forensic needs. A range of service models was required to ensure these different needs could be met. Most councils were facing issues of affordability and sustainability.' Action was needed to:

- make sure that care and support was well designed and cost effective
- allocate resources fairly, relative to needs
- develop or sustain preventive services
- further develop the potential of strategic commissioning, especially for people with complex disabilities
- use resources more efficiently
- make sure all councils adopted the best practices of councils that performed well in terms of service quality, equity and efficient use of resources (Social Work Inspection Agency, 2010a).

Issues of funding and skills continue to be barriers to supporting people appropriately in the community. An evaluation of 'Partners for Inclusion' (MacIntyre, 2010) has shown how individualised, person-centred support can successfully support people in the community who might otherwise be at risk of admission to a more restrictive setting.

### **Services and support**

The emphasis which *The same as you?* placed on services and support in the community meant that new types of service design and delivery grew up. For example, *The same as you?* recommended that local area co-ordination services should be introduced for people with learning disabilities (Recommendation 2). SWIA noted from its inspections 2005-9 that 'local

area co-ordination had been successfully developed by some councils, and was making an effective contribution to improving the quality of life of people with learning disabilities by putting them in touch with local supports, for example, in Stirling and East Dunbartonshire' (Social Work Inspection Agency, 2010a). Research also shows that people with learning disabilities and their families highly value the contribution of local area co-ordinators (Stalker et al, 2007).

Local area co-ordination services are now available in 26 of the 32 local authorities, with almost 81 whole time equivalent local area co-ordinators (National Local Area Co-ordination Development Team, 2010a). However, the implementation of local area co-ordination has varied across Scotland (Stalker et al, 2007). To address this, the National LAC Development Team, based at the Scottish Consortium for Learning Disability, published a practice framework to set standards for local area co-ordination, 'Values into Practice: A Framework for Local Area Co-ordination in Scotland' (National Local Area Co-ordination Development Team, 2010b).

The change in balance of care has been accompanied by an increase in supported living services. Supported living services can assist people with housing support, daily living skills including managing money and building community contacts. The number of hours of support provided can vary considerably, but the emphasis should be on an individual package that maximises a person's choice and control. The principle of supported living is that housing and support are not all provided by one agency.

### **Care standards**

Recommendation 22 of *The same as you?* concerned the development of national care standards. The National Care Standards set out the level of care that people using a service can expect. There are specific care standards for care homes for people with learning disabilities (Scottish Executive, 2005) which indicate what each resident can expect, including the requirement for an individual risk assessment plan. The standards also say that people with learning disabilities have the right to choose the risks they wish to take, providing there is a balance between these and the welfare of other residents and staff.

Inspections have played a part in identifying the need for service improvements and progress on these. Two multi-agency thematic inspections (Social Work Inspection Agency, 2010b , 2007) examined provision for people at risk and young people in transition. Lay assessors, including people with learning disabilities and family carers, have played a full part in the inspection of health and social care services for people with learning disabilities.

SWIA, which is now part of the Care Inspectorate, published an overview of its care inspection findings from 2005-2009. It reported that '*The same as you?* has a continuing significance and influence on empowering people to be fully included in their communities' (Social Work Inspection Agency, 2010a). From their performance inspections and multi-agency inspection of services for people with learning disabilities, they reported that what mattered most to people with learning disabilities were choice and independence, having your own home, friends, relationships and work and leisure opportunities.

Quality indicators for the support of people with learning disabilities by health services have been developed by NHS Quality Improvement Scotland (NHS QIS, 2004). The first NHS Quality Improvement Scotland review of health services focused on 4 of the 6 specific Quality Indicators. A national overview report set out the progress in achieving hospital closures (NHS QIS, 2006b). Following concerns about the care and treatment of people with learning disabilities in general health services and several high profile Fatal Accident Inquires, NHS QIS published a best practice statement on promoting access to healthcare for people with learning disabilities in 2006 (NHS QIS, 2006a). The Best Practice Statement provided a service audit tool and information on the issues that required to be addressed to enable people with learning disabilities to receive equal access to general health services.

From April 2011 Health Improvement Scotland (HIS) has responsibility for scrutinising healthcare services in Scotland including independent healthcare services. The Care Inspectorate (formerly Social Care and Social Work Improvement Scotland, SCSWIS), scrutinises social work and

social care services, including child protection and the integration of children's services.

### **Children and young people**

After *The same as you?* was published, a Children's Sub Group was set up and published its report, 'Changing Childhoods' in 2006 (Children's Sub Group, National Implementation Group for *The same as you?*, 2006). The report covered what mattered to children, early years, school years and transitions and called for effective joint working so that children and young people with learning disabilities could expect to live a life 'the same as you'.

'The National Review of Services for Disabled Children' (Scottish Government, 2011c) was undertaken to provide a strategic assessment of the children's disability landscape. The report supports the delivery of key elements in the Scottish Government's performance framework, and disabled children and young people's statutory rights to equal treatment and equality of services under equality and human rights legislation and public authorities' equality duties. Several actions are outlined, including:

- an additional, dedicated £2m investment in short breaks for families with severely disabled children
- pilot the 'for Scotland's Disabled Children' (fSDC) *Charter for Scotland's Disabled Children*<sup>3</sup> in several local authority and related health board areas
- develop and publish a 'Getting it right for every child' (GIRFEC) practice briefing setting out how the GIRFEC approach applies to disabled children
- develop and disseminate a robust evidence base of good practice across a range of key areas, such as transition
- ensure improved outcomes for disabled children through children's services plans
- strengthen the children's disability aspects of the self directed support agenda
- review learning provision for children and young people with complex additional support needs through the Doran Review<sup>4</sup>.

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<sup>3</sup> <http://www.fsd.org.uk/assets/files/fsdc-charter.pdf>

<sup>4</sup> <http://www.scotland.gov.uk/About/DoranReview>

There were no interviews with children as part of the SAY evaluation but 11 family carers of 8 children and young people were interviewed. Parents aspired to a good future for their children. Their priorities included communication support and the opportunity for their child to mix with other young people. They wanted access to short breaks to spend time with their other children.

## **School**

SAY Recommendation 24 said that ‘the Scottish Executive should consider introducing a new duty on local authorities to identify a responsible person to advise and help the person with learning disabilities and their family put the future needs assessment (FNA) into practice.’

At the time of *The same as you?* future needs assessments were required when a young person with a Record of Needs reached 14. However, the law changed in 2004 with the introduction of the Education (Additional Support for Learning) (Scotland) Act 2004, which replaced the record of needs system by co-ordinated support plans (CSPs). CSPs aim to set out:

- the reasons why a student might require additional support
- who should provide this and what form it should take
- educational goals
- details of review.

The Scottish Executive at the time aimed to ‘increase social inclusion but accept[ed] the need for special schools.’ The Standards in Scotland's Schools etc Act 2000 and certain provisions of the Special Educational Needs and Disability Act 2001 (SENDA) said that all education authorities must provide education to all children in mainstream schools and pre-school centres unless particular circumstances apply. According to Scottish Government statistics, almost two thirds (64%) of children and young people who are recorded as having additional support needs due to learning disability attend mainstream schools (Scottish Government, 2009).

The findings from the SAY evaluation were:

- the experiences of older participants confirmed that historically, education had not been viewed as a priority for people with learning disabilities
- carers with children in primary and secondary education talked about the lasting benefits of their time in school. They stressed the role of school in improving their children's skills and capacities
- in several instances these carers also expressed concerns, including that their child's capabilities might be overlooked and the lack of social inclusion of some special units within mainstream schools
- several families of children with complex needs had had to relocate or follow alternative paths to deal with the lack of appropriate school services in their areas
- all carers with children with learning disabilities mentioned that communication was their children's greatest barrier. However, gaps in communication support were identified including insufficient access to Speech and Language Therapy. Another significant challenge for pupils and families was that different communication and symbol systems were in use in different areas
- transition from school to adult education can entail the loss of friends and familiar contacts. 3 out of 7 carers interviewed had children close to the age of transition and each asserted that this was one of the most difficult times they have ever had as a family.

## **College**

*The same as you?* saw lifelong learning as part of the shift that needed to happen if people with learning disabilities were to develop their full potential. Continuing attendance at college has become part of the weekly life experience of many adults with learning disabilities. eSAY reports that around 2,400 adults with learning disabilities were undertaking a further education course during 2010 (Scottish Consortium for Learning Disability, 2011). However, some college courses are not offering people with learning disabilities the range or level of opportunities which they are looking for, particularly in preparing them for independent living or developing employment skills. At the same time, there is a need to develop more meaningful opportunities for learners with higher support needs. Even so, many students with learning disabilities have benefitted socially from the college experience.

The pattern of college attendance for adults with learning disabilities has been different from that of other young people. After full-time life skills courses, many have continued part-time for several years on learning opportunities programmes. However, short courses that do not lead to qualifications or clear outcomes are now being discontinued.

The evaluation found that:

- most of the people with learning disabilities who were interviewed (29 or 60%) had attended college at some stage. Just over a quarter (13) were attending college at the time of interview
- women appeared to be slightly more likely to be attending college than men
- college provided a place to meet new people and make friends. Attendance at college was also associated with opportunities to gain independent living skills which had often not been developed during their school years, in particular independent travel
- few people believed that their college course had helped them to get a job or would do so in the future
- 7 of the 13 people we interviewed who were still attending college were over the age of 30. Some people had attended college for some years, repeating the same course or not gaining a qualification
- some people told us that they were not able to get a college place for the coming year. Not everyone knew what other support would be in place for them in the absence of a college place
- people with learning disabilities also told us about a number of instances in which college buildings and facilities were not accessible, preventing them from attending their courses
- in a rural area the post school options could be limited.

## **Work**

Recommendation 16 of *The same as you?* said that 'local authorities need to give a much greater priority to developing a range of employment opportunities for people with learning disabilities. And, with health boards, those authorities should lead by example in employing more people with learning disabilities.'

SAY Recommendation 17 said that the 'Scottish Executive should consider raising with the Department of Social Security (now the Department for Work and Pensions) specific areas of concern related to benefits and support for people with learning disabilities.'

A minority of people with learning disabilities currently have a paid job. Where people are employed, they are often working for less than 16 hours per week. 2010 eSAY data records that the majority of people (75%) for whom employment status was known were not in employment or training for employment. 3,839 (25%) in total were in employment or training for employment; only a fifth of people in employment or training for employment were working more than 16 hours per week (Scottish Consortium for Learning Disability, 2011).

'Working for a change?' (Short-life Working Group on Employment, 2003) found that the barriers to work included:

- concerns about the effect on eligibility for benefits
- low expectations among people with learning disabilities, their families and service providers
- a lack of confidence
- discrimination and lack of awareness by employers
- poor co-ordination of employment services
- a lack of funding and resources for supported employment services.

Supported employment has been shown to increase the chances of successful employment for people with learning disabilities and to be cost effective. Beyer (2008) evaluated the outcomes of supported employment in North Lanarkshire and found that on average people with learning disabilities who used the supported employment service were:

- working for 24 hours a week and
- 95% better off before tax and 87% better off after tax.

Beyer also found that supported employment represented a significant saving to the local authority. The cost of a supported employment place was in the region of £4,000- £7,000 a year compared to £15,000 a year for

locality support services e.g. day centres. Beyer attributed the success of Supported Employment in North Lanarkshire to the council investment in time and resources, the time dedicated to understanding the capacities of each individual and expert welfare rights advice.

In the SAY evaluation:

- some people had more than one paid job, each for only a few hours per week and other people had both paid and voluntary work
- few people reported a choice of employment opportunity
- people often wanted to work more hours and be able to earn more, but they were concerned about the effect this would have on their entitlement to welfare benefits
- there was a spectrum of employment from jobs in open settings, through social firms, to more sheltered work environments
- almost a third of people with learning disabilities were volunteering regularly. People appeared to be offering more of their time per week than the general population; volunteering offers the opportunity to develop skills for the workplace, however, it may also be acting as a substitute for paid work
- earning money was an important benefit of paid work. All work, whether paid or voluntary, had numerous benefits including building confidence, getting out of the house, being part of a team, developing skills and making friends
- the routes to employment were through friends, family, social workers, specialist employability services and support providers; none of the people interviewed had accessed employment through a mainstream employability provider
- some people were undertaking training placements in order to build their skills and increase their employability, but others reported that these either stopped or carried on indefinitely without leading to work
- those caring for a person with complex needs perceived that employment opportunities were less likely to be available for their sons or daughters.

### **Day opportunities**

Recommendation 15 of *The same as you?* said that local authorities and NHS boards should ensure that people with learning disabilities have

‘modern, flexible and responsive services which support them in the community through employment, lifelong learning and getting them involved socially’. The role of day centres should change. Nobody should go to a day centre full-time, but should instead get alternative day opportunities for at least part of the week.

Between 2003 and 2010 there has been a gradual decline in the number of people with learning disabilities attending day centres, coupled with an increase in the number of adults with learning disabilities getting alternative day opportunities. More than 7,500 people access alternative day opportunities and more than half of this group do not use day services at all. However, about 1,500 people with learning disabilities still attend day services 5 days a week.

In 2006, the Scottish Consortium for Learning Disability conducted a survey of around 600 people with learning disabilities called ‘How is it going?’ (Curtice, 2006). Almost 75% of people thought that they had enough opportunities to do the things that they wanted to with their lives; 80% thought there were enough places which they really liked going to in their area. However, there were barriers to socialising and being a part of the community which included:

- a lack of support staff
- inflexibility in support provision and
- a lack of transport or inaccessible buildings.

In general, the SAY evaluation found evidence of increased variety in the day services and opportunities provided since *The same as you?* People had a varied week and spent their time in a variety of settings and activities. In addition:

- almost three quarters of the people interviewed were doing activities such as college or classes, paid or voluntary employment and other activities such as sport and creative arts which took place outside the day centre environment
- activities were often the vehicle for people to develop confidence, independent living skills and friends

- the quality of opportunities seemed to vary widely between individuals and areas
- a third of the people interviewed said that they were spending half of their week or more at home, including weekends. While spending time at home was enjoyable for some people, others felt isolated and bored
- just over half of the people who attended a day centre did so for more than 2.5 days per week. People who spent more time at the day centre tended to have greater communication and/or support needs
- people who had complex needs or communication needs and were living with a family carer were significantly more likely to attend the day centre than people who did not have these needs
- barriers to a meaningful day included low expectations of what a person was able to achieve, a lack of accessible facilities, the lack of available support staff and lack of facilities in rural areas.

## **Relationships**

*The same as you?* said that people with learning disabilities should be included and valued. They should be asked and encouraged to contribute to the community that they live in, including having the chance to make and sustain friendships and relationships. Having more friends and the chance to have a romantic and/or sexual relationship were among the priorities which people with learning disabilities chose for their lives in a survey conducted by SCLD in 2006 (Curtice, 2006).

The SAY evaluation found that:

- about one third of the respondents were able to name at least one close friend
- shared social spaces such as day services, colleges, clubs, evening classes and the workplace could provide opportunities to meet and interact with other people and build meaningful and sustainable relationships
- neighbourhood and community ties were generally positively described, but tended to provide opportunities for being known and looked out for, rather than for friendships

- apart from family and friends, support workers were most commonly referred to by people with learning disabilities as the people they could share things with
- some support staff saw it as their role to widen people's social relationships
- carers emphasised that there was a need for continuity in the support staff that worked with people with learning disabilities
- one third of the people asked said that they sometimes feel lonely. Most people in this group linked their feelings of loneliness to spending time at home
- men appeared to be slightly more likely than women to say that they felt lonely and also appeared to find it more difficult to spend a large proportion of their time at home
- in general the people said that they did not face any particular obstacles to making friends. However, others felt that getting to know people could be difficult and that they needed to develop the skills to build contacts and friendships
- a lack of inclusive, accessible facilities in some areas, especially deprived and/or rural areas, represented a significant barrier to friendships for people with learning disabilities
- a lack of support with communication and making arrangements for meetings with friends appeared to be significant obstacles for some people with learning disabilities in their opportunities to interact with other people and meet friends
- some people were dependent on family for social interaction and socialising. This was more obvious in the experiences of people with profound learning and multiple disabilities
- both people with learning disabilities and carers felt that it was important for people with learning disabilities to have their own social life beyond the family environment
- almost three quarters of people with learning disabilities interviewed said that they did not have a partner.

## **Transport**

Recommendation 18 said that 'local authorities should review their local transport services to make sure that people with learning disabilities can use public services wherever possible'.

In 2005 transport providers became liable under the Disability Discrimination Act (Disability Rights Commission, 2006a, 2006b). Local authorities in Scotland are also under a duty to have due regard to the elimination of unlawful discrimination against disabled people as well as promoting equality of opportunity for disabled people.

Recent research by Leonard Cheshire Scotland (McQuigg, 2008) found that:

- almost half of the sample said that inaccessible transport affected their ability to get a job
- around a third of respondents reported being unable to access further education because of transport problems
- two thirds of the sample said that inaccessible transport had meant that they missed a visit to family and friends; a similar proportion had missed a social occasion because of inaccessible transport.

The Scottish Centre for Social Research carried out research about why people do not use buses (Dobbie et al, 2010). The sample included 6 people with learning disabilities. The research found that people with learning disabilities reported several concerns with using buses including:

- not being given enough time to sit down or get off, the attitudes of bus drivers and a lack of accessible information on timetables and routes
- a lack of reliability, cost and inconvenience, alongside worries about anti-social behaviour.

The cost of public transport can also serve as a barrier to greater use by people with learning disabilities. The Scotland-Wide Free Bus Travel Scheme for Older and Disabled People has been in operation since 2007 and enables eligible individuals to travel for free on local and national bus services through a National Entitlement Card. However, not all people with learning disabilities are eligible to access the scheme, in some cases because they do not fulfil the eligibility criteria around learning disability, in others because they do not receive the higher rate mobility or higher/middle rate care component of Disability Living Allowance.

The findings from the SAY evaluation were that:

- local public transport services, especially bus services, were important to enable people to access work, training opportunities and college, as well as the friendship networks which are connected to these
- many found a disabled person's bus pass essential to living independently and accessing opportunities
- some people on the lower rate of Disability Living Allowance had lost their eligibility to a travel companion which limited them to only travelling locally or in the worst case, to being unable to travel
- people with more complex needs, profound learning and multiple disabilities and people who used mobility aids were much more limited in their transport options and those who did not have a motability car often relied on transport from day centres, which restricted their ability to get out and about
- barriers to the use of public transport included noise, getting on and off and knowing which train to get.

### **Support to live an independent life**

*The same as you?* recognised that people with learning disabilities had been denied opportunities to live independent lives and that this needed to change. It said that 'people with learning disabilities should be helped and supported to do everything they are able to'.

The SAY evaluation found that:

- people's preferred activities were sometimes restricted by the willingness of support workers to accompany them and support them to their chosen activity
- people with learning disabilities identified that a lack of accessible facilities sometimes prevented them from being able to participate fully
- most people felt that they could stay out late if they wanted to, although some family carers placed restrictions on this, as did the times that support workers were able to help the person

- technology could be used to restrict or enable. Some people spoke of having to be home before the alarm; others explained that if they wanted to stay out, they could have an alarm set later
- people who directed their own support, whether through direct payments or the Independent Living Fund often had more flexibility in their days
- some people were full of praise for their support workers and felt that they built their independence by helping them to learn new skills and tasks to look after their home
- some packages were tailored to supporting people with challenging behaviour, mental health problems or complex health needs within their homes and may have been preventing them from having to live in more restrictive environments
- unsurprisingly, people living in restricted settings had a much more limited sense of choice and control over their lives
- most people felt sure that they could keep correspondence and special things private and safe if they wanted to, although it was evident that there was a need for support workers or family carers to assist people with understanding what letters meant, making decisions and following up on these.

### **Choice and control**

In the past, it was assumed that people with learning disabilities were unable to make decisions and take control of their lives. *The same as you?* said that this was wrong. It said that people with learning disabilities should be at the centre of decision-making and have more control over their support.

The *Adults with Incapacity (Scotland) Act 2000* is designed to regulate the way in which decisions are made for individuals over the age of 16 who do not have the capacity to act, make decisions, communicate their decisions, understand decisions or remember their decisions on important issues such as their personal welfare, their property, their financial affairs or any medical treatment which they may require. The Mental Welfare Commission has expressed concerns around the granting of indefinite guardianship orders for some people with learning disabilities, since these types of orders lack the legal safeguards of review (Mental Welfare Commission for Scotland, 2008c).

The SAY evaluation found that:

- the majority of people (28 out of 34) felt that they had been asked about what they wanted to happen in their lives, most commonly by a support worker, a parent or a social worker
- people under 35 were significantly more likely to say that someone had asked them what they wanted to happen in their life than people over 35.

Personal life plans are one way that people with learning disabilities can take control to realise their hopes and dreams. Recommendation 3 of *The same as you?* said that people with learning disabilities should have a personal life plan if they want one. Personal life plans or person centred plans are not the same as support plans, which tend to focus on meeting the person's everyday support needs.

eSAY statistics from 2010 show that 11,249 people with learning disabilities are recorded as having a personal life plan. This represents just over 40% of the people who are known to local authorities (Scottish Consortium for Learning Disability, 2011). This is almost three times as many people as had a plan in 2003, although this is likely in part to represent improved data collection.

The SAY evaluation found that:

- about half of the people interviewed said that they had a plan which said what they wanted in life
- 10 people were able to name something from their plan that had happened, ranging from being able to access discrete social opportunities, such as holidays or visits, to bigger life choices, such as living independently or getting a job
- some people's plans had been completed several years previously and had not been reviewed
- where people who had higher support needs had been enabled to make choices meaningful to them this was often by having people

who knew them really well around them and very detailed support plans.

### **Self-directed support**

*The same as you?* said that anyone who wanted 'direct payments should be able to have them and that local authorities should feature in the list of possible providers'. Since the publication of *The same as you?*, the Scottish Government has been developing self-directed support to enable people to have greater choice and control over their support. People may choose whether to use the resource allocated to support them to arrange some or all of their support themselves through a direct payment or to ask a provider to do this or they may decide to continue to receive services arranged by their local authority.

The number of people with learning disabilities in Scotland who receive a direct payment has increased steadily, from 32 in 2001 to 1,249 in 2011 (Scottish Government, 2011d, 2010d, 2010e). However, this still represents only a small proportion of the numbers of people with learning disabilities.

In the SAY evaluation:

- in general, awareness of direct payments was low, with just under a third of people saying that they knew what a direct payment was
- some local authorities appeared to have been more active than others, with higher awareness and take-up of direct payments seen in specific areas
- people were using their direct payments to pay for support workers and there also seemed to be a trend towards using the direct payment for activities, such as days out, sports and holidays, rather than for everyday support needs
- people valued being able to choose the person or people who came to support them as a result of having a direct payment
- those people who did not have a direct payment or Independent Living Fund monies were far less able to choose or change their support if they needed to. Just under two thirds said that they did not have full choice over who supported them
- not everyone wanted to take more control over their support.

## **Advocacy**

*The same as you?* recognised that not many people then had access to advocacy. It said that people with learning disabilities should have access to advocacy because it could help to find ‘the right solutions to difficult problems’. Recommendation 11 said that ‘the Scottish Executive should continue to encourage the development of local independent advocacy services’. Advocacy can support people to understand information and choices and to make their voices heard, especially if they may find it difficult to do so by themselves.

The Mental Health (Care and Treatment) (Scotland) Act 2003 placed statutory duties upon NHS boards and local authorities to ensure that people with learning disabilities have access to an independent advocacy service and that they have the opportunity to use those services.

In the SAY evaluation:

- around a quarter of the people who took part in the interviews had used advocacy services or been involved in collective advocacy. Self advocacy helped people to grow their skills and confidence
- some of the carers we spoke to identified a gap in advocacy provision for people with communication difficulties and people with profound learning and multiple disabilities.

## **Communication**

Recommendation 10 of *The same as you?* was to include adults as well as children in the review of the effectiveness of funding speech and language therapy.

The review, conducted by Queen Margaret University, suggested that around 10% of adults with learning disabilities known to services use speech and language therapy services. A further 284 adults with learning disabilities and/or on the autism spectrum were on a waiting list to see a speech and language therapist in April 2002 (Scottish Executive, 2003).

A more recent survey (Royal College of Speech and Language Therapists, 2010) found that a third of adults with learning disabilities requiring speech

and language therapies had to wait more than 18 weeks for assessment. Some adults with learning disabilities were waiting up to a year after assessment for the appropriate intervention to commence.

During the last ten years there has been an expansion in augmentative and alternative communication (AAC) aids to assist people with communication difficulties to interact with others. In a Scottish study of the use of Talking Mats by people with learning disabilities, Murphy and Cameron (2008) found that Talking Mats improved communication, increasing the quality and quantity of communication for those people with slightly less severe communication difficulties and providing a more effective communication framework for those people with slightly more severe communication difficulties.

Communication Forum Scotland worked with partners to develop a self assessment tool in the Principles of Inclusive Communication for public authorities (Scottish Government, 2011b).

## **Engagement**

*The same as you?* said that people with learning disabilities should be asked about the services they need. The SAY evaluation found that:

- group membership, especially membership of collective advocacy groups, was also an important way to influence and improve services
- some people felt that they were excluded from opportunities and processes which would enable them to be consulted or to influence their services or communities
- intensive interaction could enable some people with complex communication needs to express their wishes
- around a quarter of the people interviewed said they had voted in an election before and the same proportion intended to vote in the Scottish Parliamentary elections held in May 2011.

## Information

*The same as you?* recognised that accurate, accessible information in all aspects of life was critical to enabling people with learning disabilities to exercise choice and control and to be included. It recommended that 'the Scottish Accessible Information Forum should consult local authorities, health boards and users and carers on how best to provide joint, one-stop, free and accessible local information services for people with learning disabilities, their families and carers. Information must also be available in community languages' (Recommendation 8).

The Scottish Accessible Information Forum (SAIF) produced a response to this recommendation in November 2002 in its report 'The same as you? and Local Accessible Information Strategies' (Scottish Accessible Information Forum, 2002). They subsequently issued a questionnaire to local authorities and health boards about their plans to produce accessible information for people with learning disabilities. Local authorities and health boards were found to vary considerably in their approaches to improving provision for people with learning disabilities and how far they worked together to do this.

Further developments have included the establishment of Health Rights Information Scotland (part of Consumer Focus Scotland), which works in partnership with NHS Scotland and other stakeholders to produce accessible information on patients' rights. SCLD has also been given a remit to promote accessible information and does so through its website and training.

The Scottish Social Attitudes Survey (Ormston et al, 2011) found that 93% of respondents thought that providing information in 'easy read' formats for people with learning disabilities was a good use of public money. The Equality Act 2010 places a duty on all public bodies to provide information in accessible formats.

The SAY evaluation found that:

- almost everyone who answered said that they got the information they needed to make choices and decisions. However, only 4 out of

16 people with communication difficulties and/or a sensory impairment answered this question

- barriers to obtaining information included the lack of a single place to go to get the information needed or being entirely dependent on their support service for information
- 19 people told us about their information preferences. More than half of these people said that they liked someone to give them information orally
- people preferred to have multiple types of information formats on a given issue. For example, they would find it helpful to have written information with pictures and the opportunity to go through this with someone, or information on CD and the chance to discuss this with a support worker
- out of 10 people half felt that they often received information in their preferred format.

### **Health and health services**

People with learning disabilities have poorer health than the general population and die younger. There is evidence that some of their ill-health is preventable. Rates of mental health problems in children and young people with learning disabilities are much higher than in those without disabilities.

*The same as you?* said that people with learning disabilities should have services that promote and protect their health and wellbeing and emphasised that people with learning disabilities should have access to the full range of general health services in the first instance. It also recognised that specialist health services could benefit people with learning disabilities.

The reasonable adjustments that would address the barriers met by people with learning disabilities include providing accessible information, treating people with respect, redesigning systems, for example to provide longer appointment times, training NHS staff in communication and positive attitudes and ensuring liaison with specialist health services.

In Scotland there have been a large number of national initiatives to improve the health of people with learning disabilities including 'Promoting Health, Supporting Inclusion' (Scottish Executive, 2002) on the

responsibilities of all nurses and midwives, the Health Needs Assessment (NHS Health Scotland, 2004), investment in all NHS Boards to reduce the health inequalities experienced by people with learning disabilities (2007-11) and the establishment of multidisciplinary networks including the Learning Disability Child and Adolescent Mental Health Services Scotland Network and the National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) (2009).

In 2008 NHS Quality Improvement Scotland undertook a national review of all general health services against Quality Indicators 2 and 3, 'promoting inclusion and well-being' and 'meeting general healthcare needs' resulting in a national overview report, 'Tackling Indifference' (NHS QIS, 2009). Good practice was noted in areas such as primary care (GP contract and health checks), acute hospital care (hospital liaison nursing posts), palliative care and end-of-life care. While progress and developments were noted in different parts of Scotland, the need to promote and ensure consistency was recognised and areas for improvement remained.

*The same as you?* states that all people with learning disabilities should be able to receive specialist learning disabilities services when they need them. However, a study published in 2002, highlighted the inequities in service provision across geographical areas of specialist learning disabilities health services in Scotland. The study reported that only 15% of children had access to specialist learning disabilities health services. All services reported that they provided for older adults with learning disabilities, adults with mental ill-health, behaviours perceived as challenging and adults with epilepsy (Smiley et al, 2002).

The SAY evaluation found that:

- people with learning disabilities who were interviewed often showed awareness of healthy eating messages, but, like anyone else, could find it challenging to put these into practice
- some people took part in regular exercise, such as swimming and walking, but were not necessarily doing exercise as often or as vigorously as is recommended

- all the women interviewed said that they tried to eat healthily, compared to just over two thirds of the men
- some support workers and families helped people to lead healthy lives
- barriers to healthy lives included relying on reheated ready meals and not having enough opportunities for exercise.

Most people said that if they were ill they would go to their local GP surgery first. Just under half said this was also where they would go for health information. A fifth said that they would ask a member of their family or a support worker; only one person said that they would refer to the internet for health resources. Some people found their doctors easy to understand and others did not. Steps to improve access to primary care included a Health Support Worker and a Health Advocacy Group. In one area all doctors and dentists had health logs for completion when a person with learning disabilities attended. Primary care services were not all involved in the care of people with complex needs.

Family carers were affected for many years by the way they were treated at the birth of their child. They emphasised that support needed to follow on from diagnosis. The transition to adult health services was particularly significant for young people with complex needs, as most of their support up to then had come from specialist child health services.

Carers wanted to see health problems identified and dealt with sooner. They also wanted to see information and support to be ready to deal with increased health needs, including the risk of dementia, as people got older. Attitudes, communication and co-ordination emerged from the carer interviews as priorities for improving the health services response to people with learning disabilities with complex health needs.

An issue that arose in the evaluation was the need for information and support about end-of-life care. Research has suggested that people with learning disabilities with cancer are less likely to: be informed of their diagnosis and prognosis; be given pain relief; and less likely to receive palliative care. In addition, few people, including people with learning disabilities will be encouraged to explore issues of a sensitive nature such

as loss, death or dying, as part of their everyday lives. Mencap's North Staffordshire Palliative Care Project (NSPCP) has produced a 'best practice' guide for the provision of end-of-life care to people with learning disabilities (Read and Morris, 2008).

## **Safety and risk**

*The same as you?* said that 'people with learning disabilities should not be picked on or treated differently from others'. It also highlighted that people with learning disabilities are more likely to experience physical or sexual abuse and are more likely to be victims of crime. 'Hidden in Plain Sight', the report into disability-related harassment (Equality and Human Rights Commission, 2011) demonstrated that people with learning disabilities are at risk of being victims of hate crime. The People First (Scotland) Grand Jury (People First (Scotland), 2011a) noted that people with learning disabilities are much more at risk from crime of all sorts - assaults, robbery, theft, sexual offences and mugging, than other people and recommended that the Association of Chief Police Officers in Scotland (ACPOS) and People First (Scotland) should work together to make sure that police training prepares officers to work supportively with people with learning disabilities in the community.

In the SAY evaluation there appeared to be a general reluctance among the people interviewed to speak about issues of bullying and harassment and it may be that this type of interview was not the best way to hear about people's experiences. However, it did find that:

- almost a quarter of the participants reported having been picked on or bullied in the past. The majority of these incidents took place at school
- men appeared to be slightly more likely than women to say that they had been picked on
- the majority of the respondents stated that they felt safe in their homes. This pattern ranged across different living situations from family homes to people living independently or in group homes. However, some concerns were expressed by those living on their own, particularly during the night hours
- several participants pointed out the contribution of telecare and technology in making them feel safer in their homes

- over two thirds of the participants stated that they felt safe in their local area and when going out and about to various places during the day
- most people interviewed were either unable or unwilling to go out at night. However, those who occasionally did had strategies to keep safe, for example, using taxis or letting someone know where they were
- being well connected to the community seemed to be an important way to ensure safety, while having someone to tell about various concerns or as an emergency contact was particularly helpful, with family first and subsequently support workers as the most frequently stated contacts
- only 4 people mentioned the police as a possible contact in case of emergency.

*The same as you?* also said that ‘all local authorities in association with health boards, NHS trusts and other agencies should develop policies and guidelines on protecting vulnerable adults. Social work departments should review their procedures on guardianship to include making a formal assessment of risk a normal part of deciding whether an application should be made. Local authorities should use the Care Programme Approach for people with learning disabilities who have complex needs whether these needs are caused by disability or vulnerability’ (Recommendation 23).

There was an inspection into services provided by Scottish Borders Council in 2004, with a follow-up joint inspection in 2005. This followed the report into the care of a woman with learning disabilities who was admitted to Borders General Hospital in March 2002, having suffered extreme levels of physical and sexual abuse within her household over an extended period (Mental Welfare Commission for Scotland and Social Work Services Inspectorate, 2004, see also Equality and Human Rights Commission, 2011).

Subsequently legislation has been introduced to afford greater protection to adults at risk of harm. The Mental Health (Care and Treatment) (Scotland) Act 2003 places a duty on a local authority to investigate if it suspects that someone over the age of 16 who has a mental disorder may be suffering

ill-treatment, neglect or financial abuse. A mental disorder includes a mental illness, a personality disorder or a learning disability.

The Adult Support and Protection (Scotland) Act 2007 was introduced to offer protection to adults who may be at risk of harm because:

- they are unable to take care of their own health or welfare, property or rights; and
- they have a disability, mental disorder, illness, physical or mental infirmity which makes them more vulnerable to harm than other people who do not.

The Act places duties upon public authorities (local authorities, health boards, the Mental Welfare Commission, the Care Commission, the Public Guardian and the relevant police forces) to co-operate with one another in the area of adult protection, where harm is suspected or is known to be taking place. It places duties on local authorities to investigate a given situation if they suspect harm is taking place and provides powers to local authorities to apply to take an adult at risk out of their environment and also to ban a perpetrator from a specific location.

All three of the Acts share common principles which support their use. These include the idea that actions taken under them should be for the benefit of the adult concerned; that any action taken should be the least restrictive option possible; that the person in question's views are taken into account and that the views of significant people in their life are also respected.

The interaction between these Acts and the Human Rights Act 1998 is of key importance in ensuring that the balance between risk management and individual freedoms is respected. For example, in the exercise of their duties, public authorities may interfere with an individual's right to private and family life; however, failure to intervene in a case involving an adult at risk could potentially also interfere with an individual's human rights.

### **Criminal justice**

SAY Recommendation 28 said that 'The Scottish Executive should commission research on the number of people with learning disabilities in

prison or in secure accommodation and the arrangements for assessing and providing them with care. Health boards, local authorities, and police forces should make sure that an appropriate adult scheme is in place to meet the needs of people with learning disabilities who come into contact with the police.’

Research for the Prison Reform Trust found that there was no consensus on the prevalence of learning disabilities among the prison population (Loucks, 2007). A study at HMP Perth stated that 1% of a sample of prisoners met the definition of a learning disability (Robinson, 2005). Myers estimated that there were around 200 people with learning disabilities in other forms of secure accommodation in Scotland, including the State Hospital, secure accommodation units for children and other secure or forensic specialist in-patient settings (Scottish Executive, 2004). She identified a lack of appropriate support and resources in place for people with learning disabilities who often had to spend time alone, increasing their isolation and preventing them from addressing offending behaviours. Responsibility for healthcare in prisons is now the responsibility of local NHS Boards.

People with learning disabilities encounter barriers to accessing the criminal justice system. The Mental Welfare Commission investigated the situation of Ms A whose abusers were not brought to justice (Mental Welfare Commission for Scotland, 2008b). There have been initiatives to improve the way in which people with learning disabilities are supported through the criminal justice system. For example, the Crown Office and Procurator Fiscals Service’s Victim Information and Advice (VIA) leaflets have been re-written in accessible language. In 2011 a Criminal Justice Handbook was launched by Scottish Government to promote best practice, to stop disability discrimination and get people to think about how to use the law and services that are in place to protect and support people with a learning disability in Scotland (Scottish Government, 2011a).

In 2010 there were 19 Appropriate Adult Services in Scotland and just over 300 trained Appropriate Adults. There have been variations in practice by Appropriate Adults schemes and the Appropriate Adults Network issued guidance and national standards (2009) to improve consistency.

Work by Capability Scotland for the Justice and Disability Steering Group (Capability Scotland, 2009) made recommendations on improving access to justice for disabled people including that:

- justice sector organisations should encourage all staff to write and explain without using jargon
- justice sector organisations should work together to ensure that people with mental health problems and/or learning disabilities receive the support necessary for full access to the justice system so that they are not treated as either above or below the law
- ACPOS and the Prosecution Service (Crown Office and Procurator Fiscal Service) should work together to reassure people with mental health problems and/or learning disabilities that crimes against them are taken seriously and will be investigated fully.

Amongst the people who took part in the SAY evaluation, 4 were living in environments or under orders which restricted their liberty. 3 of these individuals were living under Community Care and Treatment Orders with support provided 24 hours a day. One person was living in prison. All of these individuals had significant mental health needs and 3 of them said that they had spent some time in mental health hospital. The prisoner with learning disabilities interviewed for the SAY evaluation did not know what services or support would be available for him when he left prison. He said:

“I’m trying to get out. I don’t know what to do...I want to get a flat or somewhere where it helps [people with learning difficulties]. I need to see a social worker and ask her what route to go...No one has talked to me about it yet.”

### **Parents with learning disabilities**

*The same as you?* said that ‘some people with learning difficulties may choose to be parents. As with other parents, they will need a range of support and other help from their families and other agencies. Like other people, parents with learning disabilities can benefit from training and support in developing parenting skills. Some areas offer extra support which is helpful to them and their children.’

There are increasing numbers of parents with learning disabilities in the UK, although the exact number is not known either in Scotland or the UK. Around 40% of these parents are not living with their children. Parents with learning disabilities who are in contact with social care often experience a range of difficulties including poor housing and difficult neighbourhoods, poverty, unemployment and lack of information. There are disproportionate numbers of parents with learning disabilities involved in child protection proceedings.

The Human Rights Act (1998) includes a right to respect for family life; the UN Convention on the Rights of Persons with Disabilities provides a right to marry and to found a family (Article 23). A child may not be separated from parents on the basis of a disability of either the child or one or both of the parents. Local authorities have specific duties to ensure that services are provided to 'a child in need' in ways that lessen the impact of the disability and ensure that the child has the opportunity to lead as normal a life as possible. They are also required to carry out an assessment of a child's needs due to disability.

Research has also highlighted a lack of communication and joint working between services where a parent has a learning disability. This includes between children and families and adult services, and between social care and health services.

Advocates are particularly valued by parents with learning disabilities to help address issues such as inadequate housing, inaccessible information and communication, and to develop confidence and self-esteem.

The Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities were published in 2009 on behalf of the Scottish Parenting Network (Scottish Consortium for Learning Disability, 2009a). Good practice includes:

- accessible information and communication, co-ordinated work, support based on assessments of parents' needs and strengths,

long-term support and access to independent advocacy when working with parents

- where child protection procedures are necessary, promoting children's best interests and ensuring equitable treatment for parents with learning disabilities
- joint responsibility for commissioning services to meet the needs of parents with learning disabilities and their children, the involvement of parents at all stages of the process and staff training.

Recent research (NHS Fife, 2010) found that around two thirds of respondents disagreed that services met the needs of parents and pregnant women with a learning disability, and almost all agreed there were gaps in services. Recommendations from the research included staff training and developing a framework of services and support to ensure that parents could consistently access and receive the support they need.

A recent evaluation of the CHANGE resources, which are provided by NHS Health Scotland as an easy read alternative to 'Ready Steady Baby!' and 'Ready Steady Toddler!' to expectant mothers and parents with learning disabilities, found that many parents were not getting the resources in the way intended by NHS Health Scotland and highlighted a need for information and awareness raising amongst professionals to meet the needs of parents with learning disabilities (NHS Health Scotland, 2011a, 2011b).

### **People with profound learning and multiple disabilities**

SAY Recommendation 29 said that 'Local authorities, by working with health boards and the voluntary sector, should make sure that they look at the extra needs of those with profound and multiple disabilities and those of their carers. The centre for learning disability should set up a national network of support to local providers offering advice and training on the extra needs of people with profound and multiple disabilities.'

Hogg et al (2007) undertook a ten year follow-up study of 142 people with profound learning and multiple disabilities in the Tayside area, measuring different aspects of their lives against the recommendations of *The same as you?* They found that all those people (19 in total) who had been living in long stay hospitals had left those environments. However, there was an

increase in the number of people living in 'congregate care settings' (hospitals, hostels and nursing homes). Few changes to day centre attendance occurred, with all school leavers moving on to conventional day centres on finishing education. The majority of people (25 of 32) who were attending day centres in 1993 continued to do so in 2003. A fifth of the sample died during the ten year study period, the chief causes of death being respiratory disease. Factors associated with non-survival included a low ability for personal self-help, a lack of motor competence and difficulties with swallowing (dysphagia) (Hogg et al, 2007).

A literature review on support for people with complex and multiple needs (Rosengard et al, 2007), which focused on a broader group of people, found that there were gaps in services and identified a need for more creative joint planning. Curtice (2010) conducted case studies with people with high support needs, including people with profound learning and multiple disabilities, at the time of *The same as you?* She stressed the importance of support to maintain relationships and with communication to enable people with profound learning and multiple disabilities to access their citizenship rights and argued that additional support was justified to increase their capacity for participation.

*PAMIS*, a charity founded in 1992 to support people with profound learning and multiple disabilities and their families and carers, has set up a network for people with profound learning and multiple disabilities, which includes both professionals and families. Its activities include an online forum. *PAMIS* has led a campaign for 'Changing Places' toilets to make it possible for people who require adult changing facilities to spend time out and about. There are currently 64 such facilities in Scotland.

The SAY evaluation found that service co-ordination was particularly important for the families of people with profound learning and multiple disabilities, including co-ordination with health services. People with profound learning and multiple disabilities were more likely than others to be attending a day centre full-time. More needed to be done to provide appropriate post school learning and varied day opportunities and to support families with long-term planning.

## **People with learning disabilities and their families from black and minority ethnic communities**

In the 2010 eSAY return (Scottish Consortium for Learning Disability, 2011) only 1.7% of adults with learning disabilities in Scotland were recorded as having ethnic backgrounds other than 'white'. Of the 1.7%, 1.1% were classified as 'Asian, Asian Scottish', 0.3% as 'mixed', 0.2% as 'other' and 0.1% as 'black, black Scottish.' Ethnicity was recorded for 22,629 adults with learning disability (83% of those known to local authorities).

'What's Out There?' (Scottish Consortium for Learning Disability, 2010b) considered the important issues faced by people with learning disabilities from black and minority ethnic communities. 'What's Out There?' found that:

- there is very little information about learning disability and what this means which is accessible to people from black and minority ethnic communities
- many families from black and minority ethnic communities caring for someone with a learning disability are very isolated within their communities and often do not get support and understanding from their community
- some smaller communities within the black and minority ethnic population are particularly missing out on support, e.g. Chinese community, African community
- although organisations do make information and leaflets available in different community languages, often this does not reach people and they have been unclear about how to get the information to people who need it
- many stereotypes still exist about people from black and minority ethnic communities, especially about "people looking after their own" while this research found out this is not the case for many families.

3 people with learning disabilities and 4 family carers from black and minority ethnic communities took part in the SAY evaluation interviews. A worker specifically for minority ethnic families attached to an advocacy group for people with learning disabilities was highly valued by families as a source of information and support.

## **People with dementia**

SAY Recommendation 25 said that ‘health boards and local authorities should make sure that local professionals are trained to look out for early signs of dementia and so can provide assessments and appropriate responses and services’.

Adults with Down’s syndrome are more likely than adults in the general population to develop dementia. Around 55% of people with Down’s syndrome aged 60 or over develop dementia, compared with just 5% of the general population aged 65 or more. Dementia in people with Down’s syndrome is typically earlier in onset and shorter in duration than in the general population. Dementia may also be more common among other people with learning disabilities than in the general population (Strydom et al, 2007).

Longer life expectancy for people with learning disability and dementia means that the problem is becoming more visible and has implications for housing, health and social care as well as carers/families. Forbat and Wilkinson (2007) found a need for greater awareness-raising about dementia among people with learning disabilities, particularly in environments where there may be people with learning disabilities both with and without dementia.

The Scottish Government has recently published *Scotland’s National Dementia Strategy* in conjunction with COSLA, Alzheimer Scotland and the Scottish Dementia Working Group (Scottish Government, 2010c). While the Strategy makes no specific reference to people with learning disabilities who have dementia, many of the recommendations will be relevant.

The SAY evaluation found that some family carers were aware of the increased risk of dementia and increased health needs as people with learning disabilities got older and were looking for information about this.

## **The experiences of family carers**

Family carers in Scotland

*The same as you?* highlighted that families are responsible for by far the most support for people with learning disabilities. The review drew particular attention to the proportion of adults with learning disabilities who had an older carer.

The number and proportion of recorded parent carers has increased markedly since 2008 (the first year for which there is comparable data) and while relatively low in number, the proportion of sibling and relative carers has also increased. Overall, 9,259 adults were reported by eSAY as living with a family carer in 2010. This represents 43% of the adults for whom this information was known in Scotland. Of these individuals, nearly 70% lived with a parent carer and this is very likely to be an underestimate (Scottish Consortium for Learning Disability, 2011, 2010a, 2009b). Research in South Lanarkshire in 2005 identified that in that area, 40% of people with a learning disability living at home were cared for by a parent or parents aged 50 or over (Johnston and Martin, 2005).

In the SAY evaluation carers described a wide range of issues that the person they cared for needed support with, from all aspects of personal care, through to supervision and prompting, as well as practical support such as assistance to manage money. Managing risk was an issue for some families or supporting the person to travel safely or attend medical appointments. Other findings included:

- the impact of bringing up someone with a learning disability on carers' lives and those of their family included stress, the impact on siblings, having their career held back, and a life limited by a restricted income. There were also positive and life changing effects from the experience of caring for a family member with learning disabilities
- the transition from school to adult services was most often mentioned as the most difficult time for families (by 6 families). The next most commonly mentioned difficult time was the time of birth or when their son or daughter's impairment first became known (5 families).

Support to carers

*The same as you?* said that families and carers should have a range of help to support them, including training and advice to look after a person with a learning disability, access to professionals who take into account and find ways to meet their needs as carers (whether they are parents, brothers and sisters or other family members) and access to short breaks.

The right to an independent carer's assessment was introduced by the *Community Care and Health (Scotland) Act 2002*, for carers who provide or expect to provide 'regular' or 'substantial' care, whether or not the person lives with them. The Act states that carers must be seen as 'partners' in the provision of care. 'Caring Together: The Carers Strategy for Scotland 2010-2015' (Scottish Government, 2010a) set the expectation that carers should have the support to manage their caring responsibilities with confidence and in good health and to have a life outside of caring.

The evaluation found that:

- the main supports received by families caring for someone at home were day centre or day opportunities places, short breaks and housing adaptations
- a few families also had a home carer or support worker to assist their son or daughter. These supports could help with caring and in some instances also extend the opportunities of the person they cared for
- there were reports of positive service responses to changes in circumstances, though often these were triggered by a crisis. A small change could result in a crisis in a family's carefully balanced caring arrangements
- only 13 family carer interviews reported having had a carer's assessment, just under half of those who answered this question.

Short breaks

There were 2 SAY recommendations (19 and 20) about Community Based Short Breaks:

'Health boards should contribute funding and resource to developing community based short breaks alongside local authorities. Local

authorities will also be able to bid for any 'change funds' which may be made available for further developing short breaks for people with learning disabilities'.

'The Scottish Executive and local authorities should review their guidance and procedures to make sure that local authorities and health boards can arrange their short break and shared care arrangements for children and adults flexibly and with as little bureaucracy as possible'.

In 2007, *The same as you?* statistical release published by the Scottish Government noted that in a typical week in Scotland an estimated 1,935 adults with learning disabilities had some form of community short break. This was 8% of all adults with learning disabilities then known across Scotland (Scottish Government, 2008a).

SWIA reported that 'respite was a major issue, with all social work services facing a high demand from people who used services and carers for respite services, and having to manage waiting lists. This was not just an issue about the overall resources available for respite, but the way these were organised and deployed' (SWIA, 2010a). Some areas had been developing cost effective alternatives with input from local area co-ordinators, such as the Breakaway Project in Edinburgh, which sets up short breaks.

In the SAY evaluation interviews with family carers:

- short breaks were the most common support available to family carers; 16 families reported that they currently had access to these
- there was variation in how flexible access to respite was. Most families (6) felt that respite was constrained by availability. The pressure on resources meant that short breaks might have to be booked over a year in advance or that families just had to fit in with the dates offered
- some carers had struggled to get the respite that they had. This included the families of children with complex needs

- there were positive examples of respite being integrated into the support of adults with complex needs and being part of their regular reviews.

## Partners in care?

In research commissioned for *The same as you?*, Professor Kirsten Stalker found that family carers reported that they had to fight to find out what services were available (Scottish Executive, 1999). The SAY evaluation found that:

- the language of 'fight' was still very common. Three quarters of families who answered the question (18 out of 24) said that they felt they had to fight for services, whereas 6 felt that support had been offered
- most people (20 out of 26) felt that their ideas were sought and their knowledge was mostly respected and 17 out of 20 did feel that they were treated as partners in care.

## Life planning

SAY Recommendation 26 said that 'life plans for people with learning disabilities who live with their parents should include plans for a time when parents may no longer be able to provide care'. ENABLE Scotland has developed and promoted emergency plans and long-term planning for older family carers.

The evaluation interviews with family carers found that:

- concern at what would happen when the parents died or were no longer able to care was mentioned in 11 interviews and the fear of inappropriate care in 6
- concerns focused on securing a housing option and finding and resourcing appropriate support

- common to all was a wish that their son or daughter should be assured of support that the family felt would meet their needs and give them the life they would want them to have
- there was anxiety about the funding of future packages, both those that were already established and those not yet in place
- often formal planning for the future, including an emergency plan, was not yet in place. 10 families mentioned some planning, but 8 said they had no plans. All 7 families with older carers who answered the question had done some future planning
- reasons for a lack of future planning included a perceived unwillingness on the part of social work services to address the issue and families who were putting it off or did not know where to start
- only one carer said that they had a formal plan for what would happen in an emergency, although many had family who they felt would step in
- twice as many carers reported feeling sadness at some point, rather than never
- of 16 carers who answered the question about how often they had a chance to have time to themselves or to relax, 7 said they did daily, 1 said weekly, 3 monthly, but 4 said less than monthly (1 did not specify how often)
- time to relax was at a premium for single carers
- the right support for the person they had responsibility for made all the difference to whether the carer could relax
- only 15 interviews provided a response on whether the carer(s) felt able to influence developments that affected the person they cared for, but it was positive that 9 of these did feel able to do so, as against 4 who did not and 2 who were unsure
- family was the most common source of support and carers' groups and centres were the other main source of support
- barriers to informal support included not wanting to ask for help and becoming isolated because of other people's responses to the effects of impairment.

The recommendations of *The same as you?* to provide families with access to timely information and a trusted source of support that they can turn to as required remains the most common requirement voiced by family

carers. This wish for support that could be called upon throughout the stages of life was the rationale for the recommendation in *The same as you?* to appoint local area co-ordinators to provide support to individuals and families. There is now experience of successfully implementing this role in Scotland and these carer views and experience indicate that there is still a strong case for supporting families in this way.

## **Views on progress, public attitudes and priorities for the future**

### Views on progress

People with learning disabilities and carers both agreed that there have been improvements in the lives of people with learning disabilities, largely because of increased opportunities in the community.

- most people with learning disabilities thought that people with learning disabilities had more opportunities these days to live the lives they want to
- most carers thought that there had been positive changes since *The same as you?* The majority of carers (22 out of 32) thought the lives of people with learning disabilities and on the autism spectrum had improved in the last 10 years. They thought that including people in society more, through a wider range of opportunities had contributed to these changes
- family carers gave some positive examples of everyday community facilities being made more accessible including a Changing Places toilet, free access to the leisure centre for an accompanying carer and better access for wheelchairs in larger premises. The attitudes of staff in shops and leisure services were also felt to be changing.

### Public attitudes

SAY recommendation 21 said that ‘there should be a long term programme to promote public awareness about learning disabilities and including people with disabilities in the community. This should include programmes from the earliest years of education. The new centre for learning disability could be responsible for taking this forward.’

There has never been funding for a national public education programme comparable to that of 'See Me' around mental health issues and 'One Scotland, Many Cultures' around race, religion, faith and belief. However, public education work is carried out on a range of themes by many different organisations including People First (Scotland), SCLD, its partners and other organisations. For example *PAMIS*' 'Changing Places' campaign is working to increase the number of changing places toilets across Scotland, Key has Politics and Campaigning Groups, Capability Scotland's 'Barred!' campaign aims to promote better access to pubs and clubs for disabled people and ENABLE Scotland are running an older carers' campaign.

A module on public attitudes to community care, which included questions about people with learning disabilities, was included in the 2001 Scottish Social Attitudes Survey (Curtice and Petch, 2002). This found that more than half of respondents said that they felt comfortable about living next door to a person with a learning disability. Respondents were strongly in favour of individuals with support needs living in the community rather than in care homes or hospitals. This view was most common for a person with a learning disability and least common (but still the majority) for a person with dementia. Support needs, it was felt, should in the main be met by paid workers. The exception was for the person with a learning disability needing to be accompanied to a club where the potential contribution of family members and volunteers was cited. Most people interviewed thought that a person with a mental illness or a learning disability should not serve on a jury. These questions have not been repeated since. However, in the 2011 Scottish Social Attitudes report 58% of respondents said that they knew someone with a learning disability (Ormston et al, 2011).

The SAY evaluation found that:

- the majority of carers (17 out of 28) also thought that attitudes towards people with learning disabilities had improved since 'The same as you? They felt that people with learning disabilities were now more visible in the community, in mainstream schools, in the workplace or in the media and through the closure of long-stay hospitals

- however, 11 out of 13 interviewees with learning disabilities thought that people with learning disabilities were discriminated against
- among the 8 carers who thought that attitudes towards people with learning disabilities had not changed, two future areas for improvement were eliminating bullying and including more people in the workforce. Areas for improvement in the community were better signage in the community, less red tape (for example, when opening bank accounts) and the temperature of water in swimming pools (too cool for people with complex needs)
- most carers did not think that people with learning disabilities or on the autism spectrum are yet valued in Scottish society. More thought that they were 'hardly valued at all' than thought that they were valued
- the majority of carers (23 out of 30) also did not feel that the families of people with learning disabilities are treated fairly. Some carers felt taken for granted with not enough support or recompense for the caring that they did. Others thought that there was unequal access to resources. Furthermore, some family carers felt that *The same as you?* had led to more resources going to the people with learning disabilities who left long-stay learning disability hospital, while people who had been living in the family home had missed out. There was also a sense of injustice because they felt that the person they cared for had had no choice about being disabled and so there should be no question about their claim for support.

## Future priorities

Both people with learning disabilities and family carers had views on what should change:

- people with learning disabilities spoke about more support to live independently, including access to homes with support, more job opportunities, better access to public areas and transport, more chances to learn, more facilities and things to do during the day, good health care and improved awareness about people with learning disabilities

- carers said that the biggest difference to the lives of people with learning disabilities would come from more services and supports, further progress on inclusion, more understanding of people with learning disabilities and financial recognition of carers
- carers feared the loss of existing services which they felt would lead to greater isolation and reductions in benefits would penalise families. Carers were anxious that progress achieved in services for people with learning disabilities would not be maintained in the face of reduced expenditure on public services.

## **Support for change**

### Investment

Following *The same as you?* (Recommendation 4), the Scottish Government provided a Change Fund to enable local authorities to set up additional services in the community which were required as people left hospital. £8m, £12m and £16m were provided as a Change Fund between 2001 and 2004 and sustained at the level of £16 million from 2004 onwards, with an additional £4.2m allocated for 2006/7 and an additional £5m in 2007/8.

Spending on services for people with learning disabilities by local authorities stood at around £650 million in the 2010-11 financial year (Scottish Government, 2012). NHS Scotland spent £240 million on services specifically aimed at people with learning disabilities in 2008-09 (NHSScotland, Scottish Health Service Costs).

SWIA noted that learning disabilities accounts for almost a quarter of local authority expenditure on adult services in 2007/08, making it the second largest expenditure group for adult services. However, whilst spend on learning disabilities services increased by an average of 20% from 2005 to 2009, it decreased in two councils and there were major variations in expenditure between councils (Social Work Inspection Agency, 2010a).

### New organisations

Recommendation 6 of *The same as you?* was to set up a new Scottish centre for learning disability 'which would offer advice, training and support

to agencies, professionals, people with learning disabilities and parents to bring about the changes we have recommended in this review. The centre will also support the further development of advocacy services.'

In response to this recommendation, the Scottish Consortium for Learning Disability (SCLD) was set up in 2001 with funding from Scottish Government to support the implementation of *The same as you?* SCLD is a partnership of voluntary sector organisations, a self-advocacy group and universities. Half of SCLD's Board members are people with learning disabilities and family carers.

SCLD is a Centre for Excellence which works in partnership with people with learning disabilities of all ages and family carers to challenge discrimination and to develop and share good practice. SCLD's goal is an inclusive Scotland where everyone is valued and respected for who they are and what they contribute as equal citizens.

SCLD has led on support for local area co-ordination nationally and has also promoted the employment of people with learning disabilities. SCLD is also an official statistics provider and co-ordinates the annual statistical release on people with learning disabilities in Scotland on behalf of the Scottish Government through the eSAY project. Its website provides accessible information relevant to everyone with an interest in people with learning disabilities in Scotland. In addition, SCLD offers:

- training, co-delivered by people with learning disabilities
- capacity building – to strengthen others to work in partnership
- consultancy – on *The same as you?* and support to learn and change
- research and evaluation – on issues that matter to individuals and families
- information – which is accessible and based on evidence and experience.

SCLD promotes the rights of people with learning disabilities as valued citizens and co-ordinates the annual Learning Disability week. Individuals and family members demonstrate the skills and contributions they make to society by presenting at national conferences and actively participating in

the delivery of training courses and research. SCLD's Employment Champions and co trainers have raised awareness of the skills and contributions of people with learning disabilities. SCLD provides press releases and briefings on issues related to people with learning disabilities, such as the impact of changes to further education provision.

*PAMIS*, a partner in the Scottish Consortium for Learning Disability, supports a network for people affected by profound learning and multiple disabilities, as well as professionals in this area.

The Scottish Autism Service Network, based at the University of Strathclyde, began work in 2005 in response to recommendation 7 of SAY. It serves as a network to direct people affected by autism spectrum disorder to services and to share good practice, information and resources.

### **Planning and monitoring**

*The same as you?* required local authorities and health boards to plan the services they make available to people with learning disabilities according to three year 'Partnership in Practice' Agreements (PiPs) (Recommendation 1). PiPs were intended to be developed in conjunction with people with learning disabilities, their families, carers and key stakeholders in the area.

There were three sets of Partnership in Practice Agreements covering 2001-2004, 2004-2007 and 2007-2010. In 2006, the Scottish Government conducted a National Overview of the plans. A PiP Network was set up by the Scottish Government to provide a forum for discussion for those responsible for implementing PiPs.

*The same as you?* also recommended (Recommendation 9) that local registers should be set up to improve the data about the numbers of people with learning disabilities requiring services and support. The Scottish Executive developed a number of indicators to measure the progress of *The same as you?* and between 2003 and 2007, they published statistics on these measures, using aggregate data provided by each local authority area. The Scottish Government funded SCLD to consult upon and develop national data standards for a dataset of people with learning disabilities. From 2008 the annual statistics release to monitor progress on SAY has

been based on individual level data, meaning an anonymous record is returned about each person known to local authorities. Local authorities have now set up data collection systems in order to feed into the collection of statistics about adults with learning disabilities through the eSAY project and there has been a continuous improvement in the quality of the data. 'Easy read' versions of the statistics are produced.

## Conclusion

Much of the change which *The same as you?* promised has been set in motion, although progress across the different areas has been variable. People with learning disabilities, family carers, local authorities, health boards, service providers, the voluntary sector and the Scottish Government have all played a significant role in taking *The same as you?* forward.

Since *The same as you?* a body of law, policy and strategy has reinforced the recommendations through recognition of capacity, improved personalisation, greater choice and control, a commitment to independent living and increased protection from harm. At the same time, greater awareness of the human rights of disabled people has been developed, with a body of case law at both national and international level and the signature and ratification of the United Nations Convention on the Rights of Persons with Disabilities by the United Kingdom.

The principles and direction of travel established by *The same as you?* remain fit for purpose. Progress needs to be maintained in reducing barriers and discrimination, so that the aspirations of people with learning disabilities to live meaningful, fulfilled, independent, included and healthy lives can be met. In light of the pressure on public service budgets, it is essential that the best use is made of resources to achieve good outcomes for people, including those most at risk of poor health, isolation and abuse. Enabling people with learning disabilities to participate, contribute and stay connected to others, whatever their level of need, is a challenge that requires the joint commitment of a wide range of individuals and bodies. An investment in joint action to achieve these goals will be cost-effective for the public purse and lay strong foundations for future generations.

## Summary of future priorities

These are the priorities for future action that have been identified from the evaluation of *The same as you?* After the consultation process is complete, they will be used as the basis of developing recommendations for the new strategy.

Almost all of the priorities identified in this table relate to promoting, protecting, respecting and fulfilling the human rights and equality of people with learning disabilities. Public authorities are bound by the requirements of the Human Rights Act 1998, which incorporates the European Convention on Human Rights into UK and Scottish Law, and are obliged not to act in a way which is incompatible with the human rights in the Act. Public bodies are also bound by the Equality Act 2010, which seeks to ensure that people do not experience direct or indirect discrimination on the basis of age, gender or gender reassignment, pregnancy or maternity, disability, race, religion, sexual orientation, marital status or civil partnership status. The United Nations Convention on the Rights of Persons with Disabilities sets out international human rights standards for disabled people.

Priority themes and actions
<p><b>Human rights and equality</b></p> <ul style="list-style-type: none"><li>• Public authorities to continue their work to ensure compliance with the Human Rights Act 1998, Equality Act 2010 and the Public Sector Equality Duty. Equality and human rights legislation to be used to prevent inequality and discrimination.</li><li>• Ensure that people with learning disabilities have accurate, good-quality accessible information, combined with support to understand this. Ensure that people with learning disabilities have appropriate communication support. View the provision of accessible information and communication support as an equality and human rights issue.</li><li>• Ensure that there are more Changing Places toilets available throughout Scotland to enable the inclusion of people who need these. Consult with disabled people about where to locate these.</li><li>• Transport providers both locally and nationally to work with people with learning disabilities to ensure that their services are accessible.</li></ul>

## Priority themes and actions

### **Human rights and equality (continued)**

#### Hate crime and harassment

- Ensure that agencies recognise the risk of hate crime and harassment towards people with learning disabilities and consider the possibility of hate crime when people with learning disabilities report crime.
- Agencies to share information where they think hate crime may be an issue to prompt further investigation.
- Encourage people with learning disabilities to report hate crime through accessible information, third party reporting mechanisms, robust responses and the implementation of appropriate support.
- Ensure that adult support and protection legislation is working effectively and appropriately.

#### Criminal justice

- Continue work set in motion by government, criminal justice and social work agencies to ensure that people with learning disabilities do not experience discrimination in the criminal justice system and that appropriate support is in place on leaving the criminal justice system.
- Easy read information and support to be available throughout the criminal justice system.
- Association of Chief Police Officers in Scotland and Crown Office and Procurator Fiscal Service to work together to reassure people with learning disabilities that crimes against them are taken seriously and will be investigated fully.

### **Children and young people**

- Joint working is needed to ensure that children and young people with learning disabilities can expect to access the opportunities open to all children.

#### Early years

- Ensure parents are not being given negative messages by health and social care professionals on the birth of a disabled child. It is important that parents receive a positive reaction to the birth of their child and are offered the right information and support.

## Priority themes and actions

### **Children and young people (continued)**

#### Education

- Review the impact of the Curriculum for Excellence in achieving better educational outcomes for children with learning disabilities.
- Continue work to develop the differentiated curriculum.
- Improve access to sporting opportunities for children and adults with learning disabilities in education.
- Address the needs for peer support throughout education experience e.g. circles of friends.
- Engage with Doran Review, Opportunities for All and maintain links with Lifelong Learning and Skills Development Scotland.

#### Transitions from education

- Ensure positive post school education and employment outcomes.
- Ensure young people with learning disabilities leaving school and college have accessible information about their options, time to plan properly and the offer of further training or employment.
- Build on the work of the Transitions Forum to improve joint working and provide choices for individuals.
- Improve the evidence base in this area by monitoring post school destinations for young people with learning disabilities to inform policy making.

### **Work**

- Ensure a significant improvement in the numbers of people with learning disabilities in meaningful paid employment.
- Promote supported employment and access to work benefits to increase numbers of people with learning disabilities in paid employment.
- Develop individualised support to access and maintain employment.
- Address eligibility criteria for access to employability support that exclude some people with learning disabilities.
- Review and address impact of welfare benefit changes on employment chances of people with learning disabilities.
- Adopt a joined-up approach to enabling employment across social care, health, education, employability and welfare strategies.

## Priority themes and actions

### **Work (continued)**

- Promote good practice models, including Project SEARCH.
- Public sector employers to employ more people with learning disabilities in meaningful roles.

### **Choice and control**

- Complete the work of The same as you? so no-one's home is a hospital.
- Ensure people with learning disabilities have greater choice and control in their lives, including through using self-directed support to choose their own staff and outcomes and activities which are meaningful to them.
- Ensure continued progress towards support for independent living.
- Ensure support to people with learning disabilities and their families to increase their capacity to take more control over their services and support.
- Develop methods and skills to support the participation of people with communication difficulties and profound learning and multiple disabilities.
- Develop skills in the workforce in outcome-based planning with the active participation of people with learning disabilities.
- Ensure the meaningful engagement of people with learning disabilities and family carers in service design and delivery.
- Fully involve people with learning disabilities and family carers in the development and implementation of self-directed support.

### **Information and communication**

- Increase access to information and advice through third sector, Local Area Co-ordinators and others.
- Improve investment in communication support.
- Implement standards for accessible information and inclusive communication across agencies.
- Ensure accessible health information available on NHS Inform and locally.

### **Support for families and carers**

- Invest in timely information and support for families, including respite and short breaks, to enable them to plan for the future.

## Priority themes and actions

### **Support for families and carers (continued)**

- Offer capacity building support for families to meet challenges.
- Improve information access especially at times of transition including knowledge of the Adults with Incapacity Act (Scotland) 2000.
- Recognise lifelong responsibilities of carers and ensure support to plan at key stages.
- Target support for siblings and other family members who are carers (e.g. grandparents)
- Ensure carer involvement in local service redesign.

### **Ageing and dementia**

- Ensure that the implementation of the Dementia Strategy addresses the needs of adults with learning disabilities.
- Introduce dementia champions for people with learning disabilities.
- Plan for the increased numbers of older adults with learning disabilities.

### **Parents with learning disabilities**

- Parents with learning disabilities and their children should receive appropriate support and information so their families can thrive.

### **Reduce health inequalities**

- Primary care services should provide accessible health information for people with learning disabilities.
- Health improvement services must address the specific needs of people with learning disabilities.
- Ensure that support services build people's capacity to live healthy lives.
- Implementation of the NHS Quality Strategy to ensure person-centred approaches to people with learning disabilities and ensure people with learning disabilities are included in all health services.
- Develop any targeted responses as necessary.
- Ensure standards for end-of-life care so that people with learning disabilities have equal access to this support.

## Priority themes and actions

### **Public attitudes**

- Continue to support people to participate in community life in order to improve awareness and public understanding through greater interaction.

### **Poverty**

- Monitor the impact of welfare benefit changes on people with learning disabilities and their families.

### **Planning**

- Ensure joint planning for prevention and invest to save. Adopt whole life-planning for individuals and families.
- Ensure people with learning disabilities are included in other joint planning and invest to save strategies.
- National planning to ensure local provision for mental health problems.
- Capacity planning for future needs, including increasing numbers of young people with complex needs and older people with increased health needs, e.g. dementia.
- Joint commissioning of appropriate local support to improve outcomes for people with learning disabilities whose behaviour challenges services.
- People with learning disabilities should be involved from the beginning in service planning, design and delivery.

### **Outcomes and evaluation**

- Establish a clear monitoring framework for the next phase of SAY based on outcomes and align data requirements accordingly.
- National data set to include outcomes and develop national agreement with system suppliers.
- Data sharing agreements to enable monitoring of outcomes across agencies.
- Refocus SAY National Implementation Group with clear remit, coproduction approach and cross agency membership that can be accountable for progress.

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