

## CONSULTATION QUESTIONS

### **About SCLD**

SCLD is a Centre for Excellence for learning disability. SCLD is funded by the Scottish Government and is made up of 12 partner organisations. Our mission is to work in partnership with people with learning disabilities, people on the autism spectrum 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's partner organisations include 12 third sector organisations and universities: Association for Real Change (ARC), British Institute for Learning Disabilities (BILD), Badaguish Outdoor Centre, Capability Scotland, Central Advocacy Partners, Down's Syndrome Scotland, ENABLE Scotland, Key, PAMIS and the Universities of Dundee, Glasgow and St Andrews.

We work in collaboration with our Partners and other organisations to improve the lives of people with learning disabilities, people on the autism spectrum and their families.

SCLD were members of 'The same as you?' Evaluation Team which planned and undertook inclusive research with researchers with learning disabilities to evaluate the impact of 'The same as you?' All the reports from the evaluation are available at [www.sclld.org.uk/SAYevaluation](http://www.sclld.org.uk/SAYevaluation)

To find out about our work in general, please visit [www.sclld.org.uk](http://www.sclld.org.uk)

### **SCLD's strategic priorities 2012- 2015 are to:**

- Promote equality for people with learning disabilities, people on the autism spectrum and their families through influencing and evaluating policy and practice at a national and local level.
- Promote policies and practices to enable and empower people with learning disabilities and people on the autism spectrum.
- Help to build more inclusive communities by improving access to information and support.

## Key messages

- **The research evaluation of ‘The same as you?’ is a robust reflection of the lived experiences of people with learning disabilities and family carers in Scotland. The targeted subsamples in the evaluation ensured that the experiences of a wide range of individuals and families was represented.**
- **Much of what ‘The same as you?’ hoped for has been achieved but more remains to be done. People with learning disabilities should have the same chances and opportunities as other people to have jobs, receive high-quality education, be part of their communities, have choice and control, make friends, fall in love and form families.**
- **The meaningful inclusion and involvement of people with learning disabilities and family carers must continue to form the basis of developing policy, strategy and services.**
- **A proper understanding of human rights and equality must underpin and inform policy, strategy and services for people with learning disabilities and family carers. Using human rights and equality as the lens through which policy, strategy and services is developed will help to ensure people with learning disabilities can live the lives they want.**
- **Progress towards independent living must continue; cuts to services and benefits must not set people with learning disabilities and family carers back.**
- **Family carers need the right support at the right time. People with learning disabilities and family carers need services which proactively set out to help them plan for the future.**
- **We must continue to build on the research evidence about what works for people with learning disabilities and family carers and to adopt evidence-based approaches in order to improve life outcomes and reduce inequalities, including health inequalities.**

## Progress and Challenges

**Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?**

Yes  No

Please provide any comments, evidence and/or examples here

SCLD undertook the research evaluation of 'The same as you?' There are undoubtedly issues affecting people with learning disabilities and family carers which were not most appropriately addressed within the evaluation of 'The same as you?' and will merit the further attention of researchers and policy makers alongside people with learning disabilities and their families. However, the inclusive research methodology which was adopted to undertake the evaluation meant that we were able to gather a wealth of data around the experiences of people with learning disabilities and family carers during the last decade. The findings represent a detailed and robust reflection of the realities for people with learning disabilities and family carers and are a sound basis on which to plan for improving lives in the future.

People with learning disabilities and their families represent a diverse group drawn from many different backgrounds, cultures and identities. Consequently the fact that some groups will face particular challenges or experience marginalisation must always be borne in mind and addressed.

The evaluation is confirmed by earlier work we conducted. Five years on from 'The same as you?' ENABLE Scotland commissioned SCLD to survey people with learning disabilities about their experiences. 'How is it going?' reported the results of a postal questionnaire completed by or on behalf of 605 people with learning disabilities, 1 in 200 people with learning disabilities in Scotland (Curtice, 2006)

This found, like the SAY evaluation, that people with learning disabilities still wanted the things that were emphasised in 'The same as you?' but that the benefits had not been felt equally everywhere. Also friendships and community connections were a particular gap. It showed that people with learning disabilities want to learn and have wider experiences and clearly identified people's priorities as follows:

"What matters most to people with learning disabilities is getting their own home, having friends and being able to go out more. They also want to

make sure they stay in contact with family and they keep the support that is essential to their independence. They enjoy socialising more than anything else and next to that, sport. They hope for new experiences.”  
([http://www.sclد.org.uk/sites/default/files/publications/how\\_is\\_it\\_going.pdf](http://www.sclد.org.uk/sites/default/files/publications/how_is_it_going.pdf))

**Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?***

Please provide any comments and/or examples here

It is clear from the findings that much of what 'The same as you?' has been trying to achieve has been set in motion. The emphasis which is now placed on opportunities for people with learning disabilities as equal citizens in their communities, as active bearers of human rights, as employees, as husbands, wives and parents is testament to the change which has happened following on from 'The same as you?' It is critical that where progress has been slower and challenges remain the momentum for improving lives is sustained. The combined effects of community charges, tightening of eligibility criteria and cuts to welfare benefits will put at risk the progress made unless there is clear commitment to maintaining progress and funding gaps are addressed (see question 3)

#### Local Area Co-ordination

Local Area Co-ordination (LAC) was introduced to Scotland by 'The same as you?' (recommendation 2). It was to be developed to enable individuals and families to access the information and support they needed locally in order to connect with their communities and live lives of their choosing. LAC indicated the way in which services were expected to change, putting the person at the centre, enabling rather than merely providing and investing in building the capacity of individuals and families. LAC was intended to work across the boundaries of health and social care and child and adult services and to work with community groups so that they were more inclusive of people with learning disabilities.

National evaluation of LAC in 2007 showed how much the approach was valued by the individuals and families who had experienced it. An online video, 'My great independent life' tells the story of how one person's support by a local area co-ordinator has enabled them to change their life (<http://www.sclد.org.uk/local-area-co-ordination/publications>)

There are now some 86 local area co-ordinators in 21 local authorities in Scotland. However the approach is still far from universal and needs

to be adopted more widely to enable people to be better included in their local communities.

### Supported employment

The model of supported employment has been shown to be effective in enabling people with learning disabilities to obtain work and stay in work. Research by Professor Steve Beyer on the supported employment service in North Lanarkshire has shown that achieving paid employment through supported employment can also be cost effective (<http://www.sclد.org.uk/information/employment/events-and-conferences/past-present-and-future-supported-employment>). The cost per job of the supported employment service was £7,126, less than half the cost of a day service place. The people with learning disabilities in employment had reduced the proportion of their income derived from welfare benefits and were better off.

Carrongrange School in Falkirk, which provides for children with moderate, severe and complex additional support needs has an effective partnership with a supported employment service, Real Jobs Falkirk, to enable students to make the transition to supported employment. ENABLE Scotland which provides specialist employment support for people with learning disabilities has partnered with colleges to provide on site support to improve the move from college to work.

With Values into Action Scotland, SCLD has developed an accredited course ('Geeza Life Geeza Job') for support workers and managers to enable them to gain the skills to support people into work in a person-centred way.

### Supported Living

One of the most significant changes in the last 10 years has been the further development of supported living services and approaches in order to shift the balance of care away from residential support. Supported living principles maximise the control of the person, separate housing and support services and have been at the forefront of developing personalised approaches. Key is an example of an organisation that has developed separate housing and support services to offer person-centred support. Supported living is not only for people with low support needs. Partners for Inclusion in Ayrshire has shown how personalised support, including detailed support planning, can enable people with complex and challenging needs to

live fulfilled lives as members of their local communities through  
(Fitzpatrick, J, 2010

<http://www.partnersforinclusion.org/html/public/documents/PersonalisedSupport.pdf>

Macintyre, G, 2009

[http://www.sclld.org.uk/sites/default/files/publications/if\\_the\\_supports\\_right\\_shes\\_right.pdf](http://www.sclld.org.uk/sites/default/files/publications/if_the_supports_right_shes_right.pdf)

Increased awareness by national organisations

There have been significant examples of engagement by national organisations and educational institutions to develop good practice that takes account of people with learning disabilities including:

- “Getting it Right Together” materials for nurse education developed by NHS Scotland
- Good Practice Statement on access to health care by NHS Quality Improvement Scotland
- Development of easy read materials and creation of learning disability zone on NHS Inform by NHS 24
- Engagement of people with learning disabilities and family carers in educating social work and nursing students (for example, Dundee, Glasgow Caledonian and Strathclyde Universities). For good practice in involvement in social work education see <http://www.serviceusercarergoodpractice.org.uk>
- Work on the application of leadership capabilities by the Scottish Social Services Council.

It should be noted that the delivery of such initiatives has often involved specific funding support and/or input from a third sector partner, self advocacy group (s) and/or SCLD.

Participation of people with learning disabilities

There have been significant examples of people with learning disabilities and family carers taking leadership and influential roles in national and local forums and in influencing policy and practice. People First (Scotland), the national self advocacy organisation of people with learning difficulties has contributed to policy and advocated effectively for change, as well as demonstrating how people with learning difficulties can speak for themselves against discrimination. An example of their work was the Citizens’ Grand Jury in 2011 which analysed what had to change for people with learning difficulties

<http://www.uoa7.net/peoplefirst/wp-content/uploads/2011/06/citizensgrandjuryreportweb.pdf>

There are good examples of provider organisations that engage people with learning disabilities in governance (for example, C-Change), in developing strategy (for example ENABLE Scotland ACE and parent carer committee) and in influencing the organisation's strategy and practice (Key, Quarriers and many others). Down's Syndrome Scotland supported a young man to take part in the Scottish Youth Parliament.

There has also been support for people to engage outside their own organisations, for example ARC's National Involvement Network based on its Charter for Involvement and the Cross Party Group on Learning Disability in which people with learning disabilities participate.

An important change has been the use of people with learning disabilities as experts and champions by agencies whose primary remit is not learning disability. People with learning disabilities and family carers were employed as inspectors by the then Social Work Inspection Agency (now the Care Inspectorate) and NHS Quality Improvement Scotland (now Healthcare Improvement Scotland). In addition, the Mental Welfare Commission for Scotland also employs people with learning disabilities to assess and monitor services, for example for people with learning disabilities who are subject to orders under mental health law.

Local planning arising directly from 'The same as you?' where Partnership in Practice Agreements (PiPs) had to be developed by local partners to show how they planned to implement the strategy, provide the opportunity for local involvement. Thus the SAY project in Fife had a series of local strategy groups which involved people with learning disabilities and family carers, exemplifying a partnership approach to the development and implementation of local strategy which has been maintained. South Lanarkshire Council has had annual SAY conferences led by people with learning disabilities to report on its progress in implementing change, as had Fife Council and recently, Aberdeenshire Council. The Good Life Group in West Dunbartonshire produced a 'shadow' PiP to show their expectations of local strategy and services. Following the examples of 'The same as you?' itself, some local strategies and PiPs were produced in accessible formats. In Scottish Borders, the "Calling the Shots" group, set up in collaboration with SCLD and Heartfelt, has continued to input into service development.



## Innovation

Since 'The same as you?' there have been some developments that have challenged perceptions of what is possible and/or broken new ground.

- Support for parent with learning disabilities. This was not on the radar at the time of 'The same as you?'. Since then People First (Scotland) has set up groups for parents. They and ENABLE Scotland have participated with SCLD in a national Parenting Network ("Working Together with Parents") established in conjunction with the Norah Fry Centre. The network has produced case studies and published, through SCLD, national good practice guidelines. These guidelines have stimulated multi agency discussions in different parts of Scotland. Aberlour in Dundee has developed a pathfinder project which offers flexible support to parents with learning disabilities.
- Changing Place toilets. *PAMIS* offers support to individuals and families through local co-ordinators in areas where they have been funded. They also conduct research and promote good practice, for example in communication, through their sensory stories and in promoting access to leisure for people with profound learning and multiple impairments. They have had a significant impact through their Changing Places campaign for fully accessible toilets which enable people with learning disabilities and their families to be out and about in the community like anyone else. There are now 75 Changing Place toilets in Scotland, including one in the Scottish Parliament.

## Culture change

The individuals and families interviewed for the SAY evaluation thought that there had been a shift in attitudes insofar as the increased opportunities for people with learning disabilities had created a wider expectation that people with learning disabilities should be included in society. One piece of evidence of wider awareness can be found in the 2010 Scottish Social Attitudes Survey which found that 93% of people believed that providing information about public services in 'easy read' formats for people with learning disabilities is a good use of government money. Awareness-raising, such as that conducted through the media work of organisations such as Capability Scotland may have contributed to this improved understanding of the barriers people with learning disabilities face.

### **Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?**

Please provide any comments and/or examples here

Please note that issues primarily related to health, education, employment and independent living have been discussed in later questions. The issues highlighted below have been identified from the experience of work conducted by SCLD:

#### **Accessible Information**

As accessible information was a key recommendation of 'The same as you?', SCLD feels there are still some issues related to the provision of accessible information which need to be addressed.

There is still a great deal of inconsistency in the production of easy read materials. Furthermore, many organisations commissioning easy read resources do not have a realistic picture of the work and timeframe involved in producing them.

Having information available in a variety of formats is only one aspect to providing accessible information. There are many other issues which are often overlooked in ensuring information reaches its intended audiences.

Scoping how finalised materials and resources will be disseminated is vital to increasing the accessibility of information.

The rise in the use of digital media as a major vehicle of getting information out and communicating with a wide range of people may disadvantage people with learning disabilities as they may not have regular use of this kind of technology; it also assumes that this is the primary way that people access information.

People with learning disabilities and families from more marginalised communities such as black and minority ethnic communities are rarely targeted in the dissemination or in the production of alternative formats for resources (e.g. translation into community languages).

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

Although we should view the findings of the evaluation of 'The same as you?' as applying to people with learning disabilities from black and minority ethnic communities as well as those from the mainstream community, there are particular issues faced by individuals from black and minority ethnic communities as evidenced in SCLD's 'What's Out There?' report.

The experiences of people with learning disabilities from black and minority ethnic communities were largely missing from the 'The same as you?'. And even 12 years on the voices of individuals from black and minority ethnic communities are still difficult to discern. Many learning disability service providers, voluntary organisations and self-advocacy groups still do not represent the diversity of people with learning disabilities.

The 2011 eSAY Statistics Release may provide additional impetus for acknowledging that this is group of individuals and families who are currently under-represented within support services. According the 2011 figures people from black and minority ethnic communities only accounted for 1.3% of the population of people with learning disabilities known to local authorities. This is less than the 2% of the general population figures as identified in the 2001 Census.

A long-standing stereotype which has often been used to account for the low numbers of people with learning disabilities from black and minority ethnic communities is that these communities prefer to 'look after their own.' However, the interviewees who participated in the 'What's Out There?' research undermined this view point by reporting that they highly valued any support or services they received.

Therefore, encouraging and supporting more people with learning disabilities from black and minority ethnic backgrounds to participate and have a say in their future and also the future of learning disability policy in Scotland is essential. The new strategy and action plan should reflect the needs of people with learning disabilities and their families from all cultural and ethnic backgrounds. Often these needs and wants will be similar to those of the majority population but the 'What's Out There?' research emphasised that people from black and minority ethnic communities can encounter even more of a struggle in getting access to services and even when a service is accessed this is

not always appropriate to their cultural or religious identity or practice.

This research also highlighted that information provided for people with learning disabilities and their families rarely touches the lives of people from black and minority ethnic communities. Although there may be a willingness to translate into other languages, organisations have little idea of, or at least struggle to identify how to reach or publicise useful information within these communities. Accessing language support in a family's first language was also found to be problematic.

Alongside recognising that family carers from black and minority ethnic backgrounds face similar challenges to family carers from the mainstream 'white' community, there are specific barriers facing black and minority ethnic communities. The families who took part in SCLD's 'What's Out There?' research reported that they face isolation on a number of levels, and that they feel especially isolated within their own communities. A lack of understanding of what learning disability means and a fear of their communities' response often leaves families isolated even from their own extended families.

As a result many families felt the person they cared for was 'hidden' from the wider community and excluded from religious and cultural activities and expressions of their communities.

Families from black and minority ethnic backgrounds also felt they were further isolated from the wider community and had experienced hostility and racism.

Getting access to relevant and accessible information was a huge issue for families from black and minority ethnic communities. Many concepts which most working within the field of learning disability are very familiar with, such as befriending, direct payments and even the term learning disability itself just do not translate into community languages. As a result families could be left with misconceptions about what it means to have a learning disability and felt it was something which could be cured. The inability of information to communicate effectively with families in these situations also meant that they sometimes relied on other inaccurate interpretations of disability such as it being a curse on their family, a punishment from God or resulting from black magic.

Many of the families said it took considerable time for them to fully appreciate the impact of their loved one's impairment and the disabling barriers they face. All of the factors discussed above means that for those families who do manage to navigate through the complex social care system, it can take even longer to get services than for the mainstream community. For instance one of the families we spoke to had spent 16 years trying to get the needs of the person they cared for recognised and assessed.

### **Other issues**

Other issues which SCLD would highlight are:

- Support for people with learning disabilities to build friendships and relationships
- Improved support and opportunities for people with complex needs and people with profound learning and multiple disabilities
- The impact of welfare reform. The combined effects of welfare reform (including the changes to DLA, housing benefit and work-related benefits), tightening eligibility criteria for social care and employability services, charging policies and the closing of the Independent Living Fund will have a significant effect on whether the progress made in improving the lives of people with learning disability can be maintained. There is a risk that more people will fall into poverty, be at risk of exclusion and fall into crisis. It will be important to scope and track the impact of these changes to provide evidence on which to advocate for better solutions and appropriate policy changes to ensure that the new strategy can be implemented effectively.
- Implementation of self-directed support in an accessible and person-centred way, with improved information and choice for people with learning disabilities and their families
- Improved transitions from school to college and/or other opportunities (please see question 7 below)
- The development and promotion of accessible, meaningful and enjoyable further education opportunities
- Tackle the gaps in employment policy for a) older adults with learning disabilities and b) adults with learning disabilities and on the autism spectrum with higher support needs
- Continued support for local area co-ordination and its roll-out across Scotland
- Research and action on specific human rights issues which

affect people with learning disabilities, such as the implications for rights to liberty and security of indefinite guardianship orders, or continuing placement in restrictive environments where there is no funding to live in the community.

- Sustained funding for self advocacy groups. The right of access to independent advocacy was enshrined in the Mental Health (Care and Treatment) Act (Scotland) but despite this there is limited access to anything other than crisis advocacy. Access to independent advocacy should be available to all people with learning disabilities who require it and this means continuing to fund advocacy services that have particular expertise in advocacy support to people with learning disabilities and in particular self advocacy groups run by people with learning disabilities themselves.
- More children with complex needs are surviving into adulthood. It is important to estimate the expected numbers in order to inform planning for adult health and social care services.
- There is also a need to scope the housing stock available for the expected numbers of adults with learning disabilities (including those surviving into older age with additional health needs) and to compare this with estimates of the expected requirements in order to inform policy and planning.
- There needs to be better information about the likely costs of support for adults with learning disabilities on the basis of projected population so that the resource gap can be quantified. This must include the needs of adults supported by older parents.
- It is important to bring together the evidence of what is effective in terms of models of support for people with learning disabilities. It is essential that new developments, at a time of restricted budgets, are based on good practice and evidence and that ineffective models are not adopted as short-term solutions.
- There is some evidence (most recent Social Attitudes Survey) that public attitudes are becoming more intolerant towards disabled people. Joint work is required with the media, criminal justice services and health and social care partnerships to prevent any increase in hate crime or victimisation of people with learning disabilities.

## Good Practice – Organisations

**Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?**

Please provide any comments and/or examples here

SCLD is the national centre for excellence in learning disability which was established with funding from Scottish Government in response to Recommendation 6 of 'The same as you?'. SCLD is an independent company and charity and brings together 12 partner organisations who form its board: ARC, Badaguish, Capability Scotland, Down's Syndrome Scotland, ENABLE Scotland, Key, PAMIS, Central Advocacy Partners, University of Dundee, University of St Andrews and University of Glasgow.

The charity was set up to realise the ambitions of people with learning disabilities to be included in community life, in education, in leisure and recreation, in day opportunities and in employment and to generally promote the welfare of people with learning disabilities by promoting joined up services, accessible information and relevant research and providing public education, training and support to agencies, professionals and people with learning disabilities and their carers. SCLD's mission is to work in partnership with people with learning disabilities, people on the autism spectrum 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 tries to embody our mission and goals about the inclusion of people with learning disabilities and family carers through our governance structure. Our Board Members include people with learning disabilities and family carers from our partner organisations who make decisions about the strategic direction of the organisation to ensure that we are responding to the needs of people with learning disabilities across Scotland.

The main tasks of the Centre for Excellence are to: raise the profile of learning disability, promote accessible information, share good practice across Scotland, promote joint working to develop better services, engage a wide range of stakeholders and improve the evidence base. Activities which SCLD undertakes to achieve its purposes include:

public education  
training and workforce development  
consultancy and support to implement 'The same as you?'  
information and advice on accessibility  
research and policy work  
collection and analysis of the eSAY statistics on people with learning disabilities  
a National Development Programme to support Local Area Co-ordination and  
support to Project SEARCH in Scotland.

The common thread in all of our work is the process of co-production and SCLD always aims to support the meaningful inclusion and participation of people with learning disabilities as experts, as skilled colleagues, trainers, researchers. For example, SCLD has supported and continues to support a number of groups of people with learning disabilities and family carers to contribute to policy, strategy and operational decision making. These are just some examples of the groups which SCLD has supported:

- The Local Area Co-ordination National Reference Group – This is a group of people with learning disabilities, family carers and Local Area Co-ordinators. Together they set the strategic direction of the Local Area Co-ordination National Development Programme
- The Modernising Learning Disability Nursing Reference Group – This is a group of people with learning disabilities from across Scotland which supports the UK-wide programme to modernise learning disability nursing.
- The North Glasgow Forum – SCLD supports a group of people with learning disabilities who live in longer stay NHS environments about changes to service design and delivery.
- The Changing Support Changing Lives Reference Group – this is a newly created group of people from a variety of community care backgrounds who all share a common interest in the development of self-directed support. The group has direct input into the Changing Support Changing Lives project, an innovative approach by five different partners to support provider organisations with the delivery of self-directed support.
- The User and Carer Forum for the Scottish Government's Changing Lives review of Social Work – This was a forum of



individuals from a range of backgrounds brought together to discuss the Scottish Government's Changing Lives policy. They developed the concept of Citizen Leadership as well as a toolkit aimed at building the capacity of other organisations

SCLD is committed to continue to work alongside with people with learning disabilities and their families to support the rich and meaningful contribution to policy and strategy which they can make. We are committed to creating links with all organisations which work with people with learning disabilities, whether statutory, third sector or private to share good practice, to build the evidence base and to find solutions to the challenges which lie ahead.

SCLD has made a contribution to improving services for people with learning disabilities and access to services by:

### **Improving the quality of information about people with learning disabilities in Scotland**

At the time of 'The same as you?' there was no information about the actual numbers of people with learning disabilities in Scotland. In order to improve the information to inform planning and to develop better services recommendation 9 said that local authorities and NHS board should set up and maintain local registers of people with learning disabilities. In 2002 SCLD ran a national conference on behalf of Scottish Government on best practice in national data collection. Subsequently, with funding from the Modernising Government Fund it developed, on the basis of widespread consultation, national data standards for learning disability (2005). It set up the eSAY project to collect data from across Scotland using these data standards. From 2008 the eSAY project at SCLD has collected and analysed the data to provide the annual statistics release on adults with learning disabilities on behalf of Scottish Government. The data are used to monitor the progress of the implementation of 'The same as you?', for example through information on the numbers of adults with learning disabilities and on the autism spectrum known to local authorities, employment and further education status, use of day centres and alternative opportunities and uptake of Local Area Co-ordination services. Easy read versions of the statistics are also produced. All 32 local authorities in Scotland provide data and there has been a continuous improvement in the quality of data provided. For example, in 2010 the percentage of adults for which information was reported increased for every date item from 2009. SCLD is now an official statistics provider. Now that the eSAY statistics have begun to be embedded and are widely used, it will be important to continue to support their development to inform and

monitor future policy and strategy.

### **Delivering training with people with learning disabilities in order to promote changes in culture and practice**

SCLD has led the way in ensuring all that its training to improve the skills of the health and social care workforce, including third sector organisations is co delivered by people with learning disabilities. We employ a trainer with a learning disability and also a team of sessional trainers with learning disabilities to deliver our courses. For example in 2009/10 1,505 people were trained in this way including 150 NHS staff. SCLD's training team also works in an inclusive way to build the capacity of other individuals and organisations to support people with learning disabilities and their families effectively. People with learning disabilities and family carers report that their confidence increases after SCLD training. Training courses are developed to provide staff with the skills they need to support people well and include communication, enabling people to stay safe, supporting people into work and planning to achieve outcomes for individuals.

### **Supporting the development of local area co-ordination nationally**

Since 2001 SCLD has supported the development of local area co-ordination across Scotland. We chaired the short-life working group on local area co-ordination which provided the first informal guidance, including draft job descriptions. SCLD provided national training to local area co-ordinators and managers through action learning sets. We provide support to the national network of local area co-ordinators, through a regular information digest and an online community of practice, as well as regular national meetings to share good practice. SCLD developed a framework to clarify the LA role and this is widely used. Advice is given to develop LAC and the National Development Manager advocates for the development of the role in different policy areas, for example with NHS Scotland and primary care. Case studies have been developed and publicised to illustrate the benefits of the LAC role.

### **Improving Health Services**

SCLD has contributed to a large number of initiatives to improve health services. One of the first resources we produced, the video, "Just Ordinary People", where people with learning disabilities talked about

their experiences of health services, formed part of the “Getting it Right Together” training resources for nurses which NHS Education for Scotland produced in response to “Promoting Health, Supporting Inclusion” which SCLD contributed to and launched. We have continued to support Glasgow Caledonian University to ensure that all its nursing students receive training by people with learning disabilities, a recommendation of “Promoting Health, Supporting Inclusion.” In 2010-11, for example, 300 student nurses were so trained.

Other resources we have produced for NHS Scotland include “It’s Our Health Service! Improving the Health of People with Learning Disabilities: a guide for NHS services, their partners and advocacy groups.” This was commissioned by NHS Quality Improvement Scotland as part of work that we did to engage people with learning disabilities and family carers in the development of quality indicators for health services. Our consistent approach has to been to support health services to engage effectively with people with learning disabilities and family carers in order to meet their needs better. Through Equally Well we developed very well received training on learning disability awareness for acute care staff in NHS Greater Glasgow and Clyde which was co delivered by trainers with learning disabilities. We have gone on to develop interactive materials that can be used in continuing professional development which includes example of real life experiences. The effectiveness of both approaches is being evaluated.

**Providing high quality resources, developed with people with learning disabilities and family carers to show how people with learning disabilities can live better lives.**

Popular resources we have developed and disseminated include 2 DVDs on living a healthy life –“You can do it!” (active lifestyles) and “Food for Thought!” (healthy eating). Another example is a DVD explaining self-directed support. With other partners we developed a DVD to explain what happens at a Children’s Hearing to parents with learning disabilities. These resources are available online:

[www.sclد.org.uk/library-publications-video/videos](http://www.sclد.org.uk/library-publications-video/videos)

SCLD both promotes and produces accessible information for people with learning disabilities and we have recently created the Better Info-Better Lives site ([www.betterinfo.org.uk](http://www.betterinfo.org.uk)) to provide accessible information for people who use social care; we are also working closely with the NHS to make health information available on NHS Inform accessible to people with learning disabilities. SCLD’s website is an example of a plain English website and contains an area about accessible information. There were over 26,000 visits to the website

during 2011/12.

### **Publishing and disseminating good practice guidelines and toolkits**

Working with a range of partners we have developed good practice guidelines to improve services including: Effective Engagement in Social Work Education, Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities, Values into Practice Framework for Local Area Co-ordination. All these resources have been developed with people with learning disabilities and family carers and followed up to monitor their use in practice.

In particular we have disseminated the learning of our organisation and that of people who use services and family carers through our work on Citizen Leadership. Citizen leadership is about people who use services improving their own services and those of others through effective engagement. A series of co produced resources show how to do this. For example, we supported the Changing Lives User and Carer Forum to publish “Principles and Standards of Citizen Leadership” and a DVD and a resource called “Supporting You to Support Us”, together with an online gallery of good practice examples from across Scotland. This work was further embedded through training delivered by co trainers and there are examples of areas in Scotland where this training has led to people continuing to train others and influence services, for example North Ayrshire and Moray.

The SCLD library is a joint initiative of ENABLE Scotland, Down’s Syndrome Scotland, Capability and *PAMIS* which brings together specialist collections on learning disability and makes the resources available throughout Scotland by post. The joint catalogue is online and available through the Scottish Health Libraries catalogue.

### **Raising the profile of people with learning disabilities through national events and the media to promote positive images of the contribution of people with learning disabilities**

SCLD has had a strong commitment to building awareness and understanding about the lives of people with learning disabilities and encouraging good practice. In particular we have emphasised the contribution which people with learning disabilities and family carers can make to society. For example,

- SCLD co-ordinates Learning Disability Week in Scotland and encourages people with learning disabilities and family carers to

- Our Employment Champions are all people with learning disabilities who have experience of working life and who visit schools, colleges and employers to build the aspirations of young people with learning disabilities and the confidence of employers.
- Since ‘The same as you?’ we have run a series of well attended events and conferences which have highlighted the contributions of people with learning disabilities and the case for improving their services and life chances. These have included: Moving in the Right Direction, Home at Last (for Scottish Government, 2003), Equal Contributions (2004), Forgotten Citizens (with IRISS and the Open University), Equality Not Just a Duty (2007). These have all brought together mixed audiences to build a shared momentum for change.
- Through Young Scotland’s Got Talent events (with Skills Development Scotland) we have showcased the skills which young people with learning disabilities and on the autism spectrum can bring to employment and sought to raise the aspirations of young people and their families.

### **Conducting evaluations and research to show what works and an improved evidence base**

A recent example of an innovative approach to enabling people to check services has been training disabled people to be “mystery shoppers” to see whether organisations offering assistance with self-directed support are providing the information that people want. The report, “Are you being served?” is available on SCLD’s website: [http://www.sclد.org.uk/sites/default/files/mystery\\_shoppers\\_report\\_1.pdf](http://www.sclد.org.uk/sites/default/files/mystery_shoppers_report_1.pdf)

SCLD has also contributed to developing the evidence base to inform policy, strategy and service delivery and ensure that best practice about people with learning disabilities is disseminated. Some of the following are examples of this work:

- What’s Out There? – this project sought to research the experiences and views of people with learning disabilities and family carers from black and minority ethnic communities. The research found that people from black and minority ethnic communities were often excluded from formal services

- NHS 24 – this project sought to gain the views of people with learning disabilities on using the NHS 24 telephone service and ways in which the service could be made more accessible to people with learning disabilities.
- Working Together Parenting Network – As part of this Network SCLD received money from the Barings and Esme Fairbairn foundations to develop good practice guidelines to support parents with learning disabilities in recognition of the fact that parents with learning disabilities can be separated from their children
- Support to multi agency inspections of learning disability services – SCLD conducted interviews with people at risk for the multi agency inspection of services in Ayrshire.

## Good Practice - Individuals

**Q.5 What have you done, as an individual, to make positive changes within your local area?**

Please provide any comments and/or examples here

N/A

## Future Priorities - Healthcare

**Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?**

Please provide any comments and/or examples here

People with learning disabilities and their families should be able to access high-quality, safe, effective and person-centred healthcare. The best way for healthcare services to improve the things that they do would be to work closely in consultation with people with learning disabilities and family carers.

There is a need for a champion of the agenda within NHS Scotland so that work to improve understanding of people with learning disabilities within health services gets put into practice everywhere.

### **Primary Care**

'The same as you?' evaluation shows that many people with learning disabilities access healthcare through primary care services, just like everyone else, as was envisaged by 'The same as you?'. People with learning disabilities who took part in the evaluation told us that the things which helped them in a primary care setting were:

- Someone to support them to go to the doctor
- Doctors should listen to what people are telling them and use language which is easy to understand, accompanied by accessible information. Doctors should communicate with the person with learning disabilities and not with their carers, unless the person needs communication support.

- Doctors should not make assumptions about people.
- More time with the doctor so that the person can explain the problem and understand the information which the doctor gives them.
- Doctors should not keep things from people with learning disabilities; people with learning disabilities need to be able to understand what is happening to them, just like anyone else.
- Flags on patient notes which help administrative and clinical staff to know that the person has learning disabilities.

Regular health checks for people with learning disabilities can prevent problems from developing or identify conditions early on and ensure that people get the right support to manage health conditions. However, health check programmes must also be tied into sufficient resources to ensure that the services which people are referred on to have the capacity to support the person.

### **Care in hospitals or specialist services**

Many of the things which people with learning disabilities told us about primary care are also true of care in hospitals or specialist services. People with learning disabilities still need to be listened to, consulted and given information in ways that they can understand. Clinical staff should not make assumptions about the needs and preferences of people with learning disabilities without consulting them or their families. Some people with profound and multiple learning disabilities or with complex health conditions are not given the same chances to be healthy as other people by clinical staff. Sometimes this is because clinical staff make judgements about what they think is someone's quality of life without asking the person or their family. People with learning disabilities and their families must always be included in decisions about their health care.

Families told us that when the person they care for is in hospital, it can mean that they lose their benefits. Families told us that this was not fair because, in fact they have to do more caring than usual if their relative goes into hospital.

'The same as you?' set the expectation that people should be able to use non-specialist health services in the first instance and only specialist learning disability resources as required.



Specialist learning disability services should help to build the capacity of general health services.

Ways to improve the response of general healthcare services to people with learning disabilities include robust guidance and clear accountability for reducing discrimination under Equality duties and mandatory training for clinical and administrative staff throughout the NHS.

## **Healthy Living**

‘The same as you?’ evaluation found that people with learning disabilities have heard the messages about living healthy lives, but sometimes they struggle to put these into place without support. People with learning disabilities need support to choose healthy foods and to engage in sports and exercise in the community. People with learning disabilities should be able to try different sports and exercises. Sometimes the sports facilities available in communities are not accessible to people with learning disabilities, for example swimming pools might lack hoists or the water might be too cool. Support workers need to feel confident that they can support people appropriately and the health impact of social and sporting opportunities should be recognised. Employment, access to leisure, adequate income, having choice and control and being included all contribute to healthy lives. The withdrawal of such opportunities will increase health inequalities and poor health outcomes (see below).

## **The social determinants of health**

The consideration of health should include the social determinants of health. Poverty, unemployment and lack of friends can all affect the mental and physical health and wellbeing of people with learning disabilities. The outcomes for people with learning disabilities in these areas will be affected by employers, education, transport and other public services and not least, social care services and there must therefore be joint planning and work between these agencies and health services to ensure that the whole of a person’s wellbeing is taken into account. This approach should help to prevent people from developing problems and, as the Christie Commission recommends, will be more cost-effective in the long run.

## Future Priorities - Education

### **Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?**

Please provide any comments and/or examples here

Children, young people and adults with learning disabilities have the right to high-quality, inclusive educational opportunities and the support which facilitates these.

'The same as you?' evaluation found that, in general, educational opportunities for children and young people with learning disabilities have improved. However, children and young people with complex needs are still sometimes unable to access the support they need to thrive in a learning environment and in some cases this can even mean that children and young people with learning disabilities are not able to access statutory education. Joint working to ensure that health needs can be met and better access to communication support are very important to ensure good outcomes for all children.

Transitions, particularly the transition from school to college or other opportunities, are still a very difficult time for young people with learning disabilities and their families. The support which is offered during this process can often begin too late and it can be hard to co-ordinate the involvement of professionals from multiple agencies. Furthermore, people with learning disabilities are sometimes not consulted on their views and preferences and professionals involved sometimes do not know the child or young person very well. In some parts of Scotland, especially rural areas, opportunities after school can be limited. The Scottish Government's 'Opportunities for All' programme must also apply to young people with learning disabilities, who should have the same chances to pursue the outcomes they wish to achieve.

Research undertaken by the Scottish Consortium for Learning Disability in 2011 ('If I don't get a place next year') found that many further education colleges were reducing places, particularly part-time places, available to adults with learning disabilities because of a combination of cuts to funding from the Scottish Funding Council, a focus on courses tailored towards employment and a focus upon young people aged 16-19. While

SCLD would welcome the drive to build the employability skills of people with learning disabilities through further education, this may exclude people with communication needs or more complex needs from further education opportunities. People with learning disabilities may also attend school until they are 19, thus falling outwith the target age group for the Scottish Government's reforms. It is important that people with learning disabilities who finish school at 19 or older have the same opportunities as their peers leaving school at 16.

Furthermore, the push towards regionalisation may mean that colleges allocate courses for people with learning disabilities to specific campuses, excluding people with learning disabilities from campuses where the rest of the student body undertakes their courses. This threatens inclusivity and may also mean that access to college courses may become more difficult for people with learning disabilities who live at a distance from the campus in question. It is critical that the college regionalisation is not allowed to threaten access and inclusivity for students with learning disabilities. Plans for regionalisation should ensure that people with learning disabilities continue to be included in the mainstream life of the college. Regional outcome agreements should demonstrate how colleges expect to improve outcomes and reduce educational inequalities for people with learning disabilities and on the autism spectrum

In summary, many of the changes to further education policy could have a negative impact upon people with learning disabilities. However, the renewed focus on further education also presents an opportunity for the further education sector to engage with people with learning disabilities and family carers to design and deliver courses which meet the needs and preferences of people with learning disabilities in an accessible and engaging way.

## Future Priorities – Independent Living

### **Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?**

Please provide any comments and/or examples here

It is critical that local and national government and other statutory services develop a thorough understanding of what is meant by independent living. Independent living is not confined to one part of the lives of disabled people but spans across multiple aspects and demands that many different services and systems work in tandem. Independent living is defined by Independent Living in Scotland as:

**“Independent living** means all disabled people having the same **freedom, choice, dignity** and **control** as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.”

People with learning disabilities have worked hard to have the same freedom, choice, dignity and control as other citizens at home, at work and in the community during the past ten years. We must continue to develop opportunities for people with learning disabilities to be part of their communities. The inclusion of people with learning disabilities is significantly affected by access to other services such as transport and this is a particular issue in remote and rural areas. Policies, services and practices which support people to have more choice and control in their lives, such as personal life planning, whole life planning and Local Area Co-ordination have helped people with learning disabilities to achieve this. The right support at the right time, combined with accessible universal services, such as transport, can help people with learning disabilities to live as they wish. Inaccessible services and a lack of support will do the opposite. It is essential that in a landscape of community charges, tightening eligibility criteria and cuts to welfare benefits, that people with learning disabilities are still able to live the lives they want with the support they need. These changes to funding threaten to perpetuate the crisis-led approach to service management and are the antithesis of the preventative and anticipatory approaches advocated by the Christie Commission.

## Future Priorities – Employment

### **Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?**

Please provide any comments and/or examples here

People with learning disabilities, like anyone else, have multiple skills and talents to offer the workforce. Meaningful employment can offer people with learning disabilities income, a social network, and can help to improve poor health outcomes.

Barriers to employment opportunities for people with learning disabilities include both direct and indirect discrimination and a lack of understanding on the part of some employers as to how they could support people with learning disabilities to do a good job.

Reasonable adjustments in the workplace, such as job coaches and matching the job description to the person's skills, can all help to create sustainable employment opportunities.

However, the funding base of many supported employment schemes is extremely fragile and may be threatened further at a time of continuing pressure on local authority budgets. Moreover access to supported employment is uneven across Scotland with no service at all available in some areas. It is very important that through the new strategy Scottish Government and CoSLA stress the priority of employment for people with learning disabilities and recommend investment in supported employment as an effective route to achieving job outcomes. Health and social care partnerships should ensure that there is a supported employment scheme to meet the needs of people with learning disabilities in their area. Supported employment services must seek to support the person and their family through the process of looking for jobs, attaining employment and learning the job, and they must support employers to get to know the person and their needs.

Project SEARCH

(<http://www.sclld.org.uk/information/employment/project-search>)

is a programme which combines and co-ordinates the resources

of further educational establishments, employers and supported employment agencies. It is now being implemented in sites across Scotland including North and South Lanarkshire. It is of proven effectiveness in achieving job outcomes. The programme demonstrates the value of joint work between education, supported employment and business partners to achieve results. It is important that both public and private sector employers learn the lessons from this programme on how to use systematic, specific and well evidenced approaches to the support of people with learning disabilities in order to improve employment outcomes.

Young people with learning disabilities may need further targeted educational support after school to enable them to access work successfully. Further education could play a much more effective role in enabling people with learning disabilities to gain the qualifications they need to enter employment (see previous question). We have recently encountered several examples of people with learning disabilities being refused access to mainstream courses that would have provided them with a relevant qualification. Colleges should work in partnership with employability providers with experience of supporting people with learning disabilities to improve the transition from college to work.

It will be important to monitor the impact of the Opportunities for All policy to ensure that young people with learning disabilities are benefitting from the offer of a training or employment. In addition this offer should be extended to the age of, say, 21 for young people with learning disabilities and autism spectrum disorders as they experience transition later than other young people.

The current DWP work programmes present barriers to good practice. Young people in receipt of Job Seeker's Allowance are prevented from participating in the year-long intensive support offered by Project SEARCH, despite its much better record in obtaining job outcomes, evidenced in North Lanarkshire at Wishaw General Hospital. Scottish Government should continue to make representations to the Department of Work and Pensions that the needs of people with learning disabilities are not being met by existing programmes, that barriers to effective employability schemes for people with learning disabilities created by benefit rules should be removed and that specialist providers must be contracted to provide employability support if

discrimination is to be avoided and successful job outcomes achieved.

There also needs to be better integration of the development of self-directed support with the implementation of employability initiatives. Research conducted by the University of Dundee (Hall, 2010) showed that there was very low awareness of self-directed support in the employability sector. Moreover there was a risk that people with learning disabilities fell between two stools –that is, that those most likely to gain employment might now be outside the eligibility criteria for social work support and therefore not able to use self-directed support to access support for employment. Guidance on the implementation of self-directed support legislation should explicitly address how people with learning disabilities can use self-directed support to enable them to be supported to gain a qualification, find work and receive support in work.

## Future Priorities

**Q.10 What other future priorities do we need to focus on?  
(Please list these in order of importance with the most important first)**

Please provide any comments and/or examples here

- Respect for the human rights and equality of people with learning disabilities must underpin everything we do; the proper understanding of equality and human rights and using these as a lens through which to develop policy and strategy alongside people with learning disabilities will mean better policy strategy.
- Continue to focus on inclusion, participation and co-production, connecting people with learning disabilities into their services and communities by restating the vision of 'The same as you?'
- Review the circumstances of individuals who are 'stuck' in inappropriate placements whether out of area placements, delayed discharges or as younger people in older people's homes and include in the action plan clear steps to plan and resource appropriate services, preferably locally, taking on board the recommendations made in the light of Winterbourne View
- The accountability for making changes happen must be clear in the action plan and monitored locally and nationally
- The new action plan to implement SAY must be well connected with other policy agendas around human rights, health and social care integration, self-directed support, education, employability, poverty and preventative approaches
- Continue to invest in the skills and talents of people with learning disabilities through further education and employment. Raise the expectations of people with learning disabilities, family carers and professionals about what people are able to achieve
- Make sure that family carers of people with learning disabilities are properly supported with the right information and support at the right time
- Invest in whole life planning approaches in which services proactively seek solutions for people with learning disabilities and their families
- Invest in comprehensive training for professionals who



support people with learning disabilities on universal services, such as teachers and doctors