

The keys to life

Improving quality of life for people
with learning disabilities

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The Scottish
Government
Riaghaltas na h-Alba

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Ministerial Foreword

As a nation we can be proud of some of the changes in the quality of life for people with learning disabilities since *The same as you?* was published in 2000. People with learning disabilities tell us that they are generally much more accepted and valued in their communities than they ever were before. They are rightly seen as people who can contribute to Scottish society in very positive ways. For some, the biggest change was the closure of long-stay hospitals. For others, having their own tenancy or being in employment or having good friends and relationships has been transforming.

But to be truly accepted in society means being treated equally and fairly in other ways. It means having a health service that recognises and redresses the stark fact that people with learning disabilities still die 20 years earlier than the general population. This is simply not acceptable. Whilst there are many committed practitioners out there, they tend to be specialists who have chosen to work with people with learning disabilities. We need to ensure that all those who work in health care understand the health needs of people with learning disabilities, how these can differ from the general population and to respond appropriately and positively. This is not always about the application of knowledge but about an attitudinal and cultural shift in supporting individuals to lead healthier and happier lives.

That is why the emphasis in this ten year strategy is on health issues. That is not to say we are reverting back to old practices where the medical profession were able to make decisions about the social lives of people with learning disabilities. It is about improving health practice and outcomes so that people's human rights are respected and upheld. If a person's health is compromised then that is life-limiting.

People with learning disabilities should also be supported to live independently in the community wherever possible. To deliver the changes necessary to improve services requires partnership working and joint commissioning by statutory organisations. However, to deliver the changes necessary they need to involve the third sector and most importantly people with learning disabilities and their carers to ensure that developments are fit for purpose.

I would like to thank all those who have contributed to developing the strategy. People with learning disabilities are looking to us all to work with them so that they have the keys to a good life. I welcome the opportunity to work with you in translating aspirations into reality.



A handwritten signature in black ink, which appears to read "Michael Matheson". The signature is written in a cursive style with a long horizontal flourish at the end.

Michael Matheson

Minister for Public Health

COSLA Foreword

Ten years on from *The same as you?* we should celebrate the changes that strategy helped to deliver. It made progress in ensuring that people with learning disabilities are more fully included in Scottish society, and able to contribute to public life as valued members of our communities who are also parents, partners, employees, friends and carers.

However, it is also important to recognise that we still have a way to go. We face significant challenges in public funding at a time when the shape of our population is changing in a way that means there is more demand for services. Part of meeting these challenges is ensuring that services are fully tailored to individual needs and aspirations, and help people to achieve their goals in life. This new strategy sets out a vision for improved partnership working to deliver better outcomes for people with learning disabilities, and their families and carers, in the areas of life that they have told us are the most important to them. We now need to make sure this vision delivers an even greater impact over the next ten years.



Peter Johnston

Councillor Peter Johnston

COSLA Health and Well-being Spokesperson

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End
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Break
the stereotype

Break the stereotypes

Unlock resources

Commissioning of public services

Ten years ago *The same as you?*¹

Raised people's awareness of what to do

To stop separation and isolation and encourage social integration

And now finally people listen to what we say

We're onwards and upwards – we're here to stay

A poem by a group of local service users from South Lanarkshire Council

¹ *The same as you?* learning disability policy published 2000, Scottish Executive

Human Rights



shift

Culture shift

Control

In control

Alter

Alter attitudes

Delete

Delete discrimination

The human rights of people with learning disabilities

This renewed and refreshed policy has the human rights of people with learning disabilities at its heart. Also integral to it is The Healthcare Quality Strategy for NHS Scotland², published in 2010, which makes clear that whatever the individual circumstances of people's lives, including age, gender, ethnicity, disability, religion, sexual orientation, mental health, economic or other circumstances, they should have access to the right health services for their needs.

People with learning disabilities and their families represent a diverse group and come from all backgrounds, cultures and walks of life.

The same as you?, the first national learning disability review for over 30 years, articulated a number of human-rights based principles that were to be taken into account in fulfilling the recommendations of the original policy. These principles formed the bedrock of much of the activity that was undertaken to improve the lives of people with learning disabilities. Thirteen years on, these principles of valuing people with learning disabilities still hold. Everyone should have the opportunity to contribute to the communities in which they live, work and socialise. The need for people with learning disabilities to live independently, having the same choice, control and protection as all other citizens of Scotland in terms of the age-appropriate support they receive, is more relevant than ever.

The formal evaluation of *The same as you?*³ was led by Scottish Consortium for Learning Disability (SCLD) and involved asking people with learning disabilities what they thought had changed as a result of the policy. The findings, published in 2012, endorsed the criticality of taking a rights-based approach. Some comments concerned simple things like accessible information becoming the norm. Others stressed the importance of equality legislation being fully implemented to make sure that people with learning disabilities were not unduly disadvantaged. A plea was also made for strong responses to be made to discrimination and abuse.

The realisation that aspirations have to translate into positive outcomes for people is ever more pressing – particularly in the current financial climate where the distribution of available funds is under yet more

² The Healthcare Quality Strategy for NHS Scotland-putting people at the heart of our NHS. Scottish Government, 2010 <http://www.scotland.gov.uk/Publications/2010/05/10102307/0>

³ <http://www.scotland.gov.uk/Publications/2012/05/6945>

individual and societal scrutiny and where mutuality and striking a balance between the rights and the responsibilities of citizens is constantly being re-examined. The complex question of the extent to which it is both legitimate and appropriate for the State to intervene in the lives of individuals is ever present, especially when this is to be counter-balanced with the right to privacy and to a private life that all citizens should enjoy.

Meaningful change in the future will depend on much more than our collective good intentions. It is not enough to have a Strategy where tasks and processes can be ticked off as complete, unless these lead to good outcomes for those concerned. With this in mind, the Scottish Government has funded SCLD to produce a Scottish contribution to the UK review of implementation of the rights within the United Nations Convention on the Rights of Persons with Disabilities. This is a small illustration that what is needed now is a cultural shift (which has begun), true participation in our society by people with learning disabilities and empowerment to make this happen. This new Strategy aims to deliver just that.

All of this is simply a translation of what human rights law now says whether in Scotland, the UK, Europe or the United Nations. Appendix 2 sets out the legislative background. Since *The same as you?* was published in 2000, there have been many additions to statute to ensure that human rights approaches become embedded in policy development, implementation, evaluation and scrutiny. Essentially this challenges the needs approach and the 'we know best how to do this' behaviours that can sometimes be displayed by professionals, in favour of a shift to rights based on the individual's ability and opportunities. This will require all those involved to work together in partnership with the individual to achieve his or her desired outcomes.

Our recommendations reflect those expectations. They also clearly chime with ongoing work to develop a Scottish National Action Plan for Human Rights that the Scottish Human Rights Commission (SHRC) leads on.

Recommendation 1

That all public bodies involved in providing support to those with learning disabilities carry out equality impact assessments on relevant policies by June 2014 to ensure that the rights of people

with learning disabilities to dignity, equality and non-discrimination are respected and upheld.

Recommendation 2

That localities provide opportunities to promote equality for people with learning disabilities through actively involving and including them in local developments that affect them. A first step should be the provision of information that ensures greater awareness of the rights we all have under domestic law and as a result of international treaties.

Definitions and numbers



shift

Culture shift

control

In control

End

End health
inequalities

Who are people with learning disabilities?

The original policy document worked hard at coming up with an accurate definition which focused on what people with learning disabilities could do, and many organisations adopted this as the basis on which they provided support to individuals. We have re-visited this definition and want to maintain it. It is that:

People with learning disabilities have a significant, lifelong, condition that started before adulthood, which affected their development and which means they need help to:

- understand information;
- learn skills; and
- cope independently.

But this is only part of a description. It does not capture the whole person who can be much more – a friend, a family member, a community activist, a student, a parent, an employee or employer to name just a few roles. It is essential that we keep in mind all of these possibilities.

The policy covers the lifespan of an individual and for the purposes of this policy people with learning disabilities comprise of those with learning disabilities being present before the age of 18. Another distinction to make clear is that we do not include people with specific learning difficulties such as dyslexia.

People with learning disabilities should have a range of support and services to meet the following needs:

Everyday needs

For example, a place to live, security, social and personal relationships, leisure, recreation and work opportunities.

Extra needs because of their learning disabilities

For example, help to understand information, support to make decisions and plan, learn skills, help with communication, mobility or personal care.

Complex needs

For example, needs arising from both learning disabilities and from other difficulties such as physical and sensory impairment, mental health problems or behavioural difficulties.

For any of these needs the level of support will vary. A person with learning disabilities may need:

- occasional or short-term support;
- limited support, for example, only during periods of change or crisis;
- regular long-term support, perhaps every day; or
- constant and highly intensive support if they have complex or other needs which are related.

Learning disabilities and autism

The same as you? was a policy for people with learning disabilities and for those on the autism spectrum. In 2011 the Scottish Government published the first Scottish Strategy for Autism⁴. We recognise that some people with learning disabilities are also on the autism spectrum. However, people on the autism spectrum do not necessarily have learning disabilities. People with learning disabilities who also have autism will benefit from both policies.

What are the numbers of people with learning disabilities?

About 16,000 school aged children and young people, and 26,000 adults in Scotland have learning disabilities and require support. Additionally, there are considerably more adults (almost three times as many) who have learning disabilities and had additional support needs when they were at school, but who do not now identify themselves, and are not identified by others, as being disabled, and who are not currently using statutory learning disabilities services. There are more boys and men with learning disabilities than girls and women, although at older ages the gender distribution is more equal, as women typically live longer.

The proportion of people in the population with learning disabilities is influenced by a wide range of factors. It may seem surprising that estimates vary, but there are valid reasons, such as the definitions of learning disabilities used, the age groups included, and the year the

⁴ <http://www.scotland.gov.uk/Publications/2011/11/01120340/10>

estimate was made. The main approaches to estimating the number of people with learning disabilities in Scotland are by using information from Scotland's routinely collected statistics, or estimates based on statistical principles about the distribution of intelligence in the population.

Information from Scotland's routinely collected statistics

There are three main sources of relevant information that are routinely collected in Scotland. An annual census of pupils and teachers at all publicly funded schools (95% of all school-aged children in Scotland) provides information on the number of school age children with learning disabilities. The 32 local authorities return annual statistics on their adult users of learning disabilities services via the eSAY project, the information is collected in a standardised form and collated, analysed and published as official statistics by the eSAY project. General practices who participate in certain contractual arrangements with their Health Board (96% of GPs) are required to keep a database of their registered patients who have learning disabilities and are over 18 years of age.

In September 2012 there were 15,979 school children with additional support needs due to learning disabilities; 64% were boys and 36% were girls.

In 2011, the eSAY database included 26,036 adults with learning disabilities; 58% were men and 42% were women. 705 were 16 and 17 year olds who had left school. This figure is an undercount for that age group, so it is more precise to say that eSAY includes 25,331 adults with learning disabilities over the age of 18. In 2011-2012, 24,998 adults over 18 years were on the learning disabilities databases kept by GPs, suggesting there are 26,097 in total in Scotland when the non-participating practices are taken into account.

eSAY also collects information on ethnic groups and in the 2011 data collection, this showed that 22,589 people with learning disabilities were classified as white and 374 people were recorded as being of 'other' ethnic background. It was estimated in 2004 that approximately 25% of new entrants to adult social care with learning disabilities will belong to minority ethnic communities⁵.

⁵ Emerson, E., Hatton, C. (2004) *Estimating future need for adult social care services for people with learning disabilities in England*. Centre for Disability Research, Lancaster University, Lancaster

People with learning disabilities and families from black and minority ethnic (BME) communities often face major barriers in accessing services and support that meets their needs.

Estimates based on statistical principles about the distribution of intelligence in the population

The way intelligence is spread in the population is similar to other human characteristics, such as height. The majority of people are in the middle of the distribution, and few people are at either of the extreme ends; the further away from the typical people in the middle, the fewer the people there are (e.g. extremely tall or extremely short in stature; genius or learning disabilities). Statisticians define the extreme ends as about 2% of the population at the lower end, and 2% at the higher end. Measurements of “intelligence quotient” therefore use 70 as the cut off point for learning disabilities.

The same as you? was published before eSAY existed, and before GPs held a database of their adult patients with learning disabilities, so it pragmatically used this statistical definition of learning disabilities to estimate that 120,000 people in Scotland had learning disabilities. This was the best way to estimate the number of people with learning disabilities back in 1999/2000. It is accurate to the extent that the number includes all people statistically likely to be more than two standard deviations lower than the average on measures of intelligence.

However it is also inaccurate, because research has shown that a higher proportion of children than of adults have learning disabilities, and also that people with learning disabilities with health needs die at a younger age than other people, so in older age groups there is a considerably lower proportion with learning disabilities. In other words, the statistical estimate is progressively more inaccurate with older age groups. Also, this is a statistical definition; it does not take account of skills, gradual acquisition of skills, or of enabling supports that might protect a person from being disabled by their slower rate of learning. The cut-off point is arbitrary; if it were slightly higher – an IQ less than 75, rather than an IQ less than 70 - this would more than double the number of people included as having learning disabilities, and IQ cannot validly be measured with this degree of accuracy.

Research studies

There has also been research to try to establish how many people have learning disabilities. This is a challenging and expensive task, particularly so for adult populations, and there are limitations to the work that has attempted to do this. Even the most recent studies have a wide variation in reported rate, and particularly so for mild learning disabilities. Most studies have been conducted with children, and very few with adults. The rate of mild intellectual disabilities is influenced by many cultural and societal factors that determine whether a mild intellectual impairment is likely to result in a functional disability, contributing to geographic differences. The Health Needs Assessment for People with Learning Disabilities in Scotland⁶ reviewed studies up to 2003, and found that although there is a large variation in reported rates for mild learning disabilities, the range for moderate to profound learning disabilities was more consistently reported, varying from 2.7 to 3.8 per 1,000. As far as more recent studies are concerned, the considerable differences in their methods and the study findings for mild learning disabilities are such that it is not appropriate to average their results, and indeed there are likely to be some genuine geographic differences⁷.

Which of these estimates are most accurate?

Determining the most accurate estimate of the number of people with learning disabilities depends upon the purpose for which the information is required. This is because learning disability is not a “condition” with a nationally agreed definition; there are many different definitions. There is a difference between a statistical definition and a social definition. The World Health Organisation (ICD-10), American Psychiatric Association (DSM-IV), and *The same as you?* quote a definition that includes problems in adaptive functioning (skills) as well as a significantly lower intelligence level than average, so they have leaned towards a social definition. This is probably the most appropriate approach when planning statutory services and supports, because unless a significant proportion of the population who are not currently calling upon services suddenly start to do so (which seems rather unlikely), then such plans should be based around the needs of the population likely to use those services.

⁶ NHS Health Scotland (2004) *Health Needs Assessment Report. People with Learning Disabilities in Scotland*. NHS Health Scotland.

⁷ Smiley, E. (2010) The incidence of mental ill-health in adults with intellectual disabilities. *MD Thesis*, University of Glasgow.

Should the Government introduce new policies that require individuals to have to learn to behave in a new way - e.g. requiring certain information to be provided annually by each person via the internet, or introducing new national health screening programmes that might be difficult to understand and comply with if your learning is slower - then a statistical definition (adjusted for age) is probably a more appropriate estimate of the number of people who may struggle with the change. It is, however, just that – an estimate.

Commissioning of public services



Alter

Alter attitudes

Enter

Enter partnerships

Unlock

Unlock resources

Setting the scene

The key to delivering effective services is to ensure that people are provided with the outcomes that they need at the right time and in the right place.

The Christie Report – Commission on the Future Delivery of Public Services⁸ proposes an approach based on a thorough understanding of how public services could improve the quality of life and outcomes for the people of Scotland, while focusing relentlessly on prevention, early intervention and driving out costs.

It follows that any reform of organisational boundaries should be 'bottom up' - based on the reality of delivering front-line services - rather than 'top down', or solely motivated by the desire to make savings.

Demographics, economics, increasing care complexity and people's expectations are driving a rethink about what kind of health, wellbeing and social care services are needed, and about the way in which services are planned and co-ordinated to be effective in securing the best possible outcomes for the population, including people with learning disabilities.

A range of public bodies, including local authorities and the NHS, are involved in planning, delivering and purchasing services that affect the lives of people with learning disabilities. From social care, community transport, and leisure services, to district nursing, further education colleges and employment support, the way services are commissioned touches almost every part of our lives. If we are to meet these challenges, people who use services, their families, and their carers, need to be at the heart of the commissioning process.

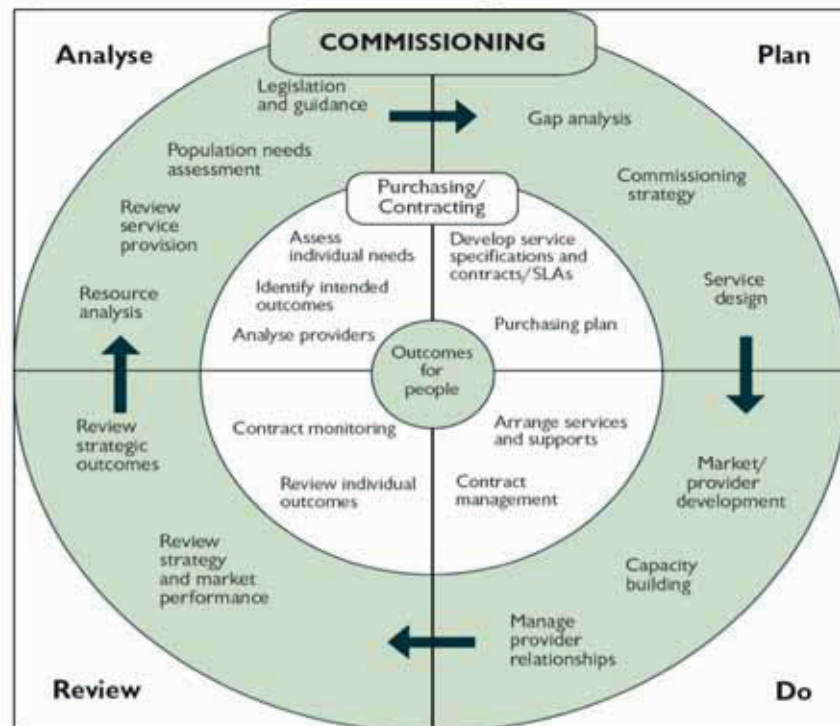
Joint commissioning

Strategic commissioning is the term used for all the activities involved in assessing and forecasting needs, linking investment to agreed desired outcomes, considering options, planning the nature, range and quality of future services and working in partnership to put these in place. Joint commissioning is where these actions are undertaken by two or more agencies working together, typically health and local government, and often from a pooled or aligned budget.

⁸ Report on the Future Delivery of Public Services by the Commission chaired by Dr Campbell Christie. Published on 29 June 2011.

Commissioning is commonly described as a cycle of strategic activities similar to that shown in Figure 1 below.

Figure 1: Joint Commissioning Model for Public Care



In this model, based on that developed by the Institute of Public Care (IPC), the Commissioning cycle (the outer circle) drives purchasing and contracting activities (the inner circle), and these in turn inform the ongoing development of Strategic Commissioning.

Joint commissioning should consider the following ten strategic outcomes which relate to statutory bodies legal obligations and national priorities, and, in doing so, will help people with learning disabilities to achieve positive outcomes:

- People have choice and control in their daily lives and are supported to live as independently as they can;
- People enjoy the best possible health and emotional wellbeing;
- People have good things to do that help them achieve their full potential;
- Carers are supported;
- People are safe, respected and included in their communities;
- People are involved in the planning, development, design and delivery of services that help them to achieve the outcomes they want;

- People are satisfied with their experience of health and social care services;
- Statutory bodies fulfil their statutory legal responsibilities, adhere to meeting quality standards, services are safe and continually improving;
- People working in services are positive about their role and supported to improve the care and treatment they provide;
- Services are efficient and responsive to local people's needs.

Integration of Adult Health and Social Care and Commissioning

The integration of adult health and social care will facilitate integration of commissioning budgets for adult services, in such a way that the source of the resources will lose its identity, for as the Cabinet Secretary has stated: “where money comes from, be it health or social care, will no longer be of consequence”⁹. This will create a single commissioning budget from which partners will commission improved outcomes for adult health and social care. For this to be effective, it will be essential that steps are taken to integrate the commissioning process.

The Integration of Adult Health and Social Care Bill is likely to place a duty on partnerships to put in place locality planning arrangements to deliver locally agreed strategic commissioning plans that have the support of the professionals and other care providers who will deliver services as well as users and carers. It is vital that these new partnership arrangements function to improve performance in the form of the delivery of outcomes for local communities, and that joint commissioning functions to ensure the specific needs of people with learning disabilities are met.

The recommendations in this chapter are designed to reorientate commissioning further towards outcomes and away from a tight focus on service volumes (e.g. hours of activities) and costs.

Recommendation 3

That by April 2015 community planning partners should ensure that local arrangements for joint commissioning are developed across relevant partner agencies and service areas to support the delivery

⁹ Nicola Sturgeon, Scottish Parliament, 15 December 2011

of agreed outcomes, and that these take account of the needs of people with learning disabilities.

Reshaping Care for Older People

We know people are now living longer and this is the same for people with learning disabilities. The Reshaping Care for Older People is a Scottish Government initiative aimed at improving services for older people by shifting care towards anticipatory care and prevention. Older people are an asset to this country and preparing for an increasingly ageing population is one of our biggest national challenges. Our older population is likely to increase by around two thirds in the next twenty years and because of this we need to change how we deliver care.

Around 90,000 older people receive some kind of care, whether in their own home, a care home or long-term hospital care. If we continue delivering care the way we do right now, an extra 23,000 people will need care by 2016. A programme for change 2011-2021¹⁰ sets out our vision and has been produced in consultation with the people of Scotland, politicians and professionals both locally and nationally. 'Older people are valued as an asset, their voices are heard and they are supported to enjoy full and positive lives in their own home or in a homely setting'.

Self-Directed Support (SDS)

The Social Care (Self-directed Support) (Scotland) Act 2013 will also provide opportunities and challenges for commissioners and providers. Self-directed support (SDS) empowers individuals to have greater choice and control over the support they receive, either through receiving a direct payment in lieu of services, or by having greater control over decisions about what types of services or supports are provided. Rather than being a passive recipient of services, citizens can become actively involved in selecting and shaping the support they receive.

The same as you? was instrumental in bringing about a focus on individuals having more control over the care and support that they receive and highlighted the role of direct payments, as one SDS option, in achieving this. People with learning disabilities have been well

¹⁰ [Reshaping Care for Older People: A Programme for Change 2011-2021](#)

represented in pilots of SDS both in Scotland and elsewhere and have indicated that they welcome the strengthened opportunity that this new legislation will offer - not to be shoe-horned into existing models of service provision. The roll-out of SDS will mean that the person receiving services will become the lead commissioner – they will work with professionals to co-produce a support plan and will make joint decisions about the type of support to be commissioned. In some cases the individual will also be the purchaser, and may even employ support staff directly.

Case study

Jane received a support service that really didn't work for her. As a young woman with learning disabilities and lots of interests and aspirations she did not accept that she had to fit her life around the support that she received. With the help of her family Jane advised the local council that she needed something different and they agreed and suggested that she and her family look at other possible options. On Jane's behalf her dad set about meeting and interviewing local support providers. It was decided to link with C-Change Scotland who offered to manage her support using an Individual Service Fund. From the beginning they negotiated with her what aspects of her support she would manage and what the organisation would do on her behalf. For example Jane paid less from her budget for service management as she agreed to take on some aspects of this role.

Jane has achieved many of her ambitions, furthering her education with a course at University of the West of Scotland; obtaining employment and developing her political interests.

Jane was keen to take greater control over her individual budget and in April 2010 successfully applied for and received her Individual budget in the form of a direct payment. She says 'I have my money so I have more say over my support.'

The SDS Act will place statutory obligations upon social work services and funding arrangements. It will provide an opportunity to further personalise the commissioning process to link to individual outcomes. Commissioners will increasingly have to develop and influence their local markets to encourage greater choice and control for service users from a more diverse range of providers; develop financial flexibility to enable resources to be re-directed from less popular services; and develop systems which provide clarity about purchasing options for SDS clients, eligibility criteria and individual pricing mechanisms for in-house and external services. This will be a challenge for commissioners and

providers alike as it heralds a move towards a co-production approach and away from long-term block contracts.

People with learning disabilities and carers have said that involvement in the decision making process leads to better outcomes and better decisions about services; they can provide information based on life experience that will help support commissioners and planners to make sure that support services are targeted and that planning leads to the most efficient use of available resources, therefore leading to better outcomes.

Recommendation 4

That the Learning Disability Strategy Implementation Group will set up a training sub group to take forward health and social care workforce development. The sub groups remit will be to work in partnership with NHS Boards, local authorities, relevant statutory bodies and third sector to support workforce development to:

- **Ensure the ongoing learning and sharing of best practice is available and accessible to all health and social care professionals to address the healthcare needs of people with learning disabilities**
- **Ensure that NHS staff, as part of their mandatory and induction training, receive training in the suite of legislation relevant to supporting people with learning disabilities in mainstream health settings**
- **Ensure that staff in high volume acute pathways for people with learning disabilities are given relevant learning disability training**
- **Ensure that health and social care staff working with people with learning disabilities are trained on use of 6D cards and Talking Mats**

Recommendation 5

That in preparation for the legal duties imposed by the Social Care (Self-directed Support) (Scotland) Act 2013, local authorities and their NHS partners should work with private, voluntary and third sector agencies to ensure that people with learning disabilities have access to a creative variety of providers and supports and are assisted to think creatively about how outcomes can be met and what assistance they may need to develop control.

Under this recommendation, health and social care partnerships should:

- gather robust information on unmet eligible need;
- ensure that future joint commissioning plans and strategies seek to shape the range of choices available to people with learning disabilities;
- combine demographic and care management information to project future eligible need;
- improve the links between the information recorded in individual assessments and the major strategic decisions about what services to commission, what type and variety of services and where;
- work in co-production with providers to stimulate the development of new services and new service models in response to what people with learning disabilities say they want; and
- build the capacity of people with learning disabilities so that they can collaborate with the Health and Social Care Partnership to design, deliver and commission a greater variety of services and supports.

An overarching requirement will be that any new provision should not be large scale and/or one which attempts to replicate long stay hospital provision of the past. Joint commissioning is a key mechanism by which integrated health, wellbeing and social care will be expected to deliver the Government agenda for better outcomes for older people, including those with learning disabilities.

The Joint Strategic Commissioning Learning and Development Framework¹¹ and the Guidance on the Procurement of Care and Support Services¹² will help those responsible for improving joint commissioning capacity in local partnership to achieve joint commissioning.

¹¹ Joint Strategic Commissioning Learning and Development Framework published by Scottish Government, NHS Scotland, COSLA and the Joint Improvement Team in 2012 <http://www.jitscotland.org.uk/action-areas/commissioning/>

¹² Guidance on the Procurement of Care and Support Services, published by the Scottish Government and COSLA in 2010. <http://www.jitscotland.org.uk/search/?m=1&start=0&q=guidance+on+the+procurement+of+care+and+support+services>

Recommendation 6

That by June 2014 COSLA, ADSW and NHS partners work with Scotland Excel to improve the quality and consistency of support for people with learning disabilities who have a long-term need for specialist residential care, by developing a national framework agreement for procurement. This should include a core service specification which focuses on outcomes for residents, the rates that will apply, and the arrangements that will be put in place to monitor and manage performance.

Recommendation 7

That by April 2015 local authorities and NHS Boards should ensure that joint commissioning plans take account of the needs of people with learning disabilities of all ages. Plans should have regard to relevant guidance, scope current and future need, identify the total resources available to meet those needs, and set out how they will be invested to secure sustainable, high quality services and supports that can deliver outcomes for individuals, including those agreed as part of person-centred care planning and self-directed support (SDS). Plans should make reference to early interventions, maximising independence and control.

Recommendation 8

That by June 2015 the Care Inspectorate and Healthcare Improvement Scotland should ensure that strategic commissioning plans, processes and implementation are examined as part of on-going scrutiny work that impacts on services for people with learning disabilities.

Health



shift

Culture shift

Control

In control

Alter

Alter attitudes

Enter

Enter partnerships

End

End health inequalities

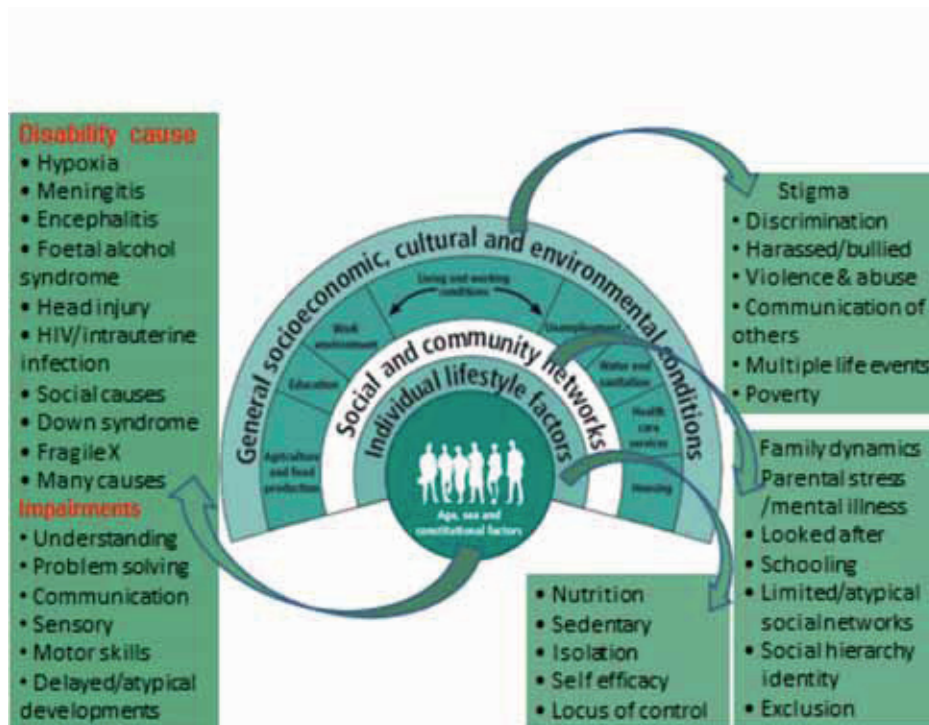
Delete

Delete discrimination

Setting the scene

The Scottish Government has set a key objective to make Scotland healthier. It will achieve this by tackling ill health and by focusing on health inequalities. To measure progress it has established two national outcomes of living longer, healthier lives and tackling the significant inequalities in Scottish society. To be able to make progress in respect of people with learning disabilities will require a much greater understanding of their specific needs in order to address them.

Wider socio-economic determinants of poor health outcomes for people with intellectual disabilities¹³



Research tells us that people with learning disabilities have some of the poorest health of any group in Scotland¹⁴. They are considerably more likely to die at an early age than the general population - on average 20 years before¹⁵. Some of the causes of death are potentially preventable, and the main causes of death differ from those of the general population. Whilst the most common causes of death for the Scottish population are

¹³ Modified from Dahlgren G, Whitehead M. Tackling inequalities in health: what can we learn from what has been tried? Background paper for *The Kings Fund International Seminar on Tackling Health Inequalities*. Ditchley Park, Oxford: King's Fund

¹⁴ NHS Health Scotland. People with Learning Disabilities in Scotland: The Health Needs Assessment Report. NHS Scotland, Glasgow. 2004.

¹⁵ Tyrer F et al. *J Intellect Disabil Res.* 2007;51:520-7.

cancer, heart disease and strokes, the most common causes of death for people with learning disabilities are respiratory disease, cardiovascular disease (related to congenital heart disease) and different forms of cancer, principally related to gullet, stomach and gall bladder rather than lung, prostate and urinary tract.

Many of the causes of learning disabilities may also lead to physical or mental ill health. This means that people with learning disabilities may be more likely to be prescribed multiple drugs due to complex and multiple health needs which, in turn, can sometimes adversely affect health through side effects and drug interactions.

In terms of prevention, people with learning disabilities are also less likely to exercise and eat healthily than the general public because they may not always have the knowledge or understanding to make healthy choices, and are reliant on others for support and communication. These issues are often added to by problems accessing the health services they need.

What is clear is that some conditions go unrecognised or are recognised at a later stage than would be the case for the general population.

Where there is a recognised condition, it may not be monitored as well unless individuals themselves, their carers and professionals proactively do this. Added to which, assumptions are sometimes made that a condition is part of the learning disability and it is not addressed because of this.

The way in which service responses are structured does not always help. One example of this is that there is no equivalent of the paediatric service for adults with learning disabilities in the NHS. Instead, responsibility within the community lies principally within primary care. There is no doubt that there is good practice in primary care, but routine exposure to the needs of people with learning disabilities because of the low numbers per average practice makes it harder to build up expertise. Overall these issues contribute to reduced life expectancy, reduced cognitive functioning, reduced quality of life, and disability and pain.

With the passage of the Health and Social Care Integration Bill there will be improved opportunities for health and social care practitioners to work more closely together in maximising their expertise to achieve best value in terms of quality outcomes for people. We know that since *The same as you?* there have been considerable investments to improve the social

care and support of people with learning disabilities, and Scotland now has inclusive policies, and more appropriate housing and support provisions for people with learning disabilities. Integration should make it possible to learn from these interventions and to spread that learning across all disciplines and locations.

Scottish Learning Disability Observatory

In order to understand more about the health inequalities faced by people with learning disabilities and to make those needs more overtly visible, the Scottish Government is funding the University of Glasgow to create a Scottish Learning Disability Observatory which will be dedicated to robustly underpin health improvement and to address health inequalities.

As the health of people with learning disabilities cannot be measured in Scotland's routinely collected health statistics, it is not possible to measure the health care they receive. Considerable information is available in Scotland about a wide range of disease areas (such as heart disease and diabetes) that has resulted in these services being able to improve pathways to better manage these diseases. It has also provided policy-makers with the information they need to take better decisions and improve health policies, but the same is not the case for people with learning disabilities due to the lack of information available. So there has been a lack of awareness of the extent of need.

The Observatory will work with and for people with learning disabilities and their families, ensuring their views and priorities inform the programme of work packages. It will measure and watch health indicators and health service responses, and support the role of adult social care and education in health. Scotland has a strong tradition of using routinely collected data to measure, monitor and improve the health of the population, and can use this information to benchmark performance between services in Scotland, and to draw comparisons across countries.

The Scottish Learning Disability Observatory will be able to provide policy makers with the evidence and data required not only to take action on the basis of improved understanding but also to clearly demonstrate improvements from these actions.

Recommendation 9

That the Learning Disability Strategy Implementation Group will work with the Scottish Government to explore the development of a HEAT target for the NHS to establish a process whereby all adults with learning disabilities using health services are identified to Information Services Division and Scottish Learning Disabilities Observatory, so they can be visible in Scottish data systems by 2015.

Recommendation 10

That by 2015, the Primary Care Division of the Scottish Government and Scottish Learning Disability Observatory will work together to develop a process of annual reporting of trends in the management of the long term conditions of people with learning disabilities.

Recommendation 11

That the Scottish Learning Disability Observatory will work to develop a better understanding of the causes of unnecessary deaths of people with learning disabilities.

Recommendation 12

That by 2016 the Scottish Consortium for Learning Disability, local authorities and the Scottish Learning Disabilities Observatory will work in partnership to provide information to Information Services Division and Analytical Services Division of Scottish Government, to identify by unique NHS numbers the adults with learning disabilities using social work resources.

Health Inequalities

Poor health can result from social isolation and deprivation. Many people with learning disabilities have experienced lifelong exclusion resulting from lack of choice and opportunity as well as experiencing significant barriers to access. People with learning disabilities are more likely to be exposed to common causes of poor health such as poverty, poor housing, and lack of employment, social isolation and discrimination.

Many people with learning disabilities experience limited verbal communication skills which impacts on others' ability to understand health needs. Both paid and family carers play an important role in

identifying health needs. Many people with more severe learning disabilities rely completely on others to communicate what their health needs are.

Communication difficulties are fundamental to explaining many of the barriers and poorer outcomes people with learning disabilities experience when using health services. Many healthcare workers have never had training in the kind of communication methods and techniques that facilitate appropriate access to services. In addition many healthcare professionals rely on individuals reporting symptoms and ill-health.

The National Needs Assessment outlined a range of barriers faced by people with learning disabilities in accessing services, including physical barriers, failure to make reasonable adjustments and negative attitudes and values from practitioners.

During 2008, as part of the on-going commitment to the quality improvement process the Scottish Government asked NHS Quality Improvement Scotland (Now Health Improvement Scotland) to undertake a national review of all general health services against Quality Indicators 2 and 3, Promoting inclusion and well-being and Meeting general healthcare needs. This work was completed in 2009 with the publication of a national overview report¹⁶. Despite varied practice across Scotland, progress was noted, with local examples of good practice and service developments that have improved access to general healthcare.

Many factors influence an individual's health and health choices. People with learning disabilities experience challenges maintaining good health because of a combination of factors, such as:

- Individual factors, for which services require to make reasonable adjustments, for example, communication needs; many co-occurring health needs; distinct health needs and low expectations of services.
- Health and social care service factors, such as: negative assumptions; inexperience and lack of knowledge; lack of experience and acknowledgement of the contribution of family and paid carers.

¹⁶ Tackling indifference Report 2009

http://www.healthcareimprovementscotland.org/previous_resources/performance_review/tackling_indifference.aspx

- Service structures, such as: inflexible and short appointments; over reliance on literacy skills; poor communication and information exchange.

Scottish Government Health Inequalities Funding

To tackle the on-going challenge of reducing the health inequality gap faced by people with learning disabilities, the Scottish Government has offered additional financial support to help NHS Boards build on the work that has been on-going since 2008 when *Equally Well*¹⁷, the report of the Ministerial Task Force on Health Inequalities, was launched.

This funding programme, from 2012-2015, will enable NHS boards and their partners to address the health inequalities recommendations arising from the evaluation of *The same as you?* and this new national strategy, as well as continuing to address the health inequality gap within the *Equally Well* report. The resources will be provided to create capacity in each area to scope and define service change, including improvements to information and partnership working between health boards which will ensure a better use of resources.

The Learning Disability Health Inequalities Network comprises of representatives from all NHS Boards and is facilitated by the Scottish Government. The Network meets on a quarterly basis to further enhance the sharing of ideas and services to avoid duplication of effort and ensure the best use of resources.

Recommendation 13

That Learning Disability Strategy Implementation Group will work with NHS National Services Scotland (National Information Systems Group) to ensure that both the Emergency Care Summary (ECS) and the Key Information Summary (KIS) meet the information needs of people with learning disabilities accessing health care.

Recommendation 14

That the Learning Disability Strategy Implementation Group will work with Healthcare Improvement Scotland to undertake a review of the Learning Disability Quality Indicators and Best Practice statement to ensure that they reflect the changing needs of people with learning disabilities. A review of general health services and

¹⁷ <http://www.scotland.gov.uk/Publications/2008/06/25104032/0>

specialist learning disability health services will be undertaken across NHS Scotland to ensure that there is full compliance with Learning Disability Quality Indicators and Best Practice statement on Promoting access to healthcare for people with learning disabilities.

Healthy Lifestyles – Prevention and Self Help

There is an increasing focus on health improvement activity for the general public around nutrition, physical activity, smoking, alcohol and drugs, cancer screening programmes and immunisation programmes¹⁸ which benefit the health of the citizens of Scotland, including people with learning disabilities. This section identifies a number of ways in which people can either avoid compromises to their health or slow up any potential deterioration. But we also know that many people with learning disabilities have fewer opportunities to make choices and decisions that impact on their health and wellbeing. Access to health improvement activity involves a range of service providers, with family and paid carers having an important role to play. Effective health improvement education must consider the wider context of individuals' lives.

Diet

Many people with learning disabilities are aware of healthy eating messages. However, it has been reported that less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet¹⁹. Carers can sometimes be unaware of the public health recommendations on healthy diets²⁰. It has also been reported that many people with learning disabilities face challenges with weight. Many more people with learning disabilities are likely to be either underweight or overweight than the general population²¹. In particular women with learning disabilities and individuals with Down's syndrome are at more risk of obesity.

¹⁸ NHSScotland Chief Executive's Annual Report 2011/12
<http://www.scotland.gov.uk/Publications/2012/11/5027>

¹⁹ Robertson J., Emerson E., Gregory N., Hatto C., Turner S., Kessissoglou S., and Hallam A. (2000) Lifestyle Related Risk Factors for Poor Health in Residential Settings for People with Intellectual Disabilities. *Research in development disabilities* **21**, 469-486

²⁰ Melville C., Hamilton S., Miller S., Boyle S., Robinson N., Pert C., et al. (2009) Carer Knowledge and Perceptions of Healthy Lifestyles for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* **22**, 298-306.

²¹ Ibid

Obesity

Obesity is a major public health concern, and the prevention and management of obesity is a priority for health care in Scotland. This is because obesity is associated with a reduced life expectancy, and strongly linked to chronic health problems, such as diabetes and cardiovascular disease.

The Scottish Government has funded Edinburgh Napier University to provide information on people with learning disabilities who have diabetes. The project will set out proposals relating to the prevention and management of diabetes in people with learning disabilities in Scotland.

Children, young people and adults with learning disabilities experience very high rates of obesity. The increased rates of obesity in children with learning disabilities, compared to children who do not have learning disabilities, are already present by the age of three years old. Adults with learning disabilities aged 16-24 experience higher rates of obesity than adults over 50 who do not have learning disabilities.

This increased prevalence and early onset of weight problems highlight the importance of reducing obesity to the health of individuals with learning disabilities clinical guidelines are clear about the types of weight management interventions and services that should be offered to people with obesity. However, there is a lack of evidence about what works for children, young people and adults with learning disabilities and obesity.

This means that in many areas people with learning disabilities and obesity find it difficult to access weight management services. To address this inequality, the Scottish Government has funded several pilot studies to develop evidence about the best ways to help individuals with learning disabilities manage their weight problems, and make healthier lifestyle choices.

Weight management for adults with learning disabilities and obesity

TAKE 5 is a multi-component weight management programme based on best practice recommendations in the SIGN clinical guidelines. Development of the TAKE 5 programme came about through partnership working between the University of Glasgow, the Glasgow and Clyde Weight Management Service, and NHS Greater Glasgow and Clyde learning disabilities services. This work has been funded by the Scottish Government. The evidence is that the TAKE 5 programme is an

acceptable and effective way for adults with learning disabilities and obesity to lose weight and improve their health and wellbeing.

Case study

When Frances took part in the TAKE 5 pilot project she was 54 years old. Her weight problems were causing pain in her knees and she had to take medication to control her diabetes. The TAKE 5 worker helped Frances, and the paid carers supporting her, to find ways to change her diet and gradually increase how much exercise she was taking. To lose weight, Frances set her own goals and regularly monitored her weight. She followed a personalised diet that aimed for an energy deficit of 600 kilocalories a day. Frances also used a pedometer to help her slowly increase how much walking she was doing. The TAKE 5 worker provided training to the paid carers to help them support Frances lose weight. By the end of the three month weight loss phase, Frances had lost over 5% of her initial body weight. Her knees were no longer painful when she walked and Frances's GP decided she no longer needed medication to control her diabetes. The TAKE 5 worker continued to see Frances once a month to provide support and advice about long term weight loss maintenance. One year after taking part in the TAKE 5 pilot project, Frances has kept the weight off, feels good and is confident about managing her weight.

Exercise

Physical inactivity is one of Scotland's major health challenges, contributing to nearly 2,500 deaths in Scotland each year.²²

There are well recognised barriers to exercise ranging from physical barriers and attitudinal barriers to support barriers. There is a strong message that people with learning disabilities view opportunities to exercise in the context of wider social factors such as the opportunity to develop friendships. Enabling people to make positive choices about their lives may prove a successful strategy in improving physical activity levels, as seen in the development of the 'You Can Do It!' DVD produced by SCLD²³.

Doing more physical activity and reducing the amount of time we spend sitting down can have a big effect on health and wellbeing. The Scottish Government has set physical activity targets for children and adults in

²² NHSScotland Chief Executive's Annual Report 2011/12
<http://www.scotland.gov.uk/Publications/2012/11/5027>

²³ Scottish Consortium for Learning Disabilities (2011). You Can Do It! DVD, Paper Bag

Scotland, and there are lots of initiatives to help people to get more active.

Many children and adults with learning disabilities do not have much opportunity to participate in physical activity. Instead, people with learning disabilities often have sedentary lifestyles. For example, children with learning disabilities spend 85% of each day sitting or lying down and a study in Glasgow found that, on average, adults with learning disabilities walk for around 15 minutes a week. These levels of inactivity cause health problems, such as heart problems or diabetes. Therefore, it is important that children and adults with learning disabilities are supported to become more active.

There are many projects in Scotland aimed at getting children and adults with learning disabilities to become more active. Everyone likes doing different types of activity so it is important that a range of opportunities is on offer. There are school-based projects to help children with learning disabilities become more active, leisure centres are finding ways to make their services more inclusive and community groups are supporting people to do more walking. Walking is a great way to become more active. Even walking for an extra 10-20 minutes a day has positive effects on health and wellbeing.

Dancing is also a fun way to be active and, with Scottish Government funding, a group of adults with learning disabilities made a dance DVD with Glasgow City Community Health Partnership²⁴.

Case study

In March 2012, the Scottish Government funded NHS Ayrshire and Arran to work in partnership with Trust Rugby International to develop an integrated rugby 7's team.

Having attended a taster session in June 2012, player C showed the appearance and physicality of an athlete, he attended the gym and other activities and had a strong desire to compete. Emotionally he was very excitable; he would let his emotions build uncontrollably to the extent of screaming when a simple request of 'give me the ball' would have been sufficient.

In the initial stages, a direct coaching approach had to be adopted to educate him that his behaviour was inappropriate at times. The challenge for the coaches came with meeting his needs and balancing that with the diverse needs of the rest of the group.

²⁴ http://www.chps.org.uk/content/default.asp?page=s619_34_1

Six months later, player C is now one of the cornerstones of the group; his fitness level is rising each week by being challenged in rugby conditioning activities. The biggest shift is with him taking personal responsibility for his emotional outbursts. He is also taking some personal responsibility asking for support to address his own nutritional needs - in his own words 'I want to change the food I want to eat'. His skill level has improved continuously over the 6 months, including his hand eye co-ordination, his speed and agility and game awareness. He has learned that it is a team game and he is now a team player in every sense.

Smoking and Drinking

People with learning disabilities are less likely to smoke or drink than the general population. However some do smoke and drink at levels which can be harmful to health²⁵. This highlights the need for accessible health improvement initiatives across health services that enable people with learning disabilities to make healthy lifestyle choices in their own home.

Good practice

During 2012 the Scottish Government funded the Inverclyde Learning Disability and Alcohol Project. The project aims to develop an evidence-based pathway in order to prevent harm from alcohol use in people with learning disabilities in Inverclyde. The project will work with people with learning disabilities to understand the issues associated with alcohol use. The project will develop an appropriate screening tool to detect hazardous and harmful use of alcohol in people with learning disabilities, develop health improvement packages to raise alcohol awareness and develop a pathway for those with harmful and dependent drinking.

Good quality general health support in the community

There will come a point where people with learning disabilities, like all citizens, will need health support beyond self-care. The literature on the health needs of people with learning disabilities in Scotland was outlined in the National Needs Assessment in 2004. We know that the majority of people with learning disabilities live in the community and have the right to access general health services provided by a wide range of

²⁵Lawrence M., Kerr S., Darbyshire C., Middleton A., Fitzsimmons L. and Watson H. (2009) Tobacco and Alcohol Use in People who have a Learning Disability: Giving Voice to their Health Promotion Needs. The Queens Nursing Institute

specialists, including GP's, practice nurses, district nurses, community pharmacists and many others.

Strengthening the commitment²⁶, which is a report of the UK Modernising Learning Disabilities Nursing review, recommended learning disability nurses should be supporting access to allow people with learning disabilities to receive care and treatment from general healthcare practitioners.

However, despite community health services being the most appropriate services to meet the general health needs of people with learning disabilities, many health specialists, including GPs, receive little training, if any, on the needs of people with learning disabilities.

To tackle the complex issues of multi-disciplinary and multi-agency training and effective joint working the Scottish Government funded NHS Western Isles to establish a Learning Disabilities Collaborative. Its purpose was to improve services so as to recognise and meet the needs of people with learning disabilities more effectively. This was achieved, in part, through training and education. eHealth and care systems to support patient pathways were also improved. Most importantly, the work of the project has been designed to ensure that all the changes and developments achieved over the duration of the project are sustainable and integrated into standard practice.

Recommendation 15

That the learning from the NHS Western Isles Collaborative is formally evaluated and its findings disseminated throughout Scotland through a Best Practice Conference to be led by NHS Western Isles and the Scottish Government in 2013. Application of the model to other areas of Scotland will be considered by 2014.

Information and advice

To get the most benefit from what is available they will need good information. Which is why NHS 24 Helpline staff²⁷ have been trained to be aware of the need to communicate effectively with callers with learning disabilities. In addition, NHS Inform²⁸ provide details of all pharmacies, GP practices and dental practices in Scotland. They can

²⁶ <http://www.scotland.gov.uk/Resource/0039/00391946.pdf>

²⁷ <http://www.nhs24.com/>

²⁸ <http://www.nhsinform.co.uk/>

also provide information about illnesses and conditions, treatments, NHS services and other support services. Within this public information system there is now an Easy Info Zone²⁹ that provides online information on health conditions, tests and treatments and wellbeing in easily accessible language to enable people with learning disabilities to be better informed.

Recommendation 16

That by 2014 the Easy Info Zone of NHS Inform is publicised to ensure that people with learning disabilities and their families and carers can benefit from its use.

Health checks

Health screening programmes for the whole population across Scotland have consistently been shown to be poorly accessed by people with learning disabilities, including: Cervical Smear Tests; Breast Screening; Dental check-up, epilepsy checks and Sensory Impairment assessments.

This low uptake of health screening services may be due to the many access barriers which people with learning disabilities experience. The much higher level of health need experienced by adults with learning disabilities compared with the general population, and the very high level of unrecognised and unmet health need, provides overwhelming evidence to support health screening programmes (health checks) specifically for people with learning disabilities.

Health checks have been widely endorsed as the way forward to reduce the current high level of unmet health need and health inequalities experienced by people with learning disabilities, in Scotland, and more widely in the UK and internationally. Studies of health checks have shown benefits in disease detection and health promotion. The NHS Greater Glasgow & Clyde health check programme was evaluated after its first year of implementation. A high level of health need was detected and met. Health economic evaluation demonstrated that it was a cost effective intervention to deliver, with lower overall costs of health care and supports for those who received a health check compared to those who did not.

²⁹ <http://www.nhsinform.co.uk/Easy-Info>

Recommendation 17

That the Learning Disability Strategy Implementation Group will work with the Scottish Learning Disability Observatory to establish and implement a targeted health screening programme for people with learning disabilities across NHS Scotland.

Good practice

NHS Lanarkshire has developed a range of resources that can equip people with learning disabilities and /or their carers (paid or unpaid) and health professionals with skills and knowledge necessary to facilitate positive health outcomes by making accessible to them national screening programmes and where necessary appropriate follow up treatment or investigations.

NHS Lanarkshire's Learning Disability Service worked with members of Lanarkshire Ace, Speak Out Advocacy and many others to develop a range of resources: Total Communication Aide (distributed across GP Practices, Acute hospitals, care providers, school nurses, relatives and carers); and five DVD's (How to check your Boobs, How to check your Balls, Going for a cervical smear, Going for a prostate exam and Bowel screening). These are available in Public Libraries and GP Practices. Twenty one easy read leaflets/booklets were also developed. All these resources are available on website www.healthelanarkshire.co.uk

Dentistry

One in three people with learning disabilities has unhealthy teeth and gums. This increases to four out of five for adults with Down's syndrome³⁰. This may be due to poor diet, poor dental hygiene, co-occurring health conditions and because oral health promotion may not always be accessible to people with learning disabilities. They may also fear dental treatment and, in some cases, will require general anesthetic in a hospital setting to resolve matters.

Dental health improvement strategies for people with learning disabilities, family carers and paid carers are of key importance to address dental health. This is why the National Oral Health Improvement Strategy³¹ for priority groups is critical. This makes clear that an oral care plan should be developed according to the assessed needs of the

³⁰ Barr O., Gilgunn J., Kane T., Moore G. (1999) Health Screening for People with Learning Disabilities by a Community Nursing Learning Disability Service in Northern Ireland. *Journal of Advanced Nursing* 29, 1482-1491.

³¹ National Oral Health Improvement Strategy for Priority Groups. Scottish Government, May 2012 <http://www.scotland.gov.uk/Publications/2012/05/7031/0>

individual. This should incorporate oral hygiene, care and treatment needs. It will be important for people with learning disabilities that the use of general anesthetic is given particular and careful consideration.

For those who are carers, the effects of a lack of attention to oral health may not always be obvious without training. The National Oral Health Improvement Strategy for priority groups recommends that:

- the Salaried Dental Service and oral health promotion teams should play a lead role in the delivery of training to staff with responsibility for caring for dependent people and those with special needs.
- training for care home staff should be undertaken as part of an ongoing programme and should be based on an appropriate training tool such as "Caring for Smiles" which was developed for this purpose.
- all care home staff, including managers, should attend training on the delivery of day to day oral healthcare to residents.
- oral health champions should be identified to promote ongoing awareness of oral health issues within the care home setting. Such individuals should attend ongoing training to support their role.

Recommendation 18

That by June 2014 all professionals working with those with learning disabilities take responsibility for assisting with implementation of the National Oral Health Improvement Strategy by promoting it at local level with individuals, carers and relevant others.

Epilepsy

People with learning disabilities who have epilepsy should, where appropriate, access the same epilepsy services as the general population. However, it is widely recognised that there are features of epilepsy presentation and management in learning disabilities which negatively affect access to, and treatment by, these largely hospital based outpatient services. Current services for the management of epilepsy in people with learning disabilities involve multiple agencies including hospital neurology services, epilepsy nurse specialists, community learning disability teams, general practitioners and practice

nurses. As well as leading to confusion about who should take the lead in managing an individual's epilepsy, there is also a lack of specialism and expertise amongst the professionals involved. SIGN 70³² states that subspecialty clinics should be available to meet the needs of specific groups such as people with learning disabilities and that a multidisciplinary approach to treatment is delivered by professionals with an expertise in epilepsy.

Recommendation 19

That by June 2015 all NHS Boards should ensure that people with learning disabilities that have complex epilepsy have access to specialist neurological services, including access to learning disabilities epilepsy specialist nurses and learning disabilities psychiatrists (where applicable).

Sensory Impairment

The term sensory impairment describes the varying degrees of hearing loss and sight loss as well as loss of both senses. Both hearing and sight loss can be present from birth, but for many people a sensory loss will occur later in life, and the longer a person lives the more likely they are to develop either or both losses.

Action on Hearing Loss estimate that there are 850,000 people with a hearing loss in Scotland and expect that this figure will double in the next 20 years. RNIB Scotland estimate that there are over 180,000 people in Scotland with significant sight loss. It is estimated by DeafBlind Scotland that there are 5,000 people in Scotland with dual sensory loss.

The Scottish Government is committed to addressing these needs for all people with a sensory impairment through the publication of See Hear which lays out a strategic framework that will be adopted at local level by health and social care agencies. A critical component is the development of local care pathways based on self-evaluation which will include recognition of the needs of people with learning disabilities.

The report recognises that people with learning disabilities are more likely to have a hearing loss and are 10 times more likely to have a sight loss. This can have a profound impact on how they are understood and are able to interact with others. Someone with communication

³² <http://www.sign.ac.uk/pdf/sign70.pdf>

difficulties, as someone with learning disabilities may have, might demonstrate challenging behaviours if they are unable to communicate a hidden and undiagnosed sensory loss.

Good practice

The Scottish Government provided funding to RNIB Scotland to produce the Bridge to Vision training DVD for optometrists and dispensing opticians who work with people who have learning disabilities.

The Audiology Services Advisory Group, which informs and monitors audiology services across Scotland, produced guidance that enables audiology service providers to respond appropriately to the audiological needs of people with learning disabilities³³.

Recommendation 20

That health and social care professionals apply the local See Hear policy to people with learning disabilities and their families and carers.

Recommendation 21

That work is commissioned in 2013 to understand and analyse the factors that promote person-centred care and individualised health outcomes for people with learning disabilities to ensure that they receive the same investigations and treatments as the general population and that reasonable adjustments are made by 2015 to achieve the same health outcomes.

The role of the GP

The same as you? evaluation³⁴ established that access to good primary care, especially having a doctor who understood their needs, was essential in improving the general health of people with learning disabilities.

NHS Health Scotland has also published tip cards³⁵ which are a quick, easy-to-use resource to help NHS staff know what to do to support disabled people.

³³Guidelines for meeting Audiological Needs of Adults with Learning Disabilities. NHS Scotland 2009 www.scotland.gov.uk/Resource/Doc/924/0092407.doc

³⁴ <http://www.sclid.org.uk/SAYevaluation>

³⁵ <http://www.healthscotland.com/uploads/documents/5809-Updated%20Tip%20Cards%20-%2031.01.08.pdf>

The GP contract in Scotland should reflect the differing health needs of people with learning disabilities as well as seeking to ensure inclusion in all areas of the Quality Outcomes Framework relevant to the general population. For example, Practices are required to maintain a register of adults with learning disabilities.

In addition, the Scottish Government introduced a Directed Enhanced Service (DES) for services to adults with learning disabilities for 2006/7 and, in the Scottish Enhanced Services Programme (SESP) from autumn 2007. This meant that GPs flagged case notes so that people with learning disabilities were provided with longer appointments and were therefore better able to communicate their needs. Some areas took great care to communicate when an appointment was to take place in a medium that people with learning disabilities understood and this had the added bonus of reducing the number of defaulted appointments. As a consequence of devolved local autonomy to NHS Boards to allow for flexibility of delivery of SESP funding, this valuable support has only been sustained in three Health Board areas. There would be merit in re-introducing and extending this approach.

The role of primary care liaison support

NHS Greater Glasgow & Clyde have a dedicated liaison team of nurses who work with General practice to support the delivery of primary health care to all adults with learning disabilities. The learning disabilities liaison team was established to increase the capacity of primary care to develop inclusive, equitable, and responsive health services for adults with learning disabilities.

The team works with General practice and specialist learning disabilities services to deliver a multi-faceted programme of work, including offering proactive health checks; training for primary health care professionals, accessible information, responding to service access issues, advice on support infrastructures to primary care, and facilitation to health improvement and anticipatory care initiatives.

All GP practices are now required to complete a template about the health needs of their adult patients with learning disabilities and to arrange a meeting with their patients to do so. There is a very high uptake of this service by general practices (well over 90%). This dedicated team, working in partnership with General practice and specialist learning disabilities teams, ensures that there is a continued

focus on anticipatory care and targeted responses to meet the needs of people with learning disabilities.

As well as this, a robustly designed randomised controlled trial (RCT) of health checks for adults with learning disabilities has recently been completed in Scotland. People with learning disabilities who received a health check from their practice nurse were found to have received much better health care in the long term conditions that practice nurses are familiar with. However areas of ill-health that are more common for people with learning disabilities were found to be overlooked.

Some inflexibility within the practices was identified as a barrier to health check delivery. The health checks took less than an hour to complete. Initially, the nurses had been apprehensive about undertaking the health checks and some thought them unnecessary. However their opinions changed after the health checks, and they perceived them to be beneficial.

The adults with learning disabilities and their carers described enjoying having the health checks. The study is the first RCT of health checks conducted in primary care in the UK health care system. It provides the scientific evidence to support the view that health checks for adults with learning disabilities should be included within the GP contract, and also identifies areas where the health checks could be improved upon.

Recommendation 22

That by the end of 2015 all NHS Boards across Scotland should ensure there is a dedicated primary care liaison resource to support General practice and primary care teams to ensure their services are equitable and, where required, targeted for people with learning disabilities.

Recommendation 23

That the Learning Disability Strategy Implementation Group will work with the Primary Care Division of the Scottish Government to explore how the GP contract in Scotland can best meet the needs of people with learning disabilities, including the possibility of the reintroduction of an enhanced service for people with learning disabilities and including additional learning disability indicators in the Scottish Quality Outcomes Framework by June 2014.

Health in Hospital

Scotland has legislation in place to ensure that people with learning disabilities have equal access to the care and support they require. However too often practitioners are unaware of the need to comply and implement fully the legislation that is in place. The Disability Equality Duty requires that all services, including health services, make reasonable adjustments to ensure that the needs of individuals are identified and addressed, thereby avoiding disadvantage which in some cases may result in significant harm and avoidable premature death. Therefore all healthcare practitioners require to have a full understanding of legislation to ensure that they respond appropriately to the needs of people with learning disabilities, thereby removing discrimination.

People with learning disabilities require access to the full range of services provided by general hospitals. However several Fatal Accident inquiries (FAI) in Scotland have highlighted the significant barriers and risks many people with learning disabilities face when using general hospital services³⁶. Several studies have reported the difficulties experienced by people with learning disabilities during admissions to hospitals³⁷.

The main themes from these studies are problems with communication, lack of staff training and the negative attitudes of staff. In an attempt to address the risk to individuals and in response to the FAI findings, many health boards across Scotland have developed general hospital liaison services, staffed by specialist nurses trained in the needs of people with learning disabilities.

³⁶ NHS Quality Improvement Scotland, 2009

³⁷ Brown et al. 2012; Bradbury-Jones et al. 2013

Good practice

NHS Greater Glasgow and Clyde have developed a hospital information booklet. This is completed in advance of the person with learning disabilities being admitted to hospital and is presented to ward staff at the point of admission. It contains personal information to help staff understand the patient's needs better, such as what they prefer to be called, their likes and dislikes, and how they can be comforted when they are distressed.

Avoidable hospital admissions

People with learning disabilities are more likely to be admitted to hospital as an emergency than people who do not have learning disabilities, and many admissions may be preventable. The commonest causes for admission are convulsions, constipation, diabetes, influenza and epilepsy. Some of these admissions could have been prevented by care provided by community nurses and family doctors.

Use of Accident and Emergency Departments

High rates of accidents and injuries occur amongst people with learning disabilities. In particular, injuries due to falls are common. This may be attributable to increased rates of epilepsy, psychopathology, medication, sensory and neurological impairments and balance problems. Some injuries are attributable to problem behaviours such as pica, self-injury and destructive behaviours³⁸. Appropriate risk assessment and management could significantly reduce the morbidity from accidents and injuries.

Good practice

Work in NHS Lothian is well established to identify and support frequent attenders to receive the healthcare and support appropriate to their needs. Definition applied as a frequent attender: more than 5 visits in 3 months or more than 10 visits in any 12 month period.

Staff are automatically alerted through NHS Lothian IT alert system which will flag that someone has reached the trigger point. The individual's circumstances are analysed by Primary Care physician within A&E to determine any reasons for frequency. This results in a letter to the individual's GP alerting them. Where appropriate, through collaboration between the individual, the GP and the Primary Care

³⁸ NHS Health Scotland 'Health Needs Assessment Report – People with Learning Disabilities in Scotland' 2004

Physician, a care plan is developed. This has demonstrated:

- More appropriate attendance
- Appropriate admissions
- Appropriate investigations
- More appropriate management and support of vulnerable people.

Where this involves people with learning disabilities the Learning Disability Nurse Liaison Service works in partnership with the A&E Primary Care physician to ensure that the holistic needs of the people with learning disabilities are considered, and that, where appropriate along with the GP, the local authority, care agency and Community Learning Disability Team are engaged in reviewing the individual's needs, and informing the care plan. Quarterly meetings to specifically consider frequent attenders at A&E are attended by the Learning Disability Nurse Liaison service to provide learning disability expertise, and to ensure that all adult support and protection issues are fully considered with and for people with learning disabilities.

The same as you? said that the general healthcare needs of people with learning disabilities should be met in the same setting as the rest of the population. This is an appropriate but challenging aspiration given the co-occurring nature of need.

Co-occurring health needs have the potential to add risk to the lives of people with learning disabilities. The quality and effectiveness of health care given to people with learning disabilities has been shown to be deficient in a number of ways. Dependence on others for mobility and feeding in hospital is more prevalent among those with learning disabilities. Family carers of people with learning disabilities sometimes feel that health professionals do not listen to them.

Case study

In 2011 Edward was an inpatient in an acute care hospital. Edward was unhappy with some areas of the care and treatment he received during his admission. He decided to share his feedback with NHS staff to highlight and reinforce the importance of delivering person- centered care. Edward was invited to work with NHS staff to improve services. Edward worked with senior staff to develop a film interview of his experience. He also worked with the Scottish Consortium for Learning Disability to produce a learning and education resource³⁹. Edwards's hard work and dedication was recognised in 2012 when he was awarded

³⁹ www.bespoken.me/video/listen-to-me-edward-s-story

NHS Greater Glasgow and Clyde Chairman's Award in the category of Patient Ambassador.

Recommendation 24

That NHS Boards and local authorities across Scotland should work in partnership to ensure that people with learning disabilities receive the appropriate levels of support in general hospitals. This should include appropriately funded support from familiar carers as well as support from specialist learning disability acute care liaison nurses.

Recommendation 25

That by the end of 2016 NHS Boards should ensure that people with learning disabilities who attend acute care hospitals, including all medical and surgical specialties and accident and emergency departments, are identified and monitored to improve outcomes of hospital care and treatment, ensuring that health care is provided in the most appropriate setting.

Dementia

The population as a whole is experiencing increased longevity and this applies as much to people with learning disabilities as it does to the general population. Studies predict a 36% increase in the numbers of older people living with learning disabilities between 2001 and 2021 as a consequence of improving health and social care⁴⁰. This signifies that this group will encounter many of the conditions associated with ageing and this will include dementia.

Although studies vary, it is recognised that people with learning disabilities experience higher rates of dementia than the general population. Figures suggest that prevalence rates are 4 times higher regardless of the cause of learning disability and that onset of the condition is about 10 years earlier than in the general population⁴¹.

By contrast, people with Down's syndrome experience significantly higher prevalence rates and earlier onset of the condition is also

⁴⁰ Estimating Future Needs/Demand for support for adults with learning disabilities in England, Institute for Health Research, Lancaster University 2004

⁴¹ Kerr, D. Dementia in people with intellectual disabilities. Centre for Research on Families and Relationships .University of Edinburgh

reported at between 30-40 years younger than the general population⁴². It is also estimated that prognosis rates are poorer with an average of 5 years between diagnosis and death⁴³.

Diagnosis itself can be difficult with typical tests not being suitable for people with learning disabilities, baseline assessments not implemented universally and problems with detection of the early signs of the condition leading to delay in referral for diagnosis and therefore treatment. Differential diagnosis must be considered and is essential in establishing correct diagnosis and appropriate interventions⁴⁴.

Pain recognition and pain management is often over looked amongst people with learning disabilities and many with dementia will experience similar levels of pain as those with cancer⁴⁵. The Scottish Government Dementia Strategy⁴⁶ specifically highlights the increasing need of people who have learning disabilities and dementia and highlights that dementia care is a national priority for the government. As part of the second National Dementia Strategy we intend to undertake a specific piece of work looking at the need for national action around linkages between dementia and other disabilities and chronic conditions; and the need for national action around early onset dementia.

Everyone with dementia – including those with learning disabilities – are entitled to receive care, treatment and support in line with the Standards of Care for Dementia in Scotland⁴⁷. People with dementia and learning disabilities should receive a multi-disciplinary assessment of their care needs, including attention to removing any barriers to effective communication between the person with dementia and service providers. The Promoting Excellence dementia skills framework⁴⁸ – which is designed to help services meet the dementia standards - requires staff working at enhanced level and above to understand the potential impact of a diagnosis of dementia on people with learning disabilities.

⁴² Holland, A.J Hon, J. Hubbart, F.A., Stevens, V.F. Watson, P. (1998). Population based study of prevalence and presentation of dementia in adults with Down's syndrome. *British Journal of Psychiatry*. 172, 493-498

⁴³ Prasher, V.P., End Stage Dementia in adults with Down's syndrome. *International Journal of geriatric Psychiatry*, 1995. 10:p.3

⁴⁴ Kerr, D., *Understanding Learning Disability and Dementia. Developing Effective Interventions.* Jessica Kingsley Publishers London and Philadelphia 2007

⁴⁵ Regnard C, Mathews D, Gibson L, Clarke C. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing* 2003;9(4)173-176

⁴⁶ <http://www.scotland.gov.uk/Publications/2010/09/10151751/17>

⁴⁷ <http://www.scotland.gov.uk/Publications/2011/05/31085414/0>

⁴⁸ <http://www.scotland.gov.uk/Publications/2011/05/31085332/0>

There is a need to recognise that dementia is a life limiting condition and that it should be approached with a focus on palliative care with partnership and coordination between both learning disability and palliative care services.

Palliative Care

Life limiting illness is more prevalent in the learning disability population with an estimated 61% of people with learning disabilities living with a specific long term illness or additional disability⁴⁹.

People with learning disabilities are less likely to access specialist palliative care than the rest of the population⁵⁰. In addition, people with learning disabilities are less likely to be informed of a diagnosis of a life-limiting or threatening illness or condition or given indications of prognosis, compared to the general population, and they are rarely encouraged to explore sensitive issues such as loss, death and dying^{51 52}. Furthermore, evidence suggests that many people with learning disabilities will not have their pain recognised or sufficiently managed as a consequence of the same factors that affect equity in accessing healthcare. Many now experience periods of increasing frailty, organ failure, cancer and dementia as well as other life-limiting conditions. It has been reported that people with learning disabilities encounter all of the major life-threatening diseases at least 5-10 years earlier than the rest of the population and that the time frame for survival is poorer⁵³. Consideration also needs to be given to the increasing numbers of infants surviving the neonatal period due to advances in medical care. Many are surviving not just infancy but into childhood and adulthood with multiple disabilities and complex health needs requiring palliative care⁵⁴.

With increasing numbers of people with learning disabilities requiring continuing care and support it is vital that we recognise that the skills

⁴⁹ Summerfield C, Gill B. Social Trends 35. London: Office for National Statistics, 2005.

⁵⁰ Gunaratnam Y, A briefing paper for managers and trustees. Widening Access to hospice care November 2000

⁵¹ Tuffrey-Wijne I. Living with learning disabilities, dying with cancer: thirteen personal stories. London. Jessica Kingsley 2010

⁵² Tuffrey-Wijne I. How to break bad news .To people with intellectual disabilities .A guide for carers and professionals. London.Jessicaa Kingsley 2013.

⁵³ Disability Rights Commission(DRC).Equal treatment:closing the gap-A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems.London:DRC, 2006.

⁵⁴ Institute for Health Research. Estimating Future Need / Demand for Support for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University ,2004.

and knowledge of health and social care staff will influence the overall experience of the individual, carers and family.

It is therefore becoming increasingly important to grasp the significance of palliative care across the age range of people with learning disabilities who have life- limiting or life- threatening illness or conditions.

It is only through inclusion, education, by making reasonable adjustments and developing robust partnerships that lead to collaborative working that people with learning disabilities will experience equity in accessing palliative care services.

In order to move forward improvements in care for people with learning disabilities who have palliative care needs it is crucial that there is a commitment to partnership working between Palliative Care and Learning Disability services⁵⁵. The array of unmet learning needs experienced by both specialist services can be addressed through joint working and learning.

Case study

An example of such partnership working is the ongoing project Learning Disabilities and Palliative Care-Building Bridges: Supporting Care which is hosted by The Prince and Princess of Wales Hospice in Glasgow and jointly led by two senior practitioners from learning disabilities and palliative care services. Key practitioners have been identified from both learning disability and palliative care services and meet regularly to develop skills, knowledge and confidence within a framework of partnership and collaborative working. The development of a care pathway, underpinned by evidence based practice, to promote the delivery of appropriate and high quality palliative care for people with learning disabilities is fundamental. A care pathway (currently being developed) aims to support practitioners across all settings including learning disability services, social care, primary care, secondary care and specialist palliative care services as well as other contributors.

⁵⁵ National End of Life Care Programme. The Route to succeed in the end of life care-achieving quality for people with learning disabilities. London :National End of Life Care Programme

Recommendation 26

That the Glasgow palliative care pathway is evaluated and rolled out nationally by 2015 to improve the care outcomes for patients with learning disabilities.

Bereavement and Loss

It is important that a strategy on learning disabilities takes into account the experience of grief following the death of someone close. Loss can be a very painful, complex and confusing mix of experiences for someone with learning disabilities⁵⁶. Some believe, however, that people with learning disabilities lack the capacity to understand complex concepts such as death and loss, which results in a lack of social recognition of the pain they are experiencing.⁵⁷ It is important that paid carers and professionals are educated in recognising and supporting people with learning disabilities who have been bereaved.

Each person with learning disabilities is an individual and will grieve as an individual. It is important not to make assumptions about grief, rather to think about what will be helpful for each individual. The person with learning disability may experience two or more major life changes in a very short time. If these changes occur in addition to loss, this may make the grieving process very difficult for the bereaved person. In addition, a number of factors can affect how someone responds to bereavement: the nature of the relationship, the circumstances around the death and the person's ability to understand and communicate.

Cultural aspects, religious and spiritual beliefs, will also impact the grieving process. Finally, existing mental health issues may further complicate grief.

Without sufficient support, people with learning disabilities do not cope well with grief. In supporting a person who is grieving, it is important to remember that grief is normal - when someone has been special to us, their death leads to a range of feelings all of which are normal.

It is also important to remember that grief can also produce physical symptoms. An understanding of the person's use of communication can help to identify how best to explain the death. This part of the process is

⁵⁶ Oswin, M. 1991. *Am I Allowed to Cry? A study of bereavement amongst people who have learning difficulties*. London: Human Horizons

⁵⁷ Doka, 2002 *Living with grief: loss in later life*. Hospice Foundation of America

important because people with learning disabilities do experience change and an explanation is necessary. People with learning disabilities may already find change very difficult. A loss will inevitably cause major changes in the person's relationships and surroundings. A process of planning for a change may be helped by considering the transitions that might take place following a loss, these also include anticipating difficult times (e.g. anniversary of loss, Christmas). In supporting people with learning disabilities who are experiencing grief it is important that they are listened to and have their experience acknowledged and validated.

Giving the person opportunities to talk about the loss can reassure them that their experiences are normal. In addition, there needs to be a wider recognition of the importance of attending rituals of remembrance for people with learning disabilities, - for example, attending the funeral.

Support from others is crucial to the person's ability to accept the reality of the loss, experience the emotions that come with loss, adjust to life without the person and find an enduring connection with them.

Independent living



Escape

Escape harm

shift

Cultureshift

Control

In control

Alter

Alter attitudes

Enter

Enter partnerships

End

End health inequalities

home

Come home

Delete

Delete discrimination

Independent living

The Independent Living in Scotland project describes independent living as ‘disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not 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’⁵⁸.

When SCLD conducted a survey of around 600 people with learning disabilities, called ‘How is it going?’⁵⁹ they described some of the positive and negative aspects of trying to achieve independence. On the positive side, almost 75% of people thought that they had enough opportunities to do the things that they wanted to with their lives. 80% of those surveyed thought there were enough places which they really liked going to in their area.

Many people with learning disabilities enjoy sport and creative arts which take place out with the day centre environment. Activities which centre on people’s hobbies and interest include bowling, swimming, golf, the gym, horse-riding, photography, drama and art. These activities are important to people with learning disabilities as they have opportunity to meet friends and be part of the local community. Community activities provide great benefits to the health and wellbeing of people with learning disabilities and this improves their quality of life.

However, the same survey also identified 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, a lack of appropriate facilities or inaccessible buildings.

So there is still some way to go in enabling people with learning disabilities to live independent lives.

Good practice

Indepen-dance is an inclusive dance development company offering creative movement classes to people with diverse abilities, their carers,

⁵⁸ <http://www.scotland.gov.uk/Publications/2013/04/8699>

⁵⁹ How is it going? Curtice 2006, SCLD Glasgow

family members and volunteers. Throughout the year, the company performs work of high artistic quality created in collaboration with professional choreographers and dancers. Independence enables individuals with diverse abilities to participate in and benefit fully from a high quality arts provision.

As strong believers in an inclusive approach, all activities are offered to people with and without disabilities. Providing everyone with the opportunity to learn from each other and share a creative experience.

The Independent Living Programme, a partnership of Scottish Government, COSLA, NHSScotland and the Scottish Coalition for Independent Living, promotes and supports the need for change and to make things better for disabled people. The partners of the programme signed a revitalised shared vision statement in March 2013⁶⁰.

Mitigating the effects of UK Welfare Reform

The economic downturn continues to have serious impacts across Scotland, with levels of debt and financial problems remaining high, and people still finding it difficult to manage in a new and complex economic and jobs market.

At the same time, the UK social security system is going through the biggest process of reform since its inception, with changes being made to multiple benefits at one time, both in terms of the structure of benefits and the means by which they are administered. These reforms bring with them radical changes to the way that people on low incomes will need to manage their finances, at a time when day to day living costs are rising.

While simplification is a core objective of the UK Government's reform programme, transition from one statutory framework to another presents a number of different needs for information, advice and representation for individuals affected. The scale of change also means that demands for help are likely to increase for all advice and information providers.

The Scottish Government is developing a Scottish-specific response to the challenges this will create for people as well as the additional pressure it may place on organisations which are in place to assist them. It is working with local authorities in respect of the impact of welfare reform on their services and future plans for administration and access

⁶⁰ <http://www.scotland.gov.uk/Publications/2013/04/8699/1>

to social security benefits. It is also directing new money to agencies helping people facing the brunt of UK benefit cuts. This will include:

- Immediate cash injection of £300,000 for services such as those provided by Citizens Advice Scotland (CAS)
- Setting up a new £1.7 million fund providing direct support to advice services
- A further £3.4 million to be spent over the next two years on helping organisations mitigate the impact of welfare reforms.

A particular concern is the decision to close the Independent Living Fund (ILF) permanently from April 2015 which included responsibility and finances being devolved to the Scottish Government instead. The Scottish Government will launch a consultation to seek views on any potential new administrative arrangements for distributing the resource in Scotland following the ILF's closure. The consultation and the development of this policy will be taken forward within the principles of this strategy.

Day Opportunities

The same as you? encouraged local authorities to review their day care services. It said that the role of day centres should change to increasingly become resource centres. It proposed that nobody should go to a day centre full-time, and instead should use it as a base to identify and participate in activities in the wider community. It promoted that day centres or support services should become more community focused by helping people with learning disabilities to access continuing education and development, real jobs, achieve their desired outcomes and become more involved in their communities.

The past 13 years has seen a considerable change in the way day services are delivered, and it is clear that most local authorities and their partners have embraced the vision set out in *The same as you?*. A range of models are now in place across Scotland, some of which involve little or no contact with day centres, and others that involve an appropriate balance of centre-based and community activities.

There has been a gradual decline in the number of people with learning disabilities attending day centres, from 8,300 in 1998, to 6,164 in 2011. This has been accompanied by an increase in the number of adults with learning disabilities getting alternative day opportunities. In 2011, 10,286 people accessed alternative day opportunities and 65% of this

group (6,695) did not use day services at all. 1,400 people with learning disabilities still attend day services 5 days a week. This includes people with profound learning disabilities and complex needs for whom there are limited options available to access alternative day opportunities.

The key point to note from the evidence is that day services are now much more person-centred and based around the assessed needs and wishes of people with learning disabilities themselves, taking into account the views of their carers.

The introduction of the Social Care (Self-Directed Support) (Scotland) Act in 2014 will see individuals and their carers increasingly taking control and making their own individual day caring arrangements. Across Scotland we already see many examples of highly individualised care packages, including people using direct payments, which do not involve buildings-based day care, and it is expected that Self-Directed Support will result in the number of people attending day services reducing further.

However, it is clear that for many people, day opportunities will continue to play an important part in the overall support arrangements. In terms of the future and ongoing development of day opportunities, local authorities and their partners should aim to have in place arrangements for individuals to access a comprehensive network of day services and resources that meet needs across the spectrum of learning disabilities.

It is recognised that for people with more complex needs and people with profound and multiple learning disabilities, day centres will continue to be an important part of their overall support arrangements. However, it is essential that services and staff continue to develop person-centred approaches that enable people to make choices and follow activities that are meaningful to them. In this context, services should continue to make progress towards community-based models of care and to support people currently dependent on buildings-based care to graduate into alternative opportunities.

The goal for many people with learning disabilities should be employment and meaningful activities. Day services can support people towards this goal through social and life skills development, and providing people with an environment in which they can directly experience the workplace and learn how to cope and thrive in this setting. This will require staff in day services to liaise closely with colleagues in further education, training and supported employment to

design programmes which enables individuals to gain skills and progress to the level they are capable of achieving.

Another important aspect of day services is the opportunity to achieve better health outcomes. Providers of day opportunities across the spectrum of needs should therefore work closely with their local health colleagues to agree actions to improve health, identify underlying health issues, and take early action to address problems. In Renfrewshire, for example, specialist learning disabilities nurses undertake health checks on adults attending a day centre for people with profound and multiple learning disabilities and provide advice for staff on effective management of health conditions.

Good practice

Where day services are located is also of importance in maximising opportunities for social integration and for achieving health benefits. South Lanarkshire and Renfrewshire Councils, for example, have both invested in new day centres based entirely within their council leisure centres. Not only has this resulted in more people with learning disabilities becoming part of the wider community, but has also achieved the positive outcome of easy access to healthy activities such as swimming and sports. In both councils, there is the added benefit of encouraging the wider public to make use of the day services resources including sensory room, dance studio and music room, thus breaking down barriers traditionally associated with learning disabilities.

Recommendation 27

That by June 2018 the Scottish Government in partnership with local authorities, the Third Sector and people with learning disabilities and carers review and further develop day opportunities that are person-centred, assets-based and values driven and that take account of staffing, education, employment and transport issues.

Housing

A good quality home is at the heart of independent living. A home which provides them with the right type of house, in the right location, is a key requirement for those who need care and support to be able to live their lives to the full.

The great majority of people, including those with learning disabilities, already live in ordinary housing – not in hospitals or care homes – and

this is where they want to stay. The need for quality housing and housing services will become more important over the next decade as a result of both the increase in the number of older people and the long standing policy objective of the Scottish Government to shift the balance of care still further away from institutional settings. It will also be important to mitigate the effects of welfare reform on those who use social housing. This is why the Scottish Government is providing an extra £2.5 million to social landlords to ensure there is advice on hand for people who will lose housing benefit due to the under-occupancy measures and other housing benefit changes being introduced by the UK Government.

Local Housing Strategies

The same as you? consultation identified a number of key issues to be taken into account in the planning and delivery of housing for people with learning disabilities. The consultation feedback also showed that one size does not fit all. There is a need for a thorough understanding and analysis of the housing needs of people with learning disabilities and this understanding should be grounded in the analysis of housing needs of people with learning disability contained within, and evidenced by, local authority local housing strategies (LHS).

Local authorities are required by the Housing (Scotland) Act 2001 to prepare a local housing strategy supported by an assessment of housing need and demand⁶¹. Local housing strategies are the sole strategic document on housing, homelessness, housing support services and fuel poverty.

National and local government have agreed that these strategies are at the heart of the new arrangements for housing and planning, both through their links to development plans and in terms of the direction of local housing investment. Accordingly, in June 2008 the Scottish Government and COSLA published new guidance jointly on local housing strategies, issued to local authorities⁶². A subsequent paper supporting the development and improvement of local housing strategies promotes good practice and supports improvement, partnership working and streamlining processes⁶³. Further guidance on review criteria for local housing strategies was published in 2009⁶⁴.

⁶¹<http://www.legislation.gov.uk/asp/2001/10/contents#pt5-pb2-11q89>

⁶²<http://www.scotland.gov.uk/Publications/2008/06/25093503/0>

⁶³<http://www.scotland.gov.uk/Topics/Built-Environment/Housing/supply-demand/deliveryframework/lhs/lhssidoc>

⁶⁴<http://www.scotland.gov.uk/Topics/Built-Environment/Housing/supply-demand/deliveryframework/lhs/lhsreviewcriteria>

Local housing strategies provide the strategic direction to tackle housing need and demand and to inform the future investment in housing and related services across the local authority area. They deal with all aspects of housing and related issues, including homelessness, fuel poverty and housing support (all of which were previously covered in separate strategies) and have a stronger focus on outcomes.

As part of the process for supporting improvement, COSLA and the Scottish Government have agreed a joint review process for local housing strategies. A panel, including representatives from the Scottish Government and local government, will review the local housing strategy against ten key criteria.

The same as you? evaluation identified a number of key issues to be taken into account in the planning and delivery of housing and related services for people with learning disabilities which the following recommendations encapsulate.

Recommendation 28

That the Scottish Government, in partnership with COSLA and Association of Local Authority Chief Housing Officers (ALACHO), should undertake a review of Local Housing Strategies (LHSs) by June 2014. This should:

- **identify examples of good practice in meeting the needs of people with learning disabilities**
- **highlight where improvement is needed**
- **make recommendations for change to be included in revised local housing strategy guidance together with a statement of resources available to deliver on the actions required, and any shortfalls remaining.**

Recommendation 29

That Local Housing Strategies (LHS) should evidence how the views of people with learning disabilities and their carers have been taken into account in their preparation, and demonstrate the extent to which such views have been reflected in final LHS plans. LHS should also demonstrate explicitly the actual and anticipated contribution of all housing sectors to meeting the needs of people with learning disabilities, including housing associations and the

private sector, together with the services which may be required to support independent living and who is best placed to provide these.

Supported living

The same as you? evaluation found that living independently encompassed a variety of different housing settings and support situations. It is important to note that living independently does not mean that people are living without support; some people receive varying amounts of support at home and this included support staff and housing adaptations. We talk about support staff in more detail in the chapter on shift the culture but it is important to note that good support staff can make a huge impact on a person with learning disabilities living as independently as possible.

Housing adaptations

Housing adaptations can help older people and disabled people live safely and independently at home.

In 2011 an independent Adaptations Working Group was established by the Scottish Government with a remit to review the organisation and funding arrangements for housing adaptations. The working group was formed in recognition that current systems for delivery of housing adaptations are unsustainable and have long-standing issues, mainly rooted in the inequalities, complexities and inefficiencies of the existing tenure based delivery arrangements.

The working group made their final report to Ministers in December 2012. They recommended fundamental change should be made to the funding and delivery arrangements for adaptations.

The report found that adaptations can provide wider social benefits. They may reduce dependence on people-based services, such as home care, supporting a more flexible lifestyle, which enables people to contribute to their communities or potentially take up employment. The provision of adaptations can also help people to remain in their own home, by reducing accidents, which might result in admission to hospital or to a care home. This means there is also a wider financial benefit, given the relatively low cost of adaptations in comparison with hospitals and care homes. This is particularly important when there is severe pressure on public spending.

Housing adaptations can range from small aids, such as handrails, to larger adaptations such as whole house redesigns to accommodate wheelchairs. Telecare also makes a contribution to people's support, independence and sense of safety within the home. Examples of this include having alarms fitted and mobile phones with GPS.

Good practice

Robert is a 41 year old with severe learning disabilities who was living at home with his parents. As both parents are now retired they were keen to see Robert established in his own home, living independently on his own or with another person. With the help of Housing Options Scotland, an organisation specialising in finding the right house in the right place, they began the process of finding suitable accommodation for Robert's needs.

Through the Access Ownership scheme, managed and funded by Link Housing Association and with the help of Housing Options Scotland, Robert's family, in partnership with the family of another disabled man, were able to buy a property near to both sets of parents. The three bedroomed property was suitably adapted for the day to day living of both men with 24 hour care in place to enable independent supported living.

Robert and his housemate are now happily settled and both families are very satisfied with the arrangements.

Supported living in Camphill communities

Not everyone with learning disabilities will choose to live in their own home. Scotland is home to twelve Camphill communities, supporting over 400 people with learning disabilities from the early years through to older age. People who need support live and work alongside co-workers. People can choose to come and share life with others by living in the communities, or by working in the community for part of the week.

Many staff in Camphill communities are trained in social pedagogy, a relationship-based approach which uses everyday living situations to help residents to learn and develop skills that will enable them to participate more fully in decision-making about their own lives, maximise their own potential and to live as independently as is possible.

Communities vary in size from supporting eight to 80 people, and can be found in rural and in urban settings. For some people, living and working in an intentional community really brings out the best in them. They tell us that this is because Camphill life means they can have a sense of belonging, make friends, develop social skills, feel safe and secure and

make a contribution. Work is, and always has been, an integral part of life in Camphill communities. Everyone has a need to be useful and active, and work within Camphill communities and social enterprises gives people a shared purpose, enabling them to make a meaningful contribution to the community and beyond.

There are also advantages for families whose relatives are supported in Camphill communities. Camphill families report feeling safe and secure in the knowledge that their loved one is being well supported. They value the holistic support provided in communities, who use a social pedagogy approach to attend to people's overall wellbeing, education and personal development.

Case study

James comes to Camphill Blair Drummond to work and be supported. He said:

"I have been coming to Blair Drummond for 6 months as a day student, I come two days a week and I attend pottery, basketry, and the garden workshops. These were the workshops I liked the best when I came to visit.

I really like the pottery and I have helped to make lots of great things. I have made mushrooms out of clay that I paint and then they get glazed. I really like to make the ladybirds, owls and tortoises. It's great fun and it helps me focus and relax. I also go to basketry where I am making different kinds of baskets that will be sold at the advent fair. This makes me proud that someone will buy my basket. Although I am quite shy I have made friends with the other students in my groups and this has made me more confident.

I also like to work out in the garden and I have planted flowers and seeds to grow vegetables and when it's raining we chop up fruit and vegetables to make jam and chutney.

I feel happy to be here."

Recommendation 30

That Camphill Scotland is funded in 2013 to prepare for practice change and training in social pedagogy by staff and residents working together to identify outcome measures for individual residents and to implement and evaluate these.

Travel and transport

Being able to use a bus or train independently is a skill that many people with learning disabilities need support to learn. It can open up new avenues and opportunities that they would otherwise be unable to access, like work or college, as well as social activities and just going out with friends.

The same as you? evaluation found that the bus is especially favoured as a method of transport while people found the train much more difficult to use, partly because it was difficult to get and off and partly because people were unsure as to which train to get on.

In 2005 transport providers became liable under the Disability Discrimination Act⁶⁵. 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.

In order for people with learning disabilities to be truly independent, it is important that transport is accessible, affordable and available.

Good practice

People who cannot travel independently are restricted. In Share Scotland's pilot project 'Journey to Success' staff will be trained as accredited travel trainers to work with 16 people with learning disabilities recruited across a range of local organisations. They will be supported over 24 weeks from a classroom setting and will be given the confidence and skills to plan and carry out journeys independently on public transport. Local transport companies will be given disability awareness information on guidance and how to best support a disabled passenger. If the pilot is successful, local authorities may be interested in future funding of it as it will enable them to reduce significant transport costs for taxis, special buses and escorts for disabled people and decrease the pressure on social work services.

The role of Local Area Co-ordinators

Achieving independence requires the expertise and support of skilled staff. Local areas co-ordinators (LACs) are highly valued in this regard.

⁶⁵Disability Rights Commission (2006a). *Disability Discrimination Act: Provision and Use of Transport Vehicles, Statutory Code of Practice, Supplement to Part 3 Code of Practice*, London: The Stationery Office

The same as you? introduced the role to provide people with learning disabilities and their families with “...a specialist worker dedicated to working with a small number of people using services in one area (to) help people and their families through the current maze of systems”⁶⁶. Since the introduction of Local Area Co-ordination the number of LACs employed in Scotland has grown from five posts in 2002⁶⁷ to over eighty in twenty local authority areas in 2013⁶⁸.

In 2010 SCLD published ‘Values into Practice: A framework for Local Area Co-ordination in Scotland’⁶⁹ in partnership with the LAC National Reference Group. This framework was developed to provide a benchmark for LAC and to support LACs to adopt the 10 principles of LAC in their day to day practice⁷⁰.

LAC is diverse and flexible in its approach to building individual capacity for independent living and growing community capacity for inclusion. LACs will work flexibly with individuals, family members and carers; community groups and associations; and public services in order to achieve positive outcomes for people with learning disabilities within their locality.

The core areas of LAC work focus on: information, signposting and guiding; developing relationships; planning, empowerment and promoting independent living; promoting inclusion; and influencing public service delivery. LAC has the potential to contribute to building a society where people with learning disabilities and autism are valued as full and equal members of society.

Good practice

The BreakAway Project, which is facilitated by LACs in Edinburgh, was introduced as part of a wider move towards giving people with learning disabilities more control over their care. BreakAway gives families a choice about how to spend their respite time, rather than allocating them a fixed number of nights at a respite centre. Users are allocated a budget and can spend it on activities of their choice. They can also pool

⁶⁶ Ibid (p12)

⁶⁷ National Local Area Co-Ordination Development Team. (2010a). Local Area Co-Ordination in Scotland: 2009-2010, Glasgow: Scottish Consortium for Learning Disability

⁶⁸ <http://www.sclد.org.uk/local-area-co-ordination/contacts-list> [accessed on the 18/04/13]

⁶⁹ National Local Area Co-Ordination Development Team. (2010b). Values into Practice: A Framework for Local Area Co-ordination in Scotland, Glasgow: Scottish Consortium for Learning Disability, available at <http://www.sclد.org.uk/library-publications/values-practice-framework> [accessed on the 31/05/13]

⁷⁰ Ibid (pages 8-9)

their budgets with others, cutting costs by sharing a support worker, transport or accommodation.

Recommendation 31

That the role of Local Area Co-ordinators is reviewed by the Scottish Government, SCLD, COSLA and ADSW by evaluating their contribution to independent living both in terms of outcomes for individuals and public value and that a joint decision is reached by June 2014 on the scale of expansion needed and the collective means to achieve this.

Advocacy

Advocacy is the process which supports people to understand information and choices and to make their voice heard, especially if they may find it difficult to do so by themselves.

There are several different types of advocacy available, as defined by the Scottish Independent Advocacy Alliance⁷¹:

- Self-advocacy. This is when a group of people, who normally have experience of using services, decides collectively about issues they would like to campaign on.
- Collective or group advocacy. This happens when a particular group of people come together and support each other round a common cause.
- Citizen advocacy. This is when ordinary people in the community work with someone who needs the support of an advocate. Citizen advocates may work with the same person for many years.
- Peer advocacy. This is when someone with very similar life experiences to the person who needs support acts as their advocate.
- Professional advocacy. Some professional advocates are paid and some are unpaid.

The same as you? said that the then Scottish Executive should encourage the development of local independent advocacy services. While some funding was offered and some people did get access to advocates, provision is still patchy across Scotland. Not everyone will need or want an advocate but, as the Joint Committee on Human Rights

⁷¹ <http://www.siaa.org.uk/content/view/14/27/>

report on the human rights of adults with learning disabilities highlighted, it is of particular value to people with profound and multiple disabilities. It is also clear that it would be helpful to provide further training for both advocates themselves and on advocacy to social care staff.

Recommendation 32

That by 2018 the Scottish Government works with the Scottish Independent Advocacy Alliance, PAMIS and SCLD to scope the need for advocacy and to develop an Action Plan together to improve delivery and uptake of independent advocacy at local level.

Shift the culture and keeping safe



Escape
Escape harm

Shift
Culture shift

Alter
Alter attitudes

Delete
Delete discrimination

Setting the scene

People with learning disabilities are now living more independently than ever and have greater access to communities and community living. However, a report published in 2012, *Loneliness and Cruelty*⁷², confirms that more people with learning disabilities are subject to abuse and harassment. This was also documented in *Hidden in plain sight*, which is a report of an inquiry into disability-related harassment published in 2011 by the Equality and Human Rights Commission. The report said that harassment is a commonplace experience for disabled people, but a culture of disbelief and systemic institutional failures are preventing it from being tackled effectively. The findings of these reports also reflect the feedback from *The same as you?* consultation. The main priorities for action were:

- Enhanced social networks for people with learning disabilities
- Creating a society where people look out for each other
- Safer public spaces
- Stronger prevention and support services from mainstream organisations

In 2012, the Scottish Government funded ENABLE Scotland to set up a Community Connections project to address the first three of these objectives. This project will research thirty local providers and organisations in North Lanarkshire to determine the type and availability of services they can provide to people with learning disabilities. The project will also work with two hundred local people with learning disabilities, through a combination of focus groups and one to one interviews, to map and identify their individual and common interests. Importantly the project will employ four people with learning disabilities, who will be able to shape and develop the project using their own experiences as well as increasing their employability, skills and confidence.

But this is only one potential example of what progress can be made in making friendships, having relationships and feeling safe to do so. There are many other pockets of work of this type across the country.

⁷² Researched and published by Lemos&Crane working with the Foundation for People with Learning Disabilities and supported by Esmée Fairbairn Foundation.
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It is clear that people with learning disabilities of all ages are keen to build social relationships and networks with their peers in the community. However, the experience since *The same as you?* was launched is that achieving this is very difficult. It requires specialised services with clear delivery models and specific aims and outcomes.

Volunteer befriending is one example of this type of provision, and since Befriending Network Scotland was established, befriending services have become increasingly professional, with agreed codes of conduct, accredited training and recognised quality assurance schemes.

One such service is Interest Link Borders's specialist learning disabilities befriending service which has created over 650 befriending links since 2001 and has 300 children, young people and adults registered with it. Interest Link Borders has around 200 volunteers, including around 50 aged 18 and under, recruited from secondary schools.

Evaluations have shown that outcomes include:

- improved confidence, self-esteem, mental & physical wellbeing and life skills,
- high quality short breaks for family carers,
- high level of impact on volunteers' skills in communicating and forming relationships with people with learning disabilities.

A survey carried out by Befriending Network Scotland and Interest Link Borders in 2012, found that only a very small percentage of people with learning disabilities currently have a befriending link. Local authorities identified 26,000 adults with learning disabilities in Scotland in 2011⁷³ and, of these, around 330 (1.27%) enjoy befriending links.

What is needed, at a preventative level is to develop and embed good practice throughout Scotland so that people with learning disabilities have more places to go to have fun, feel safe and able to disclose any anxieties that they may have when they think they are being harassed, bullied or harmed.

The experience of Interest Link Borders will be valuable in clarifying how to achieve this.

SCLD also have a contribution to make in this respect. They are funded to work with local agencies to increase the capacity of people with

⁷³ SCLD essay statistics 2011

learning disabilities to recognise hate crime and to know what to do to keep themselves safe. They will hold awareness raising events to promote good practice by frontline workers and will produce an accessible “what to do” guide, developed with people with learning disabilities. This will be part of a toolkit that will also include good practice for agencies in how to ensure appropriate responses to harassment.

Recommendation 33

That SCLD, in collaboration with ENABLE Scotland, should work with local voluntary services to:

- **encourage the setting up and expansion of befriending services and natural networks for people with learning disabilities.**
- **work with local authorities and NHS Boards to ensure that the planning, commissioning, procurement and implementation of services gives scope for the inclusion of befriending services and natural networks.**
- **record the number of people receiving befriending services and natural networks in annual eSay statistical returns.**

Relationships

The Scottish Government’s publication Growing up in Scotland: Parenting and the Community Context Report⁷⁴ recognise that the lack of resources inhibits friendship networks⁷⁵.

From *The same as you?* consultation we know that relationships are of key importance to people with learning disabilities and essential for their wellbeing, but relationships come in many different forms. Being around other people encourages people with learning disabilities to develop their social skills. Developing social skills helps them to make friends and helps them to integrate into the community. People with learning disabilities are less likely to feel lonely or isolated if they have friends, family and carers to support them.

⁷⁴ Growing up in Scotland: Parenting and the Community Context Report, Scottish Government 2009 <http://www.scotland.gov.uk/Publications/2009/03/13143448/4>

⁷⁵ Allan, G. 2005. 'Boundaries of Friendship' in McKie, L. and Cunningham-Burley, S. (eds.) *Families in Society: Boundaries and Relationships*. : Policy Press.

People with learning disabilities should be valued and be able to make friends and build relationships. They have the right to choose their friends and have choice and control in relationship situations. It is recognised that some people with learning disabilities will need support to meet others and build relationships.

Relationships take many forms. Each relationship is important to the sense of belonging, social inclusion of people with learning disabilities and important in realising the potential of people with learning disabilities to be all they can be.

Friends and partners

Having meaningful relationships is a priority for people with learning disabilities. They may be more prone to abuse and are more likely to be denied the opportunity to conduct their own lives as any adult would take for granted, including the ability to form and conduct relationships. But having the chance to make and sustain friendships and relationships is something that improves their wellbeing and quality of life. Many people with learning disabilities want that chance to have a romantic, sexual and long-term relationship.

The same as you? evaluation tells us, however, that only one third of those interviewed were able to name at least one close friend. So there is a clear need for people with learning disabilities to be given opportunities to have friends and all the benefits this can bring.

Good practice

Equal Futures⁷⁶ is an organisation led by families that believes that everyone benefits from knowing other people. This might be family, friends, colleagues, neighbours or people we know through our activities. At Equal Futures they help families set up and maintain a lifetime Circle of Support around their relative with a disability. As part of the work they do, the Scottish Government funded Equal Futures to publish a Scottish Edition of Safe and Secure – Six Steps to creating a good life for people with disabilities which helps families to form a successful Circle of Support to create a good life for people with disabilities

⁷⁶ http://www.equalfutures.org.uk/index.php?option=com_content&view=article&id=78

Recommendation 34

That by the end of 2013 the Scottish Government in partnership with Equal Futures and other relevant organisations holds a friendship event to help people with learning disabilities to be supported to have more friends.

Good practice

Dates and Mates⁷⁷ is a friendship and dating agency run by people who have learning disabilities for people who have learning disabilities. The agency is co-ordinated by C-Change. They decided to organise social events which would allow them to meet new people and have some fun. Dates and Mates has been running successfully now for some time and the people who have joined have made some really good friends as a result.

The internet is increasingly used as a means to meet friends and partners which makes it important that people with learning disabilities who use social media can do so effectively and safely. One of the problems for professionals and parents is that the signs that a person is being groomed may be subtle and difficult to recognise, and that individuals may not recognise they are being groomed either.

Good practice

NHS Lothian, with Scottish Government funding, is carrying out innovative work in this area so that young people with learning disabilities are able to protect themselves when using the internet. They are providing internet safety education to support young people with learning disabilities to develop self-protective skills in this ever-developing digital age.

Good practice

NHS Forth Valley has also been funded by the Scottish Government to develop a resource for young adults with learning disabilities to support sexual health and wellbeing. The resource will be in a photo story format and will follow 4 different characters from a group of friends as they experience different types of relationships. The resource specifically focuses on exploring the development of relationships, dating, intimacy, sex and same sex relationships for young adults with learning disabilities.

⁷⁷ <http://www.enable.org.uk/services/Friends/Pages/dates-n-mates.aspx>

The aim is to provide opportunity for support and information for people with learning disabilities to explore a range of different relationships and identify how they might use the learning from the resource to develop and sustain relationships for themselves.

Building Resilience

Not all relationships work well. Scottish Government policy is directed at supporting people to live safely within their community and to lead full and rewarding lives, free from bullying and harassment. Bullying is totally unacceptable. It is recognised that some adults and children with learning disabilities have been the subject of discrimination, exclusion, bullying and harassment and that such experiences have negative effects on their confidence as well as health and well-being. Education around prevention of bullying is key. One such project is the Scottish Government funded Open your Mind, not your mouth campaign, run by ENABLE Scotland. This campaign challenges people to think before they speak. Bullies sometimes don't realise the effect their actions can have on people with learning disabilities. The things they do and say can make people feel alone, depressed and isolated from their friends.

Many families wish to provide care and support for their family member with learning disabilities and, to enable this, building upon and developing their capacity to care of their family member is essential.

There is growing interest in the importance of developing resilience as a means to cope with life events, unexpected challenges and transitions that can be experienced by people with learning disabilities and their families. Developing resilience requires a focus on the needs of the person with learning disabilities, their family and carers and on developing capacity and responses from community resources as well as facilities to make such more accessible and responsive. Supporting people with learning disabilities to adapt to life challenges and enabling families to develop resilience, make use of community resources and build their networks of support, provides an opportunity to strengthen the capacity to self-care and shift the focus away from dependence on statutory health and social care services.

Recommendation 35

That research is undertaken to understand and analyse the factors that impact on how people with learning disabilities, their families and carers cope with adversity which will inform the development

of appropriate care and support to sustain and enhance their resilience.

Family carers

The same as you? highlighted the fact that families are responsible for by far the most support for people with learning disabilities. In 2011 the eSAY statistics on adults with learning disabilities known to local authority services said that 44% of those adults live with a family carer.

What carers need is information at the right time about the supports available locally and nationally, a range of help to support them (including training and advice) to look after a person with learning disabilities and access to professionals who help them, and access to short breaks.

The Community Care and Health (Scotland) Act 2002 introduced the right to an independent carer's assessment and, for the first time in statute, described carers as partners in providing support. Yet in *The same as you?* evaluation only 48% of family carers interviewed had been assessed. Of those who had been assessed, one of the principal benefits was signposting to supports but others indicated that the assessment had not resulted in outcomes that they would value.

The value and contribution of carers is recognised by the Scottish Government in the publication and funding to support Caring Together, The Carers Strategy for Scotland 2010 – 2015⁷⁸ which aspires to ensure that carers are supported to manage their caring responsibilities with confidence and in good health, and to have a life of their own outside caring. It is a strategy that aims to improve the lives of all carers, including those caring for people with learning disabilities.

Carers have told us that help was often only given when there was a crisis (which costs more to provide). A little help earlier might have made their lives easier and cost less. Families receive different levels and quality of services depending on where they live. Many carers said they had trouble finding out about what social work, health or other services are available and families of ethnic minority backgrounds said there was not enough information available in other languages.

⁷⁸ Caring Together The Carers Strategy for Scotland 2010 – 2015, Scottish Government, <http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

The importance of short breaks was highlighted as essential in supporting the carers to maintain the caring relationship. People with learning disabilities and their carers both benefited from the value of short breaks which are individualised and flexible.

Carers of people with learning disabilities want better support if they are to be able to care and avoid caring crisis. Small early low cost interventions will help avoid costly services when crisis happens. That is why it is important for statutory organisations and the third sector to work in partnership to deliver services to meet the individual needs of people with learning disabilities and their family carers.

Good practice

Some local authorities are implementing preventative options where the Carers Support Payment is for the direct benefit of the carer. This scheme offered unpaid carers who provide substantial and regular support to the person they are caring for with a small, one-off payment of £250. The purpose of the payment is to meet the needs of the carer rather than to provide additional support to the cared for person. This may include support to maintain the carers health and wellbeing, for example gym membership, college courses, or perhaps short breaks so carers gain a valuable break from caring and their capacity to care is sustained.

Case study

Jennie is nine and is cared for by her mum and dad, Mary and Andrew. Jennie has Cerebral Palsy and is quadriplegic. Jennie cannot walk or talk and has a tracheostomy to help her breathe. There are over 24,000 parents in Scotland who, like Mary and Andrew, care around the clock for children who have learning disabilities – many never have the opportunity to have a break. When Jennie was five Mary found out about Enable Scotland's Lend a Hand Service, which provides short break respite. Jennie now stays with carers Joanna and Graham once every fortnight.

Mary says "The difference it has made to all of our lives is amazing. Firstly for Jennie she experiences different faces, different outings, different everything and she absolutely loves it. And now I am used to having that time with Andrew I realise it is important we get that break if we are to keep everything going and give Jennie the quality of life we want. Without the short break carers who look after Jennie I don't know what we would do – it has such an impact in our lives."

Recommendation 36

That to improve the availability of flexible, good quality short breaks for people with learning disabilities and their families and carers, the Scottish Government will enhance the voluntary sector Short Breaks Fund to support children and adults with learning disabilities including to provide opportunities and develop skills and confidence.

Older carers of people who have learning disabilities have reported their concerns about the lack of support available to help them plan for the point in the future when they become unable to care. Many of these carers experience anxiety and reduced peace of mind as a result. With Scottish Government funding, ENABLE Scotland published research, *Picking up the Pieces*, which makes recommendations to improve access to emergency planning pathways via the Carers Assessment

Recommendation 37

That the Scottish Government works with Enable Scotland to build on the work set out in the 2012 report, ‘Picking Up the Pieces – Supporting carers with Emergency Planning’ so that plans are put in place to support people with learning disabilities and their carers.

Good practice

PAMIS is a registered charity working with people with profound and multiple learning disabilities (PMLD) and complex care needs, their parents and carers and interested professionals. The priority is to provide support to family carers and this is carried out through PAMIS’ dedicated Family Support Service, by co-ordinators covering 14 local authorities. Partnership working with families is at the heart of all PAMIS activities and is key to their role. PAMIS co-ordinators work with families and interested professionals to ensure that each child or adult they work with has the best possible opportunities for choice inclusion and quality of life.

Paid carers (support workers)

For many people with learning disabilities personalised supports and services enable relationships and achieve outcomes. Being supported by someone appropriate to their age, interests and personality is important. It is important that people with learning disabilities have

choice and control over who their support workers are. Support services need to ensure that services for people with learning disabilities are personalised. The transition in building that relationship is critical if the relationship is to be long term and valued by those being supported and time needs to be taken to make an appropriate match. Where relationships are not working the needs of the individual with learning disabilities is paramount to decisions on whether that relationship continues. *The same as you?* evaluation identified that continuity of staff is also emphasised by family carers as important in building relationships. Some carers felt too many support workers was not beneficial to those being supported. The evaluation found that it was essential that support workers see it as their role to widen people's social relationships.

Parents with learning disabilities

Whilst policy documents such as the National Parenting Strategy⁷⁹, Getting It Right For Every Child⁸⁰ and the Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities⁸¹ state that early intervention and the right sort of ongoing support should be available to families where there are parents with learning disabilities, we know that often the reality for these families is very different.

Disproportionate numbers of parents with learning disabilities have their children removed. Anecdotal evidence indicates that implementation of the Scottish Good Practice Guidelines is at best patchy. Evidence has also shown that human rights to respect for private and family life (article 8 European Convention on Human Rights⁸²) and the right of a child not to be separated from its parents on the basis of disability of either the child or one of the parents (article 23, para 4 UN Convention on the Rights of Persons with Disabilities) are sometimes not upheld. Steps are therefore needed to improve the support available to these families.

Clearly, as stated in the Children (Scotland) Act 1995⁸³, the needs of the child must come first, and so far as is consistent with promoting the child's welfare the local authority should provide services to promote the

⁷⁹ <http://www.scotland.gov.uk/Publications/2012/10/4789>

⁸⁰ <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

⁸¹ <http://www.sclد.org.uk/sites/default/files/Good%20Practice%20Guidelines%20for%20Supporting%20Parents%20with%20Learning%20Disabilities.pdf>

⁸² http://www.echr.coe.int/NR/rdonlyres/D5CC24A7-DC13-4318-B457-5C9014916D7A/0/Convention_ENG.pdf

⁸³ <http://www.scotland.gov.uk/Publications/2004/10/20066/44708>

upbringing of children in need by their families. Research evidence shows that in many cases children's needs can be met well by parents with learning disabilities with support. Support provided needs to be tailored to the needs of the individual parents and might include training, ongoing support and some supplementation of care as needed.

Good practice

Local Area Co-ordination team has worked closely with People First parents group and Children and Families to produce an accessible children's plan. The plan uses easy read text, symbols and pictures to create a useful working document. It is to be used with families where there are communication difficulties. The long term goal is to have an accepted council wide user friendly tool to enhance successful collaborative working to assist parents with learning disabilities to understand the steps they need to take to look after their children.

Recommendation 38

That by 2014 parents with learning disabilities should have access to local supported parenting services based on the principles of Supported Parenting and that the Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities are being followed by professionals working with parents with learning disabilities to ensure better outcomes for families.

In some people's lives, however, there will be points where it is necessary and desirable for statutory agencies to intervene. This may be simply to offer support. In other instances, it will be to inquire, investigate and to manage allegations of harm.

Protecting children, young people and adults

As children and young people progress on their journey through life, some may have temporary difficulties, some may live with challenges and some may experience more complex issues. Sometimes they, and their families, will need help and support.

No matter where they live or whatever their needs, children, young people and their families should always know where they can find help, what support might be available and whether that help is right for them.

The Getting it right for every child (GIRFEC) approach ensures that anyone providing that support puts the child or young person, and their family, at the centre.

GIRFEC is important for everyone who works with children and young people. Practitioners need to work together to support families, and where appropriate, take early action at the first signs of any difficulty – rather than only getting involved when a situation has already reached crisis point. This means working across organisational boundaries and putting children and their families at the heart of decision making – and giving all our children and young people the best possible start in life.

Improving developmental and health outcomes for children with learning disabilities: early intervention

We know that early interventions can reverse some of the possible impacts of disadvantage on children's lives. Sometimes this will be about providing social supports e.g. that enable parents to be all they can be. Sometimes this will be about building resilience in individuals and families to mitigate the potential effects of poverty and stigma. What is less clear is the extent to which these factors are relevant for children with learning disabilities, whose disability itself shapes their environment. One recent review reported an increased risk of distress in parents (especially mothers) of children with learning disabilities.

What we need is a better understanding of how children's inappropriate behaviours impact on their parents and how this can sometimes lead to a spiralling effect where stress influences the interaction and prevents the best possible outcomes being achieved. We need to understand, too, why this pattern will differ from individual to individual so that early interventions can reap maximum benefits for all concerned. The desired outcome is to improve a child's development and their health outcomes through tailored programmes and through different types of psychological support to parents as well as parenting programmes.

A recent report highlights the scarcity of research on preventions and early interventions for problem behaviours for children with learning disabilities. A population health approach to parenting interventions for children with learning disabilities would clearly be useful given their reported high rates of problem behaviours and mental health issues.

It is not clear yet how to tailor interventions to make the greatest impact. Nor is it clear who should be given priority for the most intensive

interventions. Verbal, cognitive and computer based interventions may not be accessible for everyone, and their different circumstances suggest interventions may need a different focus. Investments in “Sure Start” were implemented with considerable variation across Scotland, and it is not clear the extent to which children with learning disabilities and their families access these resources. It may be likely that in Scotland, families of children with more profound and multiple learning disabilities have poorer access to resilience building programmes such as Sure Start and parenting programmes. Interventions such as The Parents Plus Early Years programme, Stepping Stones Triple-P, and the tiered intervention, Incredible Years Parent Training programme could be suitably tailored if the information to do so was generated.

Children and Young People (Scotland) Bill

This proposed statute paves the way for fundamental reforms to the ways in which children and their families are supported as it will bring together earlier plans for separate legislation on children’s services and children’s rights into a single, comprehensive framework.

The main provisions are rights-based and are intended to:

- ensure GIRFEC is embedded in statute
- embed the rights of children and young people across the public sector in line with the United Nations Convention on the Rights of the Child (UNCRC).
- place duties on Scottish Government to take steps to further the rights of children and young people and promote and raise awareness of the UNCRC.
- require the wider public sector to report on what they are doing to take forward realisation of the rights set out in the UNCRC.

Lastly, there is a key role for Scotland’s Commissioner for Children and Young People in that powers should be extended to undertake investigations on behalf of individual children and young people.

Adult Support and Protection (Scotland) Act 2007 (ASPA 2007)

The Adult Support and Protection (Scotland) Act 2007 came into force in October 2008 and since that time there has been considerable activity both at local and national level to develop this important area of work. The core of the Scottish Government strategy is to enable the Adult Protection community, i.e. local authority partners, the scrutiny bodies, such as the Care Inspectorate, the Mental Welfare Commission,

Healthcare Improvement Scotland and other relevant bodies such as the Scottish Prison Service, and the NHS to work better together to improve the experience for adults at risk of harm in our communities.

A key activity is the setting up, in 2012, of the Adult Protection Forum, which meets quarterly. This is currently facilitated by the Scottish Government, and comprises a wide range of practitioners and representatives from the Adult Protection National Conveners' group and other interested bodies such as the Care Inspectorate, the Scottish Prison Service and the MWC.

The intention is that the Forum takes a more proactive role in leading change, drawing on experiences at a local level, because it is at the local level that good practices develop and have the most impact. In addition, the Scottish Government is working with the scrutiny bodies to develop their role in supporting a drive to continuous improvement in adult protection, greater awareness and better prevention of harm.

The Forum has five national priority projects which are:

- Financial harm;
- Adult protection in care homes;
- Service user and carer involvement;
- Adult protection in accident & emergency departments;
- National data collection.

Multi-disciplinary teams, which include scrutiny bodies, have been set up to lead on of these projects.

Good practice

Heartfelt Limited are a training and consultancy organisation based in Scotland but working throughout the UK. Most of the people who work for Heartfelt are people who have experience of using social work or social care services or care for someone who does.

Heartfelt, in partnership with South Ayrshire Council Adult Support and Protection Service, aimed to use the experience of individuals and their families that have been involved in an adult support and protection intervention and to use that experience to help inform and advise how intervention services are developed and delivered in South Ayrshire in the future. Central to this, was the need to develop the skills and confidence of workers throughout South Ayrshire; develop a toolkit of resources for use with individuals and their families and a way of approaching adult support and protection in a way that makes sense to

the people using it. Alongside this was the need to develop the confidence and capacity of individuals and their families/representatives to move from passively receiving those services to actively influencing them.

Guardianship

An adult lacks legal capacity to make a particular decision (such as where they would wish to reside on discharge from hospital) when there is evidence that s/he is unable to: understand the information relevant to the decision; or make a decision based on the information given; or act on the decision; or, communicate the decision; or retain the memory of the decision. A Guardianship Order provides the legal authority for someone to make decisions and act on behalf of a person with impaired capacity, and it would be appropriate to use it in order to safeguard and promote an adult's interests. Powers granted under an order may relate to the person's money, property, personal welfare and health.

The Adults with Incapacity Act 2000 Code of Practice provides guidance for persons authorised under guardianships⁸⁴.

Case study

Karen is in her forties and has a history of challenging behaviour. She moved into residential care as a child and now lives in supported housing with regular support from care staff, having occasional contact with her sister and a family friend. She is lonely and rarely leaves her house. The police became increasingly involved when her home was targeted as a party flat by a number of local people, including a man who was for a time her partner and who also has learning disabilities. She was increasingly subjected to verbal, financial and sometimes physical abuse and her health suffered because of the alcohol her 'friends' offered as inducement.

The Adult Support and Protection Act was used to obtain banning orders in respect of the key perpetrators, including the service user's partner, and professionals including the social worker, learning disability nurse and care staff worked together with Karen to encourage and support her to keep herself safe. The overall amount of input she received increased and regular inter-professional reviews were held. There was general agreement that Karen was safer, healthier and financially more secure as a consequence of the interventions under the Act.

⁸⁴ <http://www.scotland.gov.uk/Resource/Doc/347717/0115820.pdf>

Sexual Abuse

In 2005 the Scottish Government launched SurvivorScotland, the National Strategy for Survivors of Childhood Sexual Abuse. The aims of the strategy are to improve access to services for survivors; ensure joined up working in national and local mainstream services; raise knowledge and awareness within frontline services and for the general public and improve the lives of survivors.

Addressing the needs of survivors with learning disabilities was identified as one of the areas which required additional focus as part of the National Strategy. Since then funding has been allocated to Kingdom Abuse Survivors Project and Cornerstone to develop awareness raising for frontline staff and volunteers and to provide specialist support and counselling from a learning disability support worker.

In addition to this in 2011 the National Strategy funding supported the development of Learning Disability Six Dimension (6D) cards as a visual resource to support consultations about health and wellbeing with people with learning disabilities and to provide an opportunity for disclosure of childhood sexual abuse. Evaluation of the cards has shown that they were accessible to people with mild and moderate learning disabilities, facilitated discussion of a wider range of subjects and enabled more person centred consultations through the ability to gain more information.

The use of 6D cards has now been developed further for use along with Talking Mats. Talking Mats is an evidence based approach to support people with complex communication needs express their views, choices or perspectives on a topic. This helps GPs and other professional staff to carry out effective consultations where they can understand the impact that childhood abuse and the disclosure of that abuse can have and consider appropriate support.

The establishment of a National Confidential Forum (NCF) in 2014 will also provide an opportunity for adults with learning disabilities who were placed in institutional care as children to recount their experiences of being in care in a confidential, non-judgemental and supportive setting.

Break the stereotypes



Shift

Culture shift

Control

In control

Enter

Enter partnerships

Break

Break the stereotype

Delete

Delete discrimination

Education

The Curriculum for Excellence and the Doran Review⁸⁵ state that every child has the right to become a successful learner, confident individual, effective contributor and responsible citizen - wherever their learning is taking place. Some will face barriers to learning and will need additional support to enable them to make the most of their educational opportunities and to realise their potential. There are also strengthened and updated legal frameworks for identifying and addressing additional support needs^{86 87}.

For some children and young people, their complex range of additional support needs may be beyond the capacity of an individual local authority to cater for. They may require access to regional or national provision.

The Doran Review considered whether the current system is achieving the best possible outcomes for Scotland's children and young people, and recommended that improvements were necessary.

Most family carers have expressed a view that most children with learning disabilities should attend mainstream schools unless attending a special school would better meet their individual learning needs.

Decisions on schools are made by children and young people's families in conjunction with the education authority, based on the individual learning needs of the child or young person. The legislation on the presumption of mainstreaming is in place and guidance has been developed by the Scottish Government⁸⁸.

The placement of pupils in schools is the responsibility of education authorities in conjunction with families. In 2012, 118,034 pupils (17.6 per cent of all pupils) had additional support needs; 111,058 (94 per cent) learn in mainstream schools.

Where families have a preferred school for their child or young person they can consider making a placing request to the school of their choice. Information on choosing a school and placing requests has been

⁸⁵ The Doran Review <http://www.scotland.gov.uk/Publications/2012/11/7084/0>

⁸⁶ Education (Additional Support for Learning) (Scotland) Act 2004

⁸⁷ Education (Additional Support for Learning) (Scotland) Act 2009

⁸⁸ <http://www.scotland.gov.uk/Resource/Doc/46922/0024040.pdf>

developed by Enquire⁸⁹, the national advice and information service for additional support for learning.

The consultation of *The same as you?* highlighted that some young people with learning disabilities are not provided with careers advice on employment, training and further education. There is some good practice in Scotland but this is not consistent.

Skills Development Scotland⁹⁰ is the organisation charged with the delivery of careers advice in Scotland. Skills Development Scotland provides advice on employment, training and further education opportunities and link through schools to deliver this. Skills Development Scotland has an online resource for young people called My World of Work to help them consider their future paths. The website also sets out a range of information for those young people with additional support needs.

As part of the planning for their transition, education authorities must consider whether young people with additional support needs require extra help with their plans. If they do, planning must begin no later than one year before a known transition (like post-school transition). Education authorities must exchange information with other agencies (including social work services and skills development Scotland and health boards) to inform their plans to support the young person and there is legislation in place in relation to post-school transition⁹¹.

It is recognised that there are some concerns in relation to transition planning. The long-term plan of support for implementation of the Additional Support for Learning Act sets out the work which will be taken forward to improve transition planning. The Government's response to the Doran Review details a response to the recommendations⁹².

Opportunities for All⁹³ is an explicit commitment to offer a place in learning or training to every 16-19 year old in Scotland who is not currently in employment, education or training. It requires the post-16 learning system to re-engage young people between 16 and 19 with learning or training.

⁸⁹ <http://enquire.org.uk/publications/factsheets/choosing-a-school> and <http://enquire.org.uk/20100622/wp-content/uploads/2010/11/placing-requests.pdf>

⁹⁰ <http://www.skillsdevelopmentscotland.co.uk/>

⁹¹ <http://enquire.org.uk/20100622/wp-content/uploads/2010/11/progressing-beyond-school-after-16.pdf>

⁹² <http://www.scotland.gov.uk/Publications/2012/11/6244>

⁹³ <http://www.scotland.gov.uk/Publications/2012/11/7618>

It is important that Opportunities for All ensures that people with learning disabilities are included in this commitment.

Good practice

The objective of the Borders Green Team Enterprises is to advance learning through training for work opportunities so enhancing the experience and personal development of people with learning disabilities in the Scottish Borders. The Project 'Moving it On' aims to develop collaborative working across the Scottish Borders voluntary and public sector, to increase access to training and employment opportunities and to develop sustainable income streams to grow as a social enterprise. This project is funded by the Scottish Government and funding is for a Development Worker and Outreach worker to develop their services and open up new markets to increase the numbers of trainees from 25 to 50 over the next 3 years. The project has clear and well identified outcomes which will lead to better partnership working to avoid duplication of work and resources. Awareness of disability issues will be increased to employers and communities and outreach provided in a rural region where it is estimated that around 2,000 individuals will have learning disabilities. The proposed research into barriers will provide learning and support intervention methods.

Transitions

Post-16 transitions Policy and Practice Framework: Supporting all young people to participate in post-16 learning, training or work

This Framework positions 16+ Learning Choices - the Scottish Government's national post-16 transition planning model - within the context of the delivery of both Curriculum for Excellence and Opportunities for All. It clarifies the Scottish Government's expectations for delivery and the roles and responsibilities of the partners involved in supporting young people into further learning and training and in turn progress towards and into work. It offers local partnerships a framework for extending existing approaches to post-16 transitions to ensure that all 16-19 year olds have an appropriate offer of learning or training. It encourages local partnerships to use the Framework to guide their detailed strategic and operational planning and to establish more formal agreements across and between services to ensure sustainable local delivery.

Supporting transitions for young people with additional support needs

It is recognised that some groups of young people have additional support needs and/or personal circumstances which present significant barriers to learning and employment. Some young people have particularly complex additional support needs and may not, therefore, be able to take up employment. Where there are such concerns about aspects of wellbeing, partners should work together locally - with the young person and their parents or carers – within the GIRFEC framework to ensure the young person accesses the support they need to enable them to engage in appropriate progressive activity. Inevitably, some young people might take longer to progress and local partners may wish to extend their offer of learning or training accordingly

Building on early identification and tracking of 'at risk' children and young people - an on-going priority for local More Choices More Chances Partnerships - partners should be aware of the circumstances and needs of these young people; be alert to specific issues likely to impact on their post-16 transition; and put in place the provision required to enable them to participate and progress. For these young people, needs-led targeted assessment and planning must start early, often at the transition from primary to secondary school; and should bring in wider services as appropriate, in keeping with the GIRFEC principles and approach. Where concerns about aspects of wellbeing have been identified at any stage in the learner journey, and a Child's Plan developed to address needs and improve outcomes, transition planning should build on this assessment and plan using the GIRFEC National Practice Model.

Post-16 transitions Data Practice Framework: Supporting all young people to participate in post-16 learning, training and work

The Framework sets out the roles and responsibilities of partners to effectively share data to support young people as they move through post-16 learning and training into jobs. It sets out the framework for data sharing that will allow Scottish Government and its partners to create a system of working that appropriately supports each and every post-16 learning and training transition a young person makes from age 16 up until their 20th birthday. This system of working is central to delivery of 'Opportunities for All' and will significantly reduce the risk of a young person disengaging with learning and/or training. This Framework supports the Post-16 transitions Policy and Practice Framework.

Recommendation 39

That by 2014 local authorities, further and higher education providers, Skills Development Scotland and the Transitions Forum work in partnership within the GIRFEC assessment and planning framework to provide earlier, smoother and clearer transition pathways (to include accessible information on their options, right to benefits and Self Directed support) for all children with learning disabilities to enable them to plan and prepare for the transition from school to leavers destination.

Further or Higher Education

Evidence from the evaluation and consultation of *The same as you?* has highlighted that many young people and adults with learning disabilities want to undertake courses that lead to personal development rather than repeating life skill courses, but they are unable to access such opportunities. Where the potential for development exists, young people and adults should be given the opportunity to compete for places at our colleges and universities. Seven of the 13 people interviewed in the evaluation were still attending college well over the age of 30.

It is clear that learning opportunities continue to be of importance to people with learning disabilities throughout their lives. People with learning disabilities may take longer to learn than others and may have restricted life opportunities through which to learn and practice skills. Such learning opportunities as colleges or universities provide may therefore be a chance for adults with learning disabilities of all age groups to learn skills or interests that they might not otherwise be able to develop or maintain. Continuing attendance at college or university has therefore become part of the weekly life experience of many adults with learning disabilities, giving them social opportunities to get out the house and make friends, and their experiences indicate that there is a need to develop appropriately supported continuing educational experiences that offer the opportunity to develop and maintain interests and skills. College and university courses should be seen in the context of an inclusive environment where students with learning disabilities are an integral part of student life and not segregated to special classes.

It is important that, as with any young person leaving school, the young adult with learning disabilities gets the opportunity to use further and higher education to learn skills that relate to social skill development, daily living skills and continuing education and begin what could be a

long journey for preparation to work. We must not underestimate the role further and higher education plays in assisting the transition from school and its role in personal development at all stages. Lifelong learning needs to be seen in the context of small steps at an appropriate pace.

However, in order to be accepted into college or university, students must have the potential to develop and must demonstrate progress if they are to continue on a programme of learning.

Some people with learning disabilities found it hard to relate what they were learning at college with skills appropriate to the workplace and questioned whether these courses prepare people for the workplace. There is also a need to develop more meaningful opportunities for learners with higher support needs, who must not be overlooked through the prioritisation of employability outcomes. For example, Scotland's Colleges has established a project to improve educational provision in further education colleges for young people with profound and complex needs and this type of work needs to be built upon.

Good practice

Scotland's Colleges Profound and Complex Needs project was set up to support and enhance post-school educational choices for learners with profound and complex needs.

The project concentrated on four task areas: Curriculum for Excellence, quality assurance, transitions and support. The national events focused on aspects of each of these themes and how it impacts on this learner group. Localised training, working groups and resource days were organised to fit demand.

A statement paper⁹⁴ has been produced as part of Scotland's Colleges continued work to support the development of sector provision for learners with Profound and Complex Needs. This group of learners requires a specialist response within a college setting. The paper provides clarity to that response including a definition of the learner group and the current context of this work within 'Opportunities for All.'

Recommendation 40

That by the end of 2014 SCLD in partnership with Colleges Scotland, Skills Development Scotland and ADSW consider how people with learning disabilities access educational activities and training at college and other learning environments.

⁹⁴ <http://www.scotlandscollleges.ac.uk/Supported-Programmes/profound-and-complex-needs.html>

Employment

The Scottish Government is committed to helping people with learning disabilities who want to work, and it is our ambition that with the right support, they are able to find work in mainstream employment, suitable to their skills.

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.

In 2010, Scottish Government published a Supported Employment Framework, 'A Working Life for All Disabled People'⁹⁵. Supported employment is where disabled people learn on the job, with support from colleagues and a job coach. It provides a consistent, person-centred approach and can be in the public, private or third sector environment.

In 2012, Scottish Government published 'Working for Growth, A Refresh of the Employability Framework for Scotland' where we reinforced our commitment to supported employment and built it into mainstream employment policy. We committed to working more closely with local employability partnerships so that supported employment can become a more integrated element of local services available to those seeking work. Beyer⁹⁶ 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 per year compared to £15,000 for locality support services such as day centres.

The Scottish Government is also working with Department for Work and Pensions (DWP)⁹⁷ to increase the take up of Access to Work which is a grant administered by DWP that can pay for practical support to help disabled people do their job, such as a communicator at a job interview, a support worker or any adaptations to the workplace.

⁹⁵ <http://www.scotland.gov.uk/Publications/2010/02/23093849/5>

⁹⁶ Beyer, S (2008). *An Evaluation of the Outcomes of Supported Employment in North Lanarkshire*, North Lanarkshire: North Lanarkshire Council

⁹⁷ <http://www.scotland.gov.uk/Publications/2012/09/5609>

Good practice

Project Search is a one-year training course run for people with learning disabilities who are working towards finding a job. This programme, administered by SCLD, gives students the opportunity to experience what it's like being at work, teaches them new skills and helps them understand the demands of the working world. Students work five-days-a-week at the employer's premises, combining practical learning with classroom sessions.

Monklands Hospital, Airdrie is the latest location for the Project Search initiative which provides training and education for students with learning disabilities to help them find employment. The launch at Monklands Hospital follows on from the award winning pilot initiative at Wishaw General Hospital which saw all eight of its students go on to secure employment.

"Before I joined Project Search I lacked confidence in myself," explained one of the new students. "However, the skills and work experience I am gaining through my work placements has increased my chances of getting a job. I have also made lots of friends too which has been great". The partnership project involves NHS Lanarkshire, North Lanarkshire Council, SERCO and Motherwell College.

Review of Scotland's Supported Businesses

The Scottish Government is clear that we should focus on helping disabled people enter mainstream employment wherever possible. However, we also believe that there can be a valuable role for Supported Businesses, both as a stepping stone towards mainstream employment and for those who feel unable to progress. Some supported businesses have struggled or failed recently and the Scottish Government wishes to ensure the viability of our remaining supported businesses. Last year we commissioned an independent review of Scotland's Supported Businesses which is now complete. A final report will identify the challenges these businesses face and the kind of support needed to help them survive and grow into commercial and viable businesses.

Good practice

The bread maker⁹⁸ is an exemplary emerging Social Firm in Aberdeen; a commercially focused enterprise producing high quality breads and confectionery. The purpose of their business activities is to provide

⁹⁸ <http://www.thebreadmaker.org.uk/>

meaningful employment, training, educational opportunities and social activities to adults with learning disabilities.

The Apprenticeship Scheme offers 24 adults with learning disabilities work experience within a dedicated bakery unit and welcoming coffee house. Additionally, the bread maker's continuous personal development programme ensures that everyone has the opportunity to maximise their own potential to become a fully active member of society valued for their abilities, skills and experience. An evaluative Social Return On Investment analysis assessed the impact and effectiveness of the Apprenticeship Scheme, made possible by a contract for Support Services from Aberdeen City Council, during the 2009/10 financial year. This resulted in a Social Return On Investment ratio of £4.50 of added value for every £1.00 of investment

Case study

Thomas is a man of many skills – baker, gardener, photographer, but he has never had a job. Because Thomas has learning disabilities he has spent much of his life in institutions. Now he has his own flat, an allotment, and is about to launch his own micro-business – Thomas's Cakes. He will be supported in this partly by his ELCAP⁹⁹ support staff but mainly by miEnterprise Lothian, a Community Interest Company set up, with support from ELCAP, in August 2012, based on a model developed in Hereford.

In December 2012 miEnterprise Lothian did some test trading in the form of a Christmas Fair. Thomas made a selection of Christmas cakes, which sold out, as did his hyacinth and cyclamen planters. He is almost ready to exploit his skills commercially because miEnterprise Lothian has helped him develop a business plan, identify a route to market for his products and helped him to work out how to price his wares. It has also organised insurance, banking and tax arrangements, and will provide ongoing support with budgeting, book-keeping and accounts. Thomas belongs to the miEnterprise Lothian Business Club. Other members of the club are preparing to follow him down the pathway to trading. Nicola has just negotiated the use of space at a local community centre to prepare and package soaps and other toiletries for sale. These also sold well at the Christmas Fair. Nicola plans to trade as Soap Queen and has a business plan nearly ready.

⁹⁹ <http://www.elcap.org/>

Recommendation 41

That by 2018 the Learning Disability Implementation Group works with local authorities, NHS Boards and Third Sector organisations to develop a range of supported employment opportunities for people with learning disabilities and that those organisations should lead by example by employing more people with learning disabilities.

Volunteering

Not all people with learning disabilities will be in a position to work but will take part in volunteering. 31% of those interviewed for *The same as you?* evaluation undertook voluntary work of some kind. This reflects the national data which shows that 30% of the general population volunteer. The evaluation research suggests that people with learning disabilities approach volunteering as they would, formal, paid employment and offer a significant amount of time to voluntary organisations. Volunteering offers the opportunity to develop skills for the workplace; however, it may also be acting as a substitute for paid work where people with learning disabilities are either not accessing a paid job or the number of paid hours people can work are constrained by the welfare benefit system.

People with learning disabilities said that they volunteered as administrative workers in charity shops, sales assistants in charity shops, catering assistants, gardeners, cleaners and animal care assistants. Local area co-ordinators provide a role in supporting people with learning disabilities to volunteer within their community.

Good practice

Inspire Me, a joint project between Mencap and ENABLE Scotland, is delivering community workshops that are developing skills for volunteering in young people with learning disabilities across Scotland.

Recommendation 42

That local authorities and SCLD work in partnership with Volunteer Scotland and other relevant organisations to increase the opportunity for people with learning disabilities to volunteer within their community to develop work skills.

People with profound and multiple learning disabilities



Escape

Escape harm

Alter

Alter attitudes

Enter

Enter partnerships

End

End health inequalities

home

Come home

Delete

Delete discrimination

Definitions and numbers

It is widely acknowledged that there is a group of people with learning disabilities who have a complex range of difficulties which may include:

- profound learning disabilities
- physical disabilities that limit them in undertaking everyday tasks and often restrict mobility
- sensory impairment
- complex health needs, i.e. epilepsy or respiratory problems, eating & drinking problems
- challenging behaviour
- restricted communication, i.e. pre-verbal though a small number have some spoken or signed language

People with these characteristics are described as having profound and multiple learning disabilities (PMLD) or profound intellectual and multiple disabilities (PIMD). All, however, have the capacity to benefit from good health care and are able in various ways to communicate their satisfaction or otherwise with their quality of life.

The causes of PMLD are many and varied. They include genetic disorders, acquired brain injury or brain damage as a result of infection. Causation may be ante-, peri- or post- natal. For many there is no known causation. It is estimated that the prevalence of PMLD in the general population is 0.05 per 1,000. This figure is derived from a survey undertaken in Scotland and would lead to a figure of 2,600 people with PMLD in the country. This is possibly an underestimate and a useful working figure would be 3,000. These numbers will increase with better survival rates, not only in the neonatal period but into childhood and adulthood, due to advances in medical care.

The same as you? raised awareness of people with learning disabilities and has resulted in many improvements in services for people with PMLD. People with PMLD can and do lead meaningful lives but they require a high level of support with respect to all activities of daily living. Not only do people with PMLD require fully trained staff with specialised knowledge of their healthcare and communication needs but communities need to be made fully inclusive through the provision of both intellectual and physical access. Despite improvements in service delivery in the last decade, people with PMLD still confront barriers to good quality health care, education, leisure activities and support services.

Healthcare issues for people with profound and multiple learning disabilities

Life expectation is limited for people with PMLD, but the lessons of recent decades are that with good health and social care peoples' lives may be extended far beyond the expectations of 20 years ago.

Regrettably, there are still many premature deaths of people with PMLD caused by the lack of reasonable adjustments to facilitate their survival, causing delay or problems with diagnosis or treatment¹⁰⁰.

People with PMLD exhibit a different pattern and higher frequency of health disorders which, coupled with communication challenges, leads to barriers in accessing and receiving healthcare.

Mortality is high among people with PMLD, with over 20% of people with profound and multiple learning disabilities dying in a 10 year period¹⁰¹.

The principal causes of death arise from epilepsy, respiratory problems and difficulties in eating and drinking.

The key issue for all effective health care for people with profound and multiple learning disabilities is good communication between the family, carers and all involved health professionals. The importance of listening to the families and carers and respecting their knowledge and experience must be acknowledged by all health staff. Partnership working should also be strengthened between health professionals from the community, including allied health professionals, who have specialised knowledge of persons with PMLD and the health professionals in the acute sector. Procedures should be put in place by GPs and other community health professionals so that in the event of an emergency admission all health staff are able to respond appropriately to the needs of the person with PMLD. There is a need for specialised training for all health professionals on communication and learning disabilities in general and people with PMLD in particular.

Good practice

Communication with people with learning disabilities and complex needs is a four week programme offered to medical students at the Clinical Skills Centre, Ninewells Hospital, University of Dundee, delivered by PAMIS and family carers. This highly successful programme is a self-

¹⁰⁰ Heslop, P., Blair, P., Fleming, P. et al. (2012) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). University of Bristol: Norah Fry Research Centre

¹⁰¹ Hogg, J., Juhlberg, K. & Lambe, L. (2007) Policy, service pathways and mortality: a 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, **51**, 366-376.

selected component, offered to medical students at the Clinical Skills Centre. The medical students have the opportunity to access training from a wide range of professionals and family carers. The programme also offers the opportunity to visit a variety of care settings providing services to both children and adults.

Invasive Procedures

The health-related problems described above for people with PMLD necessitate a wide range of interventions in both the family home and in the full range of services they use, including nurseries, schools, adult day and respite services as well as NHS facilities among them acute hospitals. Such procedures include dealing with gastrostomies, tracheotomies, ventilation, responding to seizures and coping with a wide range of difficulties related to continence. It must also be noted that people with PMLD are typically underweight compared to their non-disabled peers, so when prescribing the dosage of drugs this should be taken into account. Such interventions have been described as “invasive procedures”. These procedures are not only life enhancing but lifesaving.

Family members routinely provide such healthcare support, as do many of the service providers. However a recent national survey in Scotland undertaken by PAMIS and the White Top Research Unit, University of Dundee, has shown that there are still issues. The survey identified many barriers to delivery ranging from failures in policy through to lack of staff competence¹⁰². Failure to provide the needed interventions resulted in cases of exclusion from the service or family members having to attend the service to provide the support themselves, as well as unnecessary admissions to hospital. A follow up study of services that had indicated the barriers had been overcome revealed how effective, integrated strategies could be developed¹⁰³. In such cases delivery of the procedures were seen as part of the overall programme of person centred, healthcare support. In others, however, the invasive nature of the interventions set them apart as a result of the barriers encountered.

¹⁰² Garrard, B., Lambe, L. & Hogg, J. (2010) *Invasive Procedures: Minimising Risks and Maximising Rights. Improving practice in the delivery of invasive procedures for people with profound and multiple learning disabilities -Project Report and recommendations.* Dundee: PAMIS & White Top Research Unit, University of Dundee.

¹⁰³ Hogg, J. (2012) *Delivering Invasive Procedures to People with Profound and Multiple Learning Disabilities.* How service providers succeed. Dundee: PAMIS & White Top Research Unit, University of Dundee.

There is also a growing trend for health professionals to suggest that enteral feeding should be the preferred option rather than looking into other ways of preventing aspiration. The enjoyment of eating is one of the pleasures for people and removing that should only occur as a last resort. There are regional pockets in Scotland where there are significant increases in the numbers of people with PMLD being fed non-orally. Some further research on the necessity of non-oral feeding is merited and should be conducted in the context not only of health requirements but also the impact on the quality of life on the person and their family.

In response to the research and its recommendations, the Scottish Government established a Short-Life Working Group, led by PAMIS, to develop a Scottish quality framework for the delivery of invasive procedures in a variety of settings. In addition, to the framework, a toolkit will be developed to support statutory and third sector organisations in all service settings, using good practice examples gathered by the group.

The outcome of these initiatives will be the development of an approach in Scotland that guarantees equity of healthcare treatment for all people with profound and multiple learning disabilities - regardless of the extent and complexity of their needs.

Recommendation 43

That all stakeholders involved with people with PMLD commit to the implementation of the Scottish Quality framework for the delivery of invasive procedures, which will be launched in Autumn 2013.

Annual Health Checks

There is clear evidence to suggest that the provision of regular health checks for people with profound and multiple learning disabilities by their GPs would be highly effective in identifying previously unrecognised health needs and so reduce the health inequalities faced by people with PMLD¹⁰⁴. People with PMLD cannot communicate in conventional ways when they are in pain and often it is only a change in their behaviour that gives an indication that they are experiencing pain. Public health programmes such as breast and testicle self-examination do not take

¹⁰⁴ Turner, S. (2013) *Improving the uptake of health checks for adults with learning disabilities: evidence into practice report no.6*. Improving Health and Lives: Learning Disability Observatory

into account people who do not have the capacity to carry out such examinations. Gastro-oesophageal Reflux Disease (GORD) is another common health issue for people with PMLD. This is a preventable condition which happens when the acid in the stomach washes back into the bottom of the oesophagus. As a consequence, the lining of the oesophagus becomes chemically 'burnt' which can lead to other problems

People with PMLD are also susceptible to infections from helicobacter pylori which can, if undetected, lead to stomach cancer.

Annual health checks would identify health problems at an earlier stage and reduce hospital admissions.

Oral Healthcare

People with PMLD experience inequalities in oral healthcare. There are recent examples where people with PMLD are subjected to a general anaesthetic in order to carry out an examination or basic treatment of their teeth. The wait for treatment of this kind can be over 18 weeks in some NHS areas. This is not acceptable, especially if someone is in pain from toothache. Conscious sedation is a less invasive method to enable an oral examination when a person with PMLD does not comply with treatment. The recently updated Clinical Guidelines and Integrated Pathways for the Oral Health Care of People with Learning Disabilities¹⁰⁵ describes current guidelines.

Additional training is also required for medical professionals in the role of the Welfare Guardian and to make sure this role is recognised and respected. Many families have experienced situations where this has not happened. Depending on the powers that a Welfare Guardian has and the urgency of the situation, no medical procedures should take place without the approval of the Welfare Guardian.

Transitions for people with profound and multiple learning disabilities

People with profound and multiple learning disabilities go through a number of transitions during their lifetime. The most problematic of these

¹⁰⁵ British Society for Disability and Oral Health & Faculty of Dental Surgery (2012) *Clinical Guidelines and Integrated Pathways for the Oral Health Care of People with Learning Disabilities: Reviewed and Updated 2012*. London: The Royal College of Surgeons of England

being the transitions from child to adult services and from the family home to supported living.

Child to adult services

Moving from child to adult services is often described by family carers as ‘the black hole of transition’. During their school years all of the needs of the person with profound and multiple learning disabilities, that is education, social and health, are generally met. Regrettably, this is not always the case once they move to adult services. Planning is not started early enough and recommendations from the Scottish Government state that such planning should take place no later than 12 months before a child leaves education¹⁰⁶. Research shows that there is a marked reduction in the availability of services, e.g. speech and language therapy, short-breaks, home nursing etc. once the person leaves full time education¹⁰⁷. Recommendation 11 of the Doran Review¹⁰⁸ acknowledges the need to consider the adequacy of existing legislation to ensure the transition from child to adult services for young people with complex support needs is properly coordinated, managed and delivered. There is also a need for independent advice and support for families where a daughter or son with PMLD is going through this transition.

Good practice

PAMIS Future Choices Project provides independent advice and support to the person with PMLD and their family through the process of transition from child to adult services. A Transition Planner and a Personal Communication Passport have been developed by PAMIS for each young person. These documents are person-centred and record all their specific needs and aspirations. The project collates information from education, social work and social care staff who are involved in the transition process to enable new health and social care professionals to get to know the individual. The project provides support to the whole family before, during and after the transition process.

Case study

Ann is a young woman with PMLD and complex health needs. She is approaching her final year at the community school she currently

¹⁰⁶ Scottish Government (2010) *Supporting children’s learning: code of practice*, revised edition. Edinburgh: Scottish Government.

¹⁰⁷ Mansell, J. (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities*. Tizard Centre: University of Kent.

¹⁰⁸ Scottish Government (2012) *Meeting the needs of Scotland’s children and young people with complex additional support needs: the Scottish Government’s response to the Doran Review*. Edinburgh: Scottish Government.

attends. Ann would like to attend college on leaving school and plans are underway to enable her to undertake a one a day week transition placement at the college. To ensure Ann gains maximum benefit from her transition year at college her future planning documents include a physical healthcare pathway that highlights the specialist equipment that she needs to enable her to maintain good physical health and the support required to access that equipment.

At school Ann currently requires to be supported by two Support for Learning Assistants for personal care and moving and handling to facilitate transfers to her standing frame, Samson chair or ladderback walking frame. Ann also has access to adaptive technology such as 'Big Mack' switches, switch adapted food mixer and touch screen monitor for PC. This equipment ensures that Ann has maximum opportunity to achieve both physical and intellectual access to appropriate learning opportunities.

Including a physical care pathway in her outcomes based planning process for transition means that the benefits Ann gains from using the equipment is recorded and the support she requires to access it is also recorded. The inclusion of the physical and intellectual benefits Ann gains from the use of this equipment is transparent. The recording of the support Ann requires to benefit from access to this equipment ensures that any future financial impact on adult service provision is also transparent. Including a detailed physical care pathway in transition planning documents that clearly identifies the benefits of the use of specialist equipment and the support required to access the equipment, will help ensure that someone with PMLD continues to benefit from physical and intellectual access to opportunities for further development entering adult services.

Moving from the family home to supported living

The majority of people with PMLD live at home with their families although a significant number have moved into supported living accommodation. It is very important for the long term success of supported living arrangements that family carers are involved at the planning stage to ensure that any move has a successful outcome.

Family carers know their relative best and their input is crucial to any discussions or decisions being made. Any package of care being considered must be person-centred in order to successfully meet the needs of the person with PMLD. It is also essential that planning is

carried out in plenty of time to allow accommodation to be built around the needs of the people rather than adapting existing housing to meet the needs of the intended occupants.

PAMIS' consultation with family carers found that there was strong consensus that adult services should consist of both educational and leisure activities and that there is structure and continuity to these activities. There is a growing trend in some areas towards a timetable made up entirely of different leisure activities; such activities should, however, be meaningful. These principles are laid out in *Make my Day*¹⁰⁹ and are still completely relevant and applicable seven years later. The only change has been the method of funding these services.

Meaningful activities for people with profound and multiple learning disabilities

People with profound and multiple disabilities and their family carers are all too often excluded from community activities that the rest of us take for granted. However, with the right levels of support and commitment in health, education and adult services, people with PMLD have a great contribution to make to the lives of others and can lead fulfilling lives as equal members of the community.

Accessing Further and Continuing Education

There has been some progress with opening up college courses for adults with learning disabilities. This is a most valuable source of learning but, as a recent report demonstrated¹¹⁰, there have been many cuts to college places for students with learning disabilities.

There is an urgent need for colleges and their courses to become both physically and intellectually accessible to students with PMLD. Courses must also be meaningful and learning based, as defined by Scotland's Profound and Complex Needs project team. This project has made great strides in really listening to family carers and professionals supporting them and in ensuring they now offer courses that are accessible to

¹⁰⁹ Scottish Executive (2006) *Make my day! The same as you? National Implementation Group: report of the Day Services Sub Group*. Edinburgh: Scottish Executive.

¹¹⁰ SCLD (2011) "If I don't get a place next year, I don't know what I'll do": Joint SCLD Briefing on the impact of changes to the funding of students with learning disabilities within Scottish Further Education. SCLD: Glasgow

people with PMLD. Dundee University has developed a resource for college staff on PMLD¹¹¹.

Accessing day opportunities

It is important that whatever day opportunities are on offer have a local base where the service users can have their personal and intimate care needs met safely and with dignity. Such a base enables the person to access activities in their local community while at the same time ensuring they also have available centre based activities such as multi-sensory storytelling, music and relaxation and, most importantly, a place to rest.

Good practice

Responding to the Scottish Government's Modernising Day Services consultation, South Lanarkshire Council committed to continue to offer services from centres for adults with learning disabilities. They developed a model where their day centres would become community buildings offering not only a service to people with learning disabilities, but a resource for the wider community. People with PMLD access these community centres as they are accessible environments and all include personal care areas, including Changing Places toilets¹¹².

Changing Places Toilets

The lack of suitable changing facilities in toilets in the community is one of the most restrictive practical problems preventing people with PMLD from going out and about and participating in everyday activities. This results in:

- families changing their daughters or sons on toilet floors, which is undignified and unhygienic
- heavy lifting by the carers with the potential to cause serious damage to their back.
- families opting to stay at home which increases isolation and lack of stimulation.

¹¹¹ Campbell, M. & Hogg, J. (2012) A History of Significant Research on Teaching People with Profound Disabilities: Implications for Practice. An online training resource for FE staff. Scotland's Colleges, Stirling.

¹¹² Morrison, M. (2011) New style day services in South Lanarkshire: Providing opportunities for lifelong learning and inclusion for people with PMLD. PMLD Link, **22**, no. 3, 11 – 14.

Changing Places is a UK-wide campaign with the aim of ensuring fully accessible toilets with hoists and changing benches are readily available. The campaign was started by PAMIS which has now joined forces with other groups to form the UK Changing Places Consortium.

The Consortium is led and chaired by PAMIS and Mencap and is working with four countries of the UK - Westminster, The Welsh Assembly, Northern Ireland Executive and the Scottish Government, led by Westminster's Department of Communities and Local Government. The consortium will develop a Voluntary Charter to which major providers and industries will agree to implement the provision of changing places facilities across the UK.

There are now over 500 such facilities in the UK with 84 in Scotland. The Consortium has also been successful in obtaining a standard for Changing Places facilities incorporated into the British Standards¹¹³. Architects use these standards and regulations when they are designing new public buildings.

Scottish Building Standards currently include some information about changing places toilets. At the time of writing, consideration is being given to strengthening this information for the purpose of further raising awareness of Changing Places toilets. The proposed guidance includes additional information about Changing Places toilets and acknowledges the importance of providing a network of these facilities throughout the country.

The Scottish Government and PAMIS will work together to ensure the Charter is implemented in Scotland.

Appendix 5 shows an example of a layout with essential equipment of a Changing Places toilet

Recommendation 44

That a sub group of the Learning Disability Strategy Implementation Group is set up to work together to increase the number of Changing Places toilets in Scotland to 100 by June 2015 using the conclusions and recommendations set out in the Scottish

¹¹³ BSI British Standards (2009) *Design of buildings and their approaches to meet the needs of disabled people – Code of practice*. London: BSI British Standards

Government's report 'Changing Places Toilets'¹¹⁴ and by implementing the UK wide Changing Places Consortium's Voluntary Charter in Scotland.

Bereavement and loss for people with profound and multiple learning disabilities

For people with PMLD, the experience of bereavement is further complicated due to the barriers of communication that make it difficult for them to identify and respond to their grief. Research into the mental health of people with PMLD identified bereavement as a key factor in poor mental and physical health¹¹⁵. There is a clear need for more specialist resources that enable people with PMLD to understand that something significant has happened and provide a way of communicating about bereavement.

Good practice

To date, the PAMIS Bereavement and Loss Project has held a range of meetings with parents, carers and professionals from the Tayside, Grampian and Glasgow areas. The aims of these focus groups were to explore the experience of bereavement for people with PMLD and how they can be better supported. The resource pack and training materials which PAMIS is developing will share these experiences with other parents, paid carers and professionals. These resources are intended to inform and provide general guidelines and approaches that those supporting people with PMLD should use in ways appropriate to the individual and his or her experience and situation. This work is due to be completed by October 2013.

Many therapeutic approaches have been explored with people with learning disabilities, including storytelling. One such range of books, *Books Beyond Words*, tells stories using illustrations to help people with learning disabilities explore and understand their experiences. Those books which best illustrate bereavement include, 'When Mum Died', 'When Dad Died' and 'When Somebody Dies'.

Other storytelling methods include life story work, which allows the grieving person to share and explore aspects of their relationship with the person who is now gone (Read, 2007). PAMIS are now working collaboratively with international colleagues to develop stories for people with PMLD on the topic of bereavement and loss. It is hoped that these stories can also be used more widely with all people with learning disabilities.

¹¹⁴ Building Research Establishment (BRE) Scotland (2012) *Changing Places Toilets*. Edinburgh: Scottish Government

¹¹⁵ Phillip, Lambe & Hogg, 2005

Criminal justice



shift

Culture shift

control

In control

Alter

Alter attitudes

Delete

Delete discrimination

Criminal Justice System

People with learning disabilities come into contact with the Scottish criminal justice system as:

- Witnesses
- Victims
- People accused or suspected of a crime
- People convicted of a crime.

People with learning disabilities are more likely than other people to become victims of crime because of:

- Limited ability to identify risky situations
- Lack of understanding of the motivation of others
- Communication difficulties
- Poor social understanding
- More prone to being tricked, deceived or exploited by others.
- Being targeted as 'easy victims' who will not report crimes to the authorities.
- Being more likely to live in high crime neighbourhoods.

The Offences (Aggravation by Prejudice) (Scotland) Act 2009 was introduced which means that any criminal offence committed against a person or property that is motivated by hostility towards someone based on their disability is a hate crime.

The Scottish Government believes that there is no excuse for any form of hate crime: it is simply not acceptable and it will not be tolerated. When it does happen, we want the justice system to deal with such crimes effectively so that victims have the confidence to report it, secure in the knowledge that they will receive a good level of service from the police and other agencies.

'Hidden in plain sight' is a report of an inquiry into disability-related harassment published by the Equality and Human Rights Commission in 2011. The report said that harassment is a commonplace experience for disabled people, but a culture of disbelief and systemic institutional failures are preventing it from being tackled effectively. As well as reporting on the extent of harassment, the report makes recommendations to public authorities to help them deal with the problems uncovered, such as, all individuals and organisations should know how to recognise report and respond to disability-related harassment.

Joint working between agencies, such as health, social work, housing, education and criminal justice services, is needed to help keep people with learning disabilities safe and provide the support they need.

The Scottish Government published a series of easy read booklets in March 2011 for people with learning disabilities and the criminal justice system¹¹⁶. These booklets were intended to give people with learning disabilities enough information to be better able to exercise their rights and responsibilities within Scotland's criminal justice system. A resource for professionals was also produced.

Advocacy services can be very helpful to individuals with learning disabilities who are involved in the criminal justice system and will help them to speak up for their rights in that context. More information on advocacy can be found at www.siaa.org.uk/content/view/14/27/

Police Scotland has also recently published its equality strategy¹¹⁷.

Victims and witnesses

In 2010-11, 35% of those people reported as having learning disabilities reported that they had been a victim of crime – this compares with a Scottish average of 18%.

Where there is a significant risk that the quality of their evidence will be diminished by reason of mental disorder, as defined in section 328(1) of the Mental Health (Care and Treatment) (Scotland) Act 2003 (i.e. “any mental illness, personality disorder, learning disability however caused or manifested”), witnesses (and victims who are witnesses) are considered to be vulnerable and are entitled, at the discretion of the court, to use special measures to assist them give their evidence. The special measures are a live television link, a screen, a supporter, giving evidence in chief in the form of a prior statement and taking evidence by commissioner.

The Victims and Witnesses Bill was introduced to the Scottish Parliament on 6 February 2013. It makes a number of changes to improve the way in which vulnerable witnesses are identified and supported when required to give evidence. One of these changes is to give Scottish Ministers an Order-making power which will allow limited

¹¹⁶ <http://www.scotland.gov.uk/Topics/Health/Support-Social-Care/Support/Learning-Disability-Autism>

¹¹⁷ <http://www.scotland.police.uk/whats-happening/news/2013/May/165803>

pilots to be carried out of new special measures, to allow these to be tested and evaluated before deciding whether they should be rolled out across Scotland.

The impetus behind this is that there are no special measures at present which offer support specifically to those with communication needs. The Scottish Government consider that such measures could be of use to some vulnerable witnesses. Intermediaries and witness profiling are two promising measures which have been suggested to date – there may well be more. Intermediaries may be useful in ensuring that witnesses with communication support needs can understand questions put to them and can communicate their answers effectively, and witness profiling would allow an assessment of the individual's potential to be a credible and competent witness to be presented to the court before any trial. The Scottish Government intend to study these in more detail to see whether there is merit in piloting either or both of these measures. All of the provisions in the Bill are intended to apply equally to all victims and witnesses, including those with learning disabilities.

More generally, the Scottish Government is working to improve the process of witness citation. The aim is to make the process easier to understand for all, including those with learning disabilities. The aim is to introduce measures that improve the likelihood of cases going ahead and to reduce the number of times that people are called to court.

Accused or suspected of committing a crime

People with learning disabilities who are accused or suspected of committing a crime will often require extra support to help them understand the criminal justice system and to ensure that the treatment they receive within that system is fair and equal to other people in the same situation.

It is important that professionals working in the criminal justice sector are aware of the steps that they can take to ensure that a person with learning disabilities can access suitable mechanisms to provide the additional support that they need. This can assist in explaining and understanding the criminal justice system and what is happening to the individual, as well as assisting the relevant agency to get the information required.

A guide explaining the role of the various agencies was produced in 2011 entitled 'People with Learning Disabilities and the Criminal Justice

System'. This provides useful information for police, lawyers, court staff, social workers and prison staff to assist them to deal effectively with people with learning disabilities, of people who they suspect may have learning disabilities.

More work is needed to ensure that this guide is readily available to practitioners and that they are supported to implement its findings.

Criminal Justice (Scotland) Bill

The Criminal Justice (Scotland) Bill, planned for introduction to the Scottish Parliament in 2013, will implement the recommendations of Lord Carloway in his expert Review of Criminal Law and Practice (2011). Under the changes recommended by Lord Carloway, the revised criminal justice system will start from a simplified, unitary system of arrest, on reasonable grounds for suspicion, and detention. An arrest will trigger a set of rights for the suspect securing access to a lawyer, with particular protections for child suspects and vulnerable adults. These protections will ensure that the specific needs of vulnerable individuals are met, including those with learning disabilities, and that such individuals are fully supported and able to participate in the investigation.

Fundamental to ensuring people are fully supported in the criminal justice system in Scotland is the service delivered by Appropriate Adults. The current non-statutory role of an Appropriate Adult is to facilitate communication during police procedures between the police and adult suspects, accused, victims, and witnesses (aged 16 or over) who have a mental disorder or learning disability. Appropriate Adults are specifically recruited for their experience (professional or otherwise) in working with mentally disordered people, and their communication skills. They are often social workers or health professionals (although they do not fulfil the Appropriate Adult role in that professional capacity). Appropriate Adults are expected to successfully complete nationally recognised training and follow the Scottish Appropriate Adult Network National Guidance.

Lord Carloway's Review made recommendations in relation to individuals who have permanent or semi-permanent vulnerabilities that affect their fitness to be interviewed, when arrested and detained as a suspect by the police. Individuals with learning disabilities may be assessed as vulnerable. In brief, the provisions will provide a succinct and accessible statutory definition of a vulnerable adult suspect (aged 18 or over). The provisions will also define the role of an Appropriate

Adult in supporting such suspects, thereby establishing in statute the existing role currently delivered by the non-statutory service.

Another recommendation from the Review, is that a 'Letter of Rights' be introduced without delay. The Letter of Rights will provide all suspects held in police custody with written information on their procedural rights under the European Convention on Human Rights, as provided for in domestic legislation. The Scottish Government has held informal discussions with third sector and voluntary organisations, including advocacy organisations for people with learning disabilities, to determine how best to make such a document accessible to people with learning disabilities. The Government plans to continue working with these organisations to design and introduce an easy-read version of the Letter of Rights in Scotland, which will enhance accessibility to important information on an individual's rights and ensure those with learning disabilities are able to participate effectively in the criminal justice system and are fully aware of the support services available.

Young People

The Scottish Government recognises young people in the Justice system as one of the key groups of young people who need more choices and chances to keep them engaged in learning and supported to make positive life choices. Building on early identification and tracking of 'at risk' children and young people - an ongoing priority for local More Choices More Chances Partnerships - partners should be aware of the circumstances and needs of these young people; be alert to specific issues likely to impact on their post-16 transition; and put in place the provision required to enable them to participate and progress. For these young people, needs-led targeted assessment and planning must start early, often at the transition from primary to secondary school; and should bring in wider services as appropriate, in keeping with the GIRFEC principles.

Partners will recognise that some groups of young people have additional support needs and/or personal circumstances which present significant barriers to learning and employment. Some young people have particularly complex additional support needs and may not, therefore, be able to take up employment. In such cases, partners should work together locally - with the young person and their parents or carers - to ensure the young person can engage in appropriate progressive activity. Inevitably, some young people might take longer to

progress and local partners may wish to extend their offer of learning or training accordingly.

Recommendation 45

That with immediate effect, justice organisations should ensure they develop easy read and other accessible information resources for all literature they produce that is available to the public.

Recommendation 46

That a national criminal justice action group to be established in 2013, consisting of professionals in this field and working in partnership with people with learning disabilities, to identify challenges and promote opportunities and influence change and to provide support for people with learning disabilities in the criminal justice system.

Recommendation 47

That by the end of 2014 all relevant organisations to review and implement recommendations of ‘No-One Knows – Prisoners with Learning Difficulties and Learning Disabilities, Scotland’ where they have not already.

Recommendation 48

That all professionals involved in the criminal justice system have access to the 2011 guide ‘People with Learning Disabilities and the Criminal Justice System’ and consider how they can best support people with learning disabilities in that context.

The newly constituted Equalities sub – group of the Justice Board, representing all policy and operational interests in Justice, will oversee progress in implementing these recommendations.

Prison Health

There is an increasing focus on people with learning disabilities entering the Criminal Justice System in Scotland. There is a range of factors that contribute to offending behaviours in people with learning disabilities including substance misuse, communication disorders and challenging behaviours relating to co-existing pervasive developmental disabilities,

such as Attention Deficit Hyperactivity Disorder, Feotal Alcohol Spectrum Disorder and Autistic Spectrum Disorder. There is clear international evidence of the co-existing complex health needs experienced by people with learning disabilities which include both mental and physical challenges.

As the population of people with learning disabilities increases, with a rise in the number of young people with developmental disorders and the associated health needs and complex behaviour presentations, there is a need to understand and analyse the nature and extent of the health and support needs of people with learning disabilities within the criminal justice system to ensure that their distinct needs are recognised and addressed. Offender rehabilitation programmes need to be reviewed and amended so that these are responsive to their specific needs thereby aiming to minimise reoffending and victimisation.

Recommendation 49

That research will be undertaken across the Criminal Justice System in Scotland by Scottish Consortium for Learning Disability and NHS Greater Glasgow and Clyde to understand and analyse the nature and extent of the health needs of people with learning disabilities within the criminal justice system to support the development of appropriate responses that address the distinct health and rehabilitation needs.

Complex care



Escape

Escape harm

shift

Culture shift

Alter

Alter attitudes

Enter

Enter partnerships

End

End health inequalities

home

Come home

Delete

Delete discrimination

Complex Care

The term complex care is generally used to describe people with learning disabilities who require more intensive support and includes people with challenging behaviour, autism spectrum disorder, mental health needs, people with profound and multiple disabilities, offending behaviour, or a combination of these. The last two groupings are discussed in some depth in the chapters on people with profound and multiple learning disabilities and criminal justice.

Definitions and Numbers

Although much is written regarding definitions and descriptors of complex needs, the reality is that, any need is as relatively 'complex' as the ability of services to respond to it. The challenges can be minor to major and can be addressed in the community at times but in other instances in-patient support will be needed.

Definitions and criteria continue to be a source of ongoing debate as there is a legitimate view that someone whose behaviour presents a challenge may be doing so because their needs are not being recognised or responded to appropriately. The challenges take many forms including aggression, self-harm, destructiveness and disruptiveness. The term is also used when a person's behaviour puts them or those around them at risk of harm or leads to poorer quality of life.

But, as the Mansell Report¹¹⁸ made clear, quality services for people with learning disabilities should be able to provide sufficiently skilful support to prevent problems arising in the first place, to manage them when they occur and to implement relatively sophisticated long-term arrangements for management, treatment and support.

If this was the case, then specialised challenging behaviour services will then be able to focus on people who present the greatest challenges. It is those who present these severe challenges that this strategy focuses on. The most frequently used definition is that 'severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is

¹¹⁸http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities¹¹⁹

Over the past 10 years Positive Behaviour Support has become internationally recognised as the most appropriate, person-centred, and value-based approach to challenging behaviour¹²⁰. This includes functional assessment of behaviours, and the need for a range of proactive and reactive strategies to address the behaviour over time, recognising that for some people, challenging behaviour is a long-term and chronic issue in their support. Positive Behaviour Support is the recommended approach to supporting people with learning disabilities who also have behavioural difficulties.

Good practice

In order to address the recommendation from the Mansell Report on skilling up local agencies to increase their ability in supporting people with complex needs and significantly challenging behaviour, The Richmond Fellowship have developed and delivered a Professional Development Award in Management of Behaviour Support. This is a university accredited qualification in Positive Behaviour Support-the only one of its kind in Scotland.

For some people with learning disabilities and challenging behaviour, restrictive interventions may be necessary. Restrictive interventions, such as physical restraint, and other types of restriction e.g. seclusion, are still a significant element of support for people with challenging behaviour and complex needs; however there is a lack of clear guidance or standards for use, particularly for community-based social care services. This is a complex and controversial area, but the MWC provided guidance on the use of seclusion¹²¹ in 2007 and new guidance is expected soon.

Taking the eSAY figure of approximately 26,000 adults known to services as of 2011 and applying Emerson's suggested prevalence rate of 10-15% equates to between 2,600 and 3,900 individuals who may present such a challenge¹²².

¹¹⁹ Emerson, 1995, 44

¹²⁰ Carr, E.G., Horner, R.H., Turnbull A.P., Marquis, J., Magito-McLaughlin, D., McAtee, M.L., Smith, C.E., Anderson-Ryan, K., Ruef, M.B. & Doolabh, A. (1999) Positive Behavioral Support for People with Developmental Disabilities: A Research Synthesis. Washington: American Association on Mental Retardation.

¹²¹ <http://www.mwcscot.org.uk/media/51894/The%20use%20of%20seclusion.pdf>

¹²² Emerson et al 2000

Autism Spectrum Disorder

The Scottish Autism Strategy defines autism spectrum disorder as a lifelong developmental disorder that affects people differently, with some individuals being able to live independently whilst others will need very specialist support. It makes clear that what everyone with the condition will have in common is difficulty in three areas of functioning which are sometimes referred to as the triad of impairments. What this means is that people are likely to experience problems with communication and social interaction and may also exhibit restrictive, repetitive and stereotypical routines of behaviour.

Recent studies suggest that a rate of around 1 in 100 is currently the best estimate of the prevalence in children and adults¹²³. Based on eSAY figures and an adult prevalence of around 20-33%¹²⁴, there are between 5,200 and nearly 8,600 adults with learning disabilities who also have autism.

Mental Health

The Scottish Government Mental Health Strategy 2012-15¹²⁵ is directed at both improving mental health and treating mental illness and many of the commitments made there apply to people with learning disabilities as to any other citizen.

Again terminology is problematic here but the Strategy defines a number of terms. The first is 'mental illness' where there is or may be a diagnosis of a particular condition within a document such as the ICD 10 Classification of Mental and Behavioural Disorders published by the World Health Organisation. The term 'mental disorder' refers to the broader category of personality disorder and mental illness which follows the definition made in section 328 of the Mental Health (Care and Treatment) (Scotland) Act 2003¹²⁶. Under this section people with learning disabilities are defined as having a mental disorder. 'Mental health problems' refer to the more ambiguous territory which includes those with illness but also those facing challenges to their psychological wellbeing but who do not have a persisting mental illness or disorder.

¹²³ National Statistics, 2004, Chapter 8 www.esds.ac.uk/doc/5269/mrdoc/pdf/5269technicalreport.pdf

¹²⁴ Emerson & Baines, 2010

¹²⁵ <http://www.scotland.gov.uk/Publications/2012/08/9714>

¹²⁶ <http://www.legislation.gov.uk/asp/2003/13/contents>

MWC are notified of every person subject to compulsory treatment under the Mental Health Care and Treatment (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2001¹²⁷ and the Criminal Procedures (Scotland) Act 1995¹²⁸. The MWC carries out a Learning Disability Census every two years which highlights the numbers of people with learning disabilities who are subject to compulsory treatment. In 2008 the figure was 272, in 2010 it was 338 and in 2012 it was 351. In terms of the latter figure, 78% (272) were in-patients of which 89% (242) were in specialist beds and 25% of whom had an additional diagnosis of autism or probable autism. The Commission do not hold figures on those that are not compulsorily detained.

It is also known that people with learning disabilities tend to be subject to compulsion for longer than those without. In 2010, the median length of compulsion for those with learning disabilities was 3.5 years compared with 1.7 years for those without learning disabilities.

It is crucial to have well planned, robust and agreed eligibility and admission/discharge criteria, care pathways and interface between general psychiatry and learning disability services for people with mental health problems to ensure that people with learning disabilities receive the most needs responsive services.

Progress on complex care delivery since *The same as you?*

This section attempts to describe progress since *The same as you?* in terms of complex need but in so doing does not break down the commentary into specific observations on assessment and treatment or forensic or challenging need. Whilst it focuses primarily on NHS provision there are aspects that refer to both local authority and care home provision. The aspiration here is to provide a high level set of observations on which to build the considerable and sustained work that is still needed.

The same as you? acknowledged that in closing long-stay hospitals that there would still be a need to retain a small number of in-patient beds. These were identified as being for a range of specific purposes. The first was for those whose need for specialised or complex health assessment or treatment could not be met in the community (probably not more than

¹²⁷ <http://www.legislation.gov.uk/asp/2000/4/contents>

¹²⁸ <http://www.legislation.gov.uk/ukpga/1995/46/contents>

150 to 200 people in Scotland). The second group was people on statutory orders some of whom will be offenders with mental health problems. The third group was a small number of people whose treatment may be lengthy or who need a more supportive setting for a long period.

An annual single occasion survey of the use of learning disability In-patient services has been carried out since 2007¹²⁹ with the support of the Royal College of Psychiatrists in Scotland. Since 1980, there has been a reduction in adult in-patient beds from over 7,000 to the May 2012 census figure of 318. This figure falls within *The same as you?* estimate of a requirement of between 300-400 places across Scotland.

The same as you? also recommended that Health Boards should aim to reduce their assessment and treatment places specifically for people with learning disabilities to four for every 100,000 population across the country as a whole and that they should plan for appropriate community services to avoid in-patient assessments and treatment.

Considering the information from the 2012 single occasion survey, half of Scotland's NHS Board areas appear to have met this target whilst there are five Boards who have more than double the number of recommended In-patient beds.

The same as you? also recommended 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.

Although the programme of closure of long-stay hospitals for people with learning disabilities was realised by the mid to late 2000s, some NHS Boards have still not made community-based service re-provision for individuals in 'longer-stay' NHS residential services as opposed to In-patient assessment and treatment beds, and some of these longer-stay beds remain on the geographical site of the former long stay hospitals.

Of the 318 individuals identified in the 2012 survey, 52 individuals have been placed out of local learning disability services. Additionally, 78 of these 318 have been admitted to current In-patient services directly from long-stay Hospitals and 97 individuals had been in 'hospital' for more

¹²⁹ Perera, C., Simpson, N., Douds, F., Campbell, M., (2009) A survey of learning disability services in Scotland in 2007. *Journal of Intellectual Disabilities* 13:161.

than 5 years. 88 individuals (around 27%) were categorised as delayed discharges.

Delayed Discharge

A delayed discharge occurs when a person cannot be discharged from hospital once treatment has been completed because care in a more appropriate setting is not available.

Delayed discharge is a common challenge in most European nations and one that few healthcare systems have successfully eradicated. Significant progress has been made in Scotland since numbers peaked in October 2001. At that time there were 2,162 people delayed for more than 6 weeks and the average length of delay was 153 days. This compares with January 2013 when 57 people were delayed for more than 6 weeks and the average delay had reduced to 21 days.

However, it is clear that too many people still wait too long to be discharged from hospital once treatment is completed. New targets have been set for the maximum timescale for delays, and no person should now be delayed for longer than 28 days. This will reduce to 14 days by April 2015. Integration of adult health and social care will go a long way to reducing delayed discharges.

An important factor in the management of delayed discharge is the mechanism for reporting these numbers through a single NHS system with robust governance and performance frameworks. For people with learning disabilities leaving a period of hospital admission is often reliant on a multi-agency approach. This requires a joint reporting system between health and local authority partners. Having health & social care integration provides opportunities for local services to work more closely together in minimising any length of stay within NHS provision for people with learning disabilities.

Additionally, integration will provide opportunities to strengthen joint planning, commissioning, provision and governance in services for people with complex needs. There should be more early and intensive involvement with care providers in the planning and delivery of more specialist and individualised services and supports for people with complex needs.

The Scottish Government aims to support people closer to home, or within their own homes, avoiding hospital admission where ever possible

is equally applicable to people with learning disabilities. For many people with learning disabilities this requires a flexible approach to prevent admission to NHS beds. However, for some people a prolonged period of challenging circumstances can lead to irretrievable placement breakdown and crisis resulting in admission to ensure safety and protection from harm.

On admission many people will have experienced a complete breakdown of their placement. Assessment and treatment can be a fairly quick process for some where a change of environment, medication review or more intensive support has been required. The process of discharge however may involve the re-commissioning of a complete package, identifying suitable accommodation and development of a support provider.

From the point of 'ready for discharge' where there is joint agreement between NHS and local authority colleagues discharges which are complex in nature can take an extended period of time to achieve. Where there are additional complexities or disputes over funding this can extend considerably.

Case study

John is a young man with learning and physical disabilities who is energetic enthusiastic and always on the go. He lived at home with his family until his late teens when he moved into his own home supported by a third sector provider. Initially, he established good relationships with his support staff but found it difficult to focus on everyday tasks. John wanted to make friends, to find a girlfriend and to be free from the stigma of constant support from others.

John began to challenge what he viewed as control and a focus on things that didn't interest him. He was frustrated at the lack of understanding others had of his speech and the relationship with his support staff began to deteriorate. He was determined to go out without support and often found himself in situations he hadn't planned for or couldn't cope with. A downward spiral of events led to a decision to initiate welfare guardianship.

Within a matter of months his placement broke down and he was admitted to a mental health facility against his wishes. He challenged the staff and attempted to leave. At this point it was difficult to envisage how he could be discharge to a community setting. John lived in this ward for nearly nine months before he was referred to the learning disabilities In-

Patient Service and was transferred to a small unit. This was designed to look at feel like a flat, but was part of a bigger NHS admission service.

The staff team developed a support plan based on positive behavioural support and John found it easy to communicate with them. After about 12 months he was less impulsive, able to think through his decisions and plan his day, his relationships improved and his detention was revoked. A major challenge was his desire to live in another local authority area and the additional complexities surrounding this. John's discharge was becoming considerably delayed.

Senior NHS staff and local authority colleagues met him to consider what was required to fulfil his wishes. It would involve negotiations between a number of local authorities and an appraisal of the achievable options within a reasonable timescale. An action plan describing the milestones to be achieved and escalation of potential disputes would need to be developed.

Within three months an agreement was reached to provide support within a neighbouring local authority area and accommodation found. Support providers were introduced to the NHS team to establish a sound understanding of John's needs and his future needs. A discharge plan was agreed and date for discharge set. He is now settling in to his new life.

Out of Area placements

Individuals with challenging behaviour, complex mental health problems, autistic spectrum disorder and those who offend are at particular risk of being placed out of area¹³⁰. Additionally there is a requirement for specialist education and/or specialist health care to be precipitant factors¹³¹.

Out of area placements for people with learning disabilities are not a new phenomenon (Allen 2008)¹³² and these appear to generally be a

¹³⁰ Allen, D, Lowe, K, Brophy, S & Moore, K (2007) ; ' Predictors, costs and characteristics of out-of-area placements for people with intellectual disability and challenging behaviour'. Journal of Intellectual Disability Research 51(6) 409-16

¹³¹ Brown, M and Paterson, D (2008) ; ' Out-of-area placements in Scotland and people with learning disabilities : a preliminary population study'. Journal of Psychiatric and Mental Health Nursing, 2008, 15, 278-286

¹³² Allen, D (2008) ; 'Failing to plan *is* planning to fail : out-of-area placements for people with learning disabilities'. Advances in Mental Health and Learning Disabilities, Vol 2 Issue 3, September 2008

symptom of a wider systems failure which frequently includes lack of effective local service commissioning and response. There appears to be a variety of reasons for out of area placements, with the defining characteristic being a challenge to local authority and health services which they cannot meet. Although the statistics appear less robust from a Scottish perspective, there is on-going work to develop this data.

Such placements can have a significant impact on individuals, families, carers and services. The individual can be placed not only out of their local authority or health board area, but in many cases out of country, which has major implications for and challenges to, the sustaining of close relationships and quality of life outcomes. The 'Winterbourne View Review: Concordat: A Programme for Action'¹³³ puts forward recommendations and commitments which might usefully be applied to a Scottish context in terms of the importance of retaining family links to ensure that individuals in out of area placements can be kept safe and have their needs met.

Out of area placements are generally high cost¹³⁴ and generate significant issues around robust and transparent service monitoring, regulation and governance ; including the 'visibility' of quality outcomes for users of these services and even in some circumstances, incidences of abuse and neglect^{135 136} .

Furthermore, Allen asserts that, rather than being the result of any meaningful commissioning process, out of area placements are actually a consequence of an absence of one, and do not significantly provide a superior service.

Placement of people with learning disabilities out of local services into independent, private or other specialist services can also place a considerable, unplanned for, and immediate support demand on 'receiving' health and social care services.

The Mansell Report and its subsequent updating in 2007 provide clear policy and strategic guidance on the development of sufficiently

¹³³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127312/Concordat.pdf

¹³⁴ McGill, P & Poynter, J, (2011) ; ' How much will it cost ? Characteristics of the most expensive residential placements for adults with learning disabilities ' Tizard Learning Disability Review, Vol 16, Issue 2, 54-57

¹³⁵ Pring, J (2003) ; 'Silent Victims: The Longcare Scandal and Britain's Continuing Failure to Protect Society's Most Vulnerable'. London: Gibson Square Books.

¹³⁶ Department of Health, (2012) ; ' Department of Health Review ; Winterbourne View Hospital

responsive local services for people with complex support needs. It makes recommendations around service improvements, the need to produce better outcomes, demonstrate value for money and support the families and carers of people with complex support needs.

NHS Education for Scotland has helped to produce, 'The Psychological therapies Matrix' which is a guide to planning and delivering evidence-based Psychological Therapies in Scotland¹³⁷ and which provides information on therapeutic approaches, service gaps and advice on appropriate governance arrangements. There is a need to continue to expand the evidence base relating to therapeutic interventions to support complex needs, with a responsively skilled workforce and workforce development strategies in place, informed by the support needs of individuals and significant demographic changes.

The Scottish Government has led a UK wide modernising learning disability nursing review - 'Strengthening the commitment'¹³⁸. The review recommendations aim to develop and maximise the role of the learning disability nursing workforce to effectively support and care for people with learning disabilities across the life span; including those who have complex needs.

The SEAT region Managed Care Network Report on People with a Learning Disability with Complex Care Needs¹³⁹, represents a model of care for people with complex needs which should be developed within the context of health and social care integration to provide a range of quality services that are effective, efficient and personalised as far as possible.

Good practice

NHS Education for Scotland has helped produce an educational resource, 'Working with People who have a Learning Disability and Complex Needs : The Essentials' ; which aims to offer workers supporting people with learning disabilities and complex needs

¹³⁷ NHS Education for Scotland (2012) ; 'The Psychological Therapies Matrix'
<http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/matrix/the-psychological-therapies-matrix.aspx>

¹³⁸ The Scottish Government (2012) ; 'Strengthening the commitment: The report of the UK Modernising Learning Disabilities Nursing Review'
<http://www.scotland.gov.uk/Resource/0039/00391946.pdf>

¹³⁹ NHS Scotland SEAT Region (2012) ; ' The Full Spectrum of Care for People with a Learning Disability who have Complex Care Needs'

opportunities to develop their knowledge, skills and values in ways that maximise the involvement of service users and families and increase health and wellbeing.

People with learning disabilities who have complex needs may require supports at any time of the day and night, and service responses may require to have a 24/7 capacity to respond if they are to effectively meet people's needs. In order to realise this there is a requirement for services to be planned and provided around robust care pathways, inter-service communications, individually planned, and corporately arranged proactive supports and crises responses.

In summary, although it may be the case that community based services and specialist teams for people with learning disabilities are becoming increasingly more responsive to meeting complex care needs at home, there remains a challenge to strengthen local capacity and competence around meeting complex needs. Some NHS Boards have by the provision of a specialist 'tier' of service, like additional support teams, to support local area service teams and services, but this model appears not to have been universally embraced and applied. It is up to services (health care, social care, justice and carer organisations) to coordinate their expertise to ensure that the individual's needs are met and that they do not remain inpatients after their need for this level of care has diminished. There is an extensive research base indicating that the complex needs described and discussed in this section, represent a significant challenge to community care and supports, and to inclusion in, and access to opportunities which enhance quality of life.

Recommendation 50

That NHS Boards and local authorities are required to develop Joint Discharge Agreement Protocols which are informed by the EDISON reporting system and include escalation for resolution of disputes, excessive delays and local and national planning for those for whom no alternative community placements exist. The possibility of including these in Single Outcome Agreements will be taken to the National Community Planning Group for consideration.

Recommendation 51

That a Short Life Working Group be set up to establish the Scottish data on out of area placements and report on its findings on how Scotland builds the capacity needed to deliver the specialist

services required more locally with an outcome that by 2018 people with learning disabilities and complex care needs who are currently in facilities out with Scotland should be supported to live nearer their family in Scotland.

Recommendation 52

That the Scottish Government, COSLA and ADSW should scope public sector investment in high-cost care packages and explore opportunities for developing alternative models of provision by June 2015, including through self-directed support, and by developing housing with support, to improve outcomes for individuals and their families and ensure value for money.

Appendix 1 Summary of recommendations

Human Rights

Recommendation 1

That all public bodies involved in providing support to those with learning disabilities carry out equality impact assessments by June 2014 to ensure that the rights of people with learning disabilities to dignity, equality and non-discrimination are respected and upheld.

Recommendation 2

That localities provide opportunities to promote equality for people with learning disabilities through actively involving and including them in local developments that affect them. A first step should be the provision of information that ensures greater awareness of the rights we all have under domestic law and as a result of international treaties.

Commissioning of Public Services

Recommendation 3

That by April 2015 community planning partners should ensure that local arrangements for joint commissioning are developed across relevant partner agencies and service areas to support the delivery of agreed outcomes, and that these take account of the needs of people with learning disabilities.

Recommendation 4

That the Learning Disability Strategy Implementation Group will set up a training sub group to take forward health and social care workforce development. The sub group's remit will be to work in partnership with NHS Boards, local authorities, relevant statutory bodies and third sector to support workforce development to:

- ensure the on-going learning and sharing of best practice is available and accessible to all health and social care**

professionals to address the health care needs of people with learning disabilities;

- ensure that NHS staff, as part of their mandatory and induction training receive training in the suite of legislation relevant to supporting people with learning disabilities in mainstream healthcare settings;
- ensure that staff in high volume acute pathways for people with learning disabilities are given relevant learning disability training;
- ensure that health and social care staff working with people with learning disabilities are trained on use of 6D cards and Talking Mats.

Recommendation 5

That in preparation for the legal duties imposed by the Social Care (Self-directed Support) (Scotland) Act 2013, local authorities and their NHS partners should work with private, voluntary and third sector agencies to ensure that people with learning disabilities have access to a creative variety of providers and supports and are assisted to think creatively about how outcomes can be met and what assistance they may need to develop control.

Recommendation 6

That by June 2014 Convention of Scottish Local Authorities (COSLA), Association of Directors of Social Work (ADSW), and NHS partners work with Scotland Excel to improve the quality and consistency of support for people with learning disabilities who have a long-term need for specialist residential care, by developing a national framework agreement for procurement. This should include a core service specification which focuses on outcomes for residents, the rates that will apply, and the arrangements that will be put in place to monitor and manage performance.

Recommendation 7

That by April 2015 local authorities and NHS Boards should ensure that joint commissioning plans take account of the needs of people with learning disabilities of all ages. Plans should have regard to relevant guidance, scope current and future need, identify the total resources available to meet those needs, and set out how they will

be invested to secure sustainable, high quality services and supports that can deliver outcomes for individuals, including those agreed as part of person-centred care planning and self-directed support (SDS). Plans should make reference to early interventions, maximising independence and control.

Recommendation 8

That by June 2015 the Care Inspectorate and Healthcare Improvement Scotland should ensure that strategic commissioning plans, processes and implementation are examined as part of on-going scrutiny work that impacts on services for people with learning disabilities.

Health

Recommendation 9

That the Learning Disability Strategy Implementation Group will work with the Scottish Government to explore the development a HEAT target for the NHS to establish a process whereby all adults with learning disabilities using health services are identified to the Information Services Division and the Scottish Learning Disability Observatory, so they can be visible in Scottish data systems by 2015.

Recommendation 10

That by 2015, the Primary Care Division of the Scottish Government and Scottish Learning Disabilities Observatory will work together to develop a process of annual reporting of trends in the management of the long term conditions of people with learning disabilities have.

Recommendation 11

That the Scottish Learning Disabilities Observatory will work to develop a better understanding of the causes of unnecessary deaths of people with learning disabilities.

Recommendation 12

That by 2016 the Scottish Consortium for Learning Disability, local authorities and the Scottish Learning Disability Observatory will work in partnership to provide information to Information Services Division and Analytical Services Division, Scottish Government, to identify by unique NHS numbers the adults with learning disabilities using social work resources by 2016.

Recommendation 13

That the Learning Disability Strategy Implementation Group will work with NHS National Services Scotland (National Information Systems Group) to ensure that both the Emergency Care Summary (ECS) and the Key Information Summary (KIS) meet the information needs of people with learning disabilities accessing health care.

Recommendation 14

The Learning Disability Strategy Implementation Group will work with Healthcare Improvement Scotland to undertake a review of the Learning Disability Quality Indicators and Best Practice statement to ensure that they reflect the changing needs of people with learning disabilities. A review of general health services and specialist learning disability health services will be undertaken across NHS Scotland to ensure that there is full compliance with Learning Disability Quality Indicators and Best Practice statement on Promoting access to healthcare for people with learning disabilities.

Recommendation 15

That the learning from the NHS Western Isles Collaborative is formally evaluated and its findings disseminated throughout Scotland through a Best Practice Conference to be led by NHS Western Isles and the Scottish Government in 2013. Application of the model to other areas of Scotland will be considered by 2014.

Recommendation 16

That by 2014 the Easy Info Zone of NHS Inform is publicised to ensure that people with learning disabilities and their families and carers can benefit from its use.

Recommendation 17

That the Learning Disability Strategy Implementation Group will work with the Scottish Learning Disability Observatory to establish and implement a targeted health screening programme for people with learning disabilities across NHS Scotland.

Recommendation 18

That by June 2104 all professionals working with those with learning disabilities take responsibility for assisting with implementation of the National Oral Health Improvement Strategy by promoting it at local level with individuals, carers and relevant others.

Recommendation 19

That by June 2015 all NHS Boards should ensure that people with learning disabilities that have complex epilepsy have access to specialist neurological services, including access to learning disabilities epilepsy specialist nurses and learning disability psychiatrists, where applicable.

Recommendation 20

That health and social care professionals apply the local See Hear policy to people with learning disabilities and their families and carers.

Recommendation 21

That work is commissioned in 2013 to understand and analyse the factors that promote person-centred care and individualised health outcomes for people with learning disabilities to ensure that they receive the same investigations and treatments as the general population and that reasonable adjustments are made by 2015 to achieve the same health outcomes.

Recommendation 22

That by the end of 2015 all NHS Boards across Scotland should ensure there is a dedicated primary care liaison resource to support general practice and primary care teams to ensure their

services are equitable and where required targeted for people with learning disabilities.

Recommendation 23

That the Learning Disability Strategy Implementation Group will work with the Primary Care Division, Scottish Government to explore how the GP contract in Scotland can best meet the needs of people with learning disabilities, including the possibility of the reintroduction of an enhanced service for people with learning disabilities and including additional learning disability indicators in the Scottish Quality Outcomes Framework by June 2014.

Recommendation 24

That NHS Boards and local authorities across Scotland should work in partnership to ensure that people with learning disabilities receive the appropriate levels of support in general hospitals. This should include appropriately funded support from familiar carers as well as support from specialist learning disability acute care liaison nurses.

Recommendation 25

That by the end of 2016 NHS Boards should ensure that people with learning disabilities who attend acute care hospitals, including all medical and surgical specialties and accident and emergency departments, are identified and monitored to improve outcomes of hospital care and treatment, ensuring that healthcare is provided in the most appropriate setting.

Recommendation 26

That the Glasgow palliative care pathway is evaluated and rolled out nationally by 2015 to improve the care outcomes for people with learning disabilities.

Independent Living

Recommendation 27

That by June 2018 the Scottish Government in partnership with local authorities, the Third Sector and people with learning disabilities and carers review and further develop day opportunities that are person-centred, assets-based and values driven and that take account of staffing, education, employment and transport issues.

Recommendation 28

That the Scottish Government, in partnership with COSLA and Association of Local Authority Chief Housing Officers (ALACHO), should undertake a review of Local Housing Strategies (LHSs) by June 2014. This should:

- identify examples of good practice in meeting the needs of people with learning disabilities**
- highlight where improvement is needed**
- make recommendations for change to be included in revised local housing strategy guidance together with a statement of resources available to deliver on the actions required, and any shortfalls remaining.**

Recommendation 29

That LHS should evidence how the views of people with learning disabilities and their carers have been taken into account in their preparation, and demonstrate the extent to which such views have been reflected in final LHS plans. LHS should also demonstrate explicitly the actual and anticipated contribution of all housing sectors to meeting the needs of people with learning disabilities, including housing associations and the private sector, together with the services which may be required to support independent living and who is best placed to provide these.

Recommendation 30

That Camphill Scotland is funded in 2013 to prepare for practice change and training in social pedagogy by staff and residents

working together to identify outcome measures for individual residents and to implement and evaluate these.

Recommendation 31

That the role of Local Area Co-ordinators is reviewed by the Scottish Government, SCLD, COSLA and ADSW by evaluating their contribution to independent living both in terms of outcomes for individuals and public value and that a joint decision is reached by June 2014 on the scale of expansion needed and the collective means to achieve this.

Recommendation 32

That by 2018 the Scottish Government works with the Scottish Independent Advocacy Alliance, PAMIS and SCLD to scope the need for advocacy and to develop an Action Plan together to improve delivery and uptake of independent advocacy at local level.

Shift the culture and keeping safe

Recommendation 33

That SCLD, in collaboration with ENABLE Scotland, should work with local voluntary services to:

- encourage the setting up and expansion of befriending services and natural networks for people with learning disabilities.**
- work with local authorities and NHS Boards to ensure that the planning, commissioning, procurement and implementation of services gives scope for the inclusion of befriending services and natural networks.**
- record the number of people receiving befriending services and natural networks in annual eSay statistical returns.**

Recommendation 34

That by the end of 2013 the Scottish Government in partnership with Equal Futures and other relevant organisations holds a

friendship event to help people with learning disabilities to be supported to have more friends.

Recommendation 35

That research is undertaken to understand and analyse the factors that impact on how people with learning disabilities, their families and carers cope with adversity which will inform the development of appropriate care and support to sustain and enhance their resilience.

Recommendation 36

That to improve the availability of short breaks for people with learning disabilities and their families and carers, the Scottish Government will enhance the voluntary sector Short Breaks Fund to support children and adults with learning disabilities and their carers including to provide opportunities to develop skills and confidence.

Recommendation 37

That the Scottish Government works with ENABLE Scotland to build on the work set out in the 2012 report, ‘ Picking Up the Pieces – Supporting carers with Emergency Planning’ so that plans are put in place to support people with learning disabilities and their carers.

Recommendation 38

That by 2014 parents with learning disabilities should have access to local supported parenting services based on the principles of Supported Parenting and that the Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities are being followed by professionals working with parents with learning disabilities to ensure better outcomes for families.

Break the stereotypes

Recommendation 39

That by 2014 local authorities, further and higher education providers, Skills Development Scotland and the Transitions Forum

work in partnership within the GIRFEC assessment and planning framework to provide earlier, smoother and clearer transition pathways (to include accessible information on their options, right to benefits and Self Directed support) for all children with learning disabilities to enable them to plan and prepare for the transition from school to leavers destination.

Recommendation 40

That by end of 2014 SCLD in partnership with Colleges Scotland, Skills Development Scotland and ADSW consider how people with learning disabilities and carers can access educational activities and training at college and other learning environments.

Recommendation 41

That by 2018 the Learning Disability Implementation Group works with local authorities, NHS Boards and Third Sector organisations to develop a range of supported employment opportunities for people with learning disabilities and that those organisations should lead by example by employing more people with learning disabilities.

Recommendation 42

That local authorities and SCLD work in partnership with Volunteer Scotland and other relevant organisations to increase the opportunity for people with learning disabilities to volunteer within their community to develop work skills

People with Profound and Multiple Learning Disabilities

Recommendation 43

That all stakeholders involved with people with PMLD commit to the implementation of the Scottish Quality framework for the delivery of invasive procedures, which will be launched in Autumn 2013.

Recommendation 44

That a sub group of the Learning Disability Implementation Group is set up to increase the number of Changing Places toilets in

Scotland to 100 by June 2015 using the conclusions and recommendations set out in the Scottish Government's report 'Changing Places Toilets' and by implementing the UK-wide Changing Places Consortium's Charter in Scotland.

Criminal Justice

Recommendation 45

That, with immediate effect, justice organisations should ensure they develop easy read and other accessible information resources for all literature they produce that is available to the public.

Recommendation 46

That a National Criminal Justice Action Group is to be established in 2013, consisting of professionals in this field and working in partnership with people with learning disabilities, to identify challenges and promote opportunities and influence change and to provide support for people with learning disabilities in the criminal justice system.

Recommendation 47

That by the end of 2014 all relevant organisations will review and implement recommendations of 'No-one Knows –Prisoners with Learning Difficulties and Learning Disabilities, Scotland' where they have not already.

Recommendation 48

That all professionals involved in the criminal justice system have access to the 2011 guide 'People with Learning Disabilities and the Criminal Justice System' and consider how they can best support people with learning disabilities in that context.

(The newly constituted Equalities sub – group of the Justice Board, representing all policy and operational interests in Justice, will oversee progress in implementing these recommendations).

Recommendation 49

That research will be undertaken across the criminal justice system in Scotland by SCLD and NHS Greater Glasgow & Clyde to understand and analyse the nature and extent of the health needs of people with learning disabilities within the criminal justice system to support the development of appropriate responses that address the distinct health and rehabilitation needs.

Complex care

Recommendation 50

That NHS Boards and local authorities are required to develop Joint Discharge Agreement Protocols which are informed by the EDISON reporting system and include escalation for resolution of disputes, excessive delays and local and national planning for those for whom no alternative community placements exist. The possibility of including these in Single Outcome Agreements will be taken to the National Community Planning Group for consideration.

Recommendation 51

That a Short Life Working Group be set up to establish the Scottish data on out of area placements and report on its findings on how Scotland builds the capacity needed to deliver the specialist services required more locally with an outcome that by 2018 people with learning disabilities and complex care needs who are currently in facilities out with Scotland should be supported to live nearer their family in Scotland.

Recommendation 52

That the Scottish Government, COSLA and ADSW should scope public sector investment in high-cost care packages and explore opportunities for developing alternative models of provision by June 2015, including through self-directed support, and by developing housing with support, to improve outcomes for individuals and their families and ensure value for money.

Appendix 2 Human rights – legislative background summary and timeline

The Human Rights Act 1998

This came into force in the UK in October 2000 and it brings into effect expectations of the European Court of Human Rights with which all public bodies have to comply.

The Act sets out the fundamental rights and freedoms to which individuals in the UK have access, including a right to life, freedom from torture or degrading treatment, the right to liberty and security, freedom from slavery and forced labour as well as the right to a fair trial and that there should be no punishment without law. It also covers respect for private and family life, home and correspondence as well as freedom of thought, belief, religion and expression. It makes clear the right to marry and start a family as well as to be protected from discrimination and to the peaceful enjoyment of your property. It also provides for the right to education and to participate in free elections.

Convention on the Rights of People with Disabilities 2007

The UK Government agreed to the United Nations Convention on the Rights of People with Disabilities in 2007, formally ratifying it in 2009. The Convention is an agreement between different countries whereby those that sign up must ensure that the rights of disabled people are respected and upheld. It means that countries will not treat people differently or unfairly because of their disability and that disabled people are to have the same rights as everyone else. It is not about giving individuals new legal rights but it can be used with the laws already in each country to change things for disabled people.

The European Court for Human Rights¹⁴⁰ explains this as having the right to having a life, saying what you think, having the best possible health, having the opportunity to be educated and to live in the community. It is also makes clear that government and other public organisations have a duty to work together to make this a reality by, for example, producing information in ways that disabled people can understand.

¹⁴⁰ http://www.echr.coe.int/echr/homepage_EN

Equality Act 2010

This came into force in October 2010 and replaces previous anti-discrimination law with a consolidated Act to make the law simpler and to remove inconsistencies.

It covers nine protected characteristics which cannot be used to treat people unfairly, those being age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

The Act sets out the different ways in which it is unlawful to treat someone, including direct or indirect discrimination, harassment, and victimisation and failing to make a reasonable adjustment for a disabled person. The Act prohibits unfair treatment in the workplace, when providing goods, facilities or services, when exercising public functions, in the disposal and management of premises, in education and by associations (like private clubs).

Appendix 3 Scotland's Human Rights Bodies and what they do

Scotland has two human rights bodies – the Equality and Human Rights Commission (EHRC) and the Scottish Human Rights Commission (SHRC).

The EHRC is a UK statutory body established under the Equality Act 2006 which took over the responsibilities of the Commission of Racial Equality, the Disability Rights Commission and the Equal Opportunities Commission.

The EHRC aims to reduce inequality, eliminate discrimination, strengthen good relationships between people and promote and protect human rights. It enforces equality legislation and encourages compliance with the Human Rights Act as well as giving advice and guidance to businesses, the voluntary and public sectors and to individuals.

One of the EHRC's activities is to conduct Inquiries. An example of one such Inquiry of great relevance to people with learning disabilities is its Disability Harassment Inquiry, *Hidden in Plain Sight*, which was published in August 2011.

The SHRC was set up through the Scottish Human Rights Act 2006 and is independent of UK and Scottish Parliaments and Governments. It promotes and protects the rights of everyone on Scotland by increasing awareness, recognition and respect for human rights and makes them more relevant and easier to apply in everyday life. It describes its role as being dedicated to helping everyone understand their rights and responsibilities that we have to each other and to our community.

The SHRC is working with all public bodies, civic society and others to develop a Scottish National Action Plan for Human Rights - a road map – to make all human rights real. This will be evidence-based and will use the results of the recently published three year research project, *Getting It Right? – Human Rights in Scotland*¹⁴¹. The latter highlighted both good practice and gaps across eight internationally recognised human rights themes of dignity and care, health, where we live, education and work, private and family life, safety and security, living in detention and access to justice and the right to an effective remedy.

¹⁴¹ *Getting it Right? Human Rights in Scotland* published October 2012, Scottish Human Rights Commission

Appendix 4 – Health needs

The following section is taken from *The same as you?* health report¹⁴² and looks specifically at those health needs which the literature presents as either occurring more often for people with learning disabilities or have the potential to add risk to the lives of people with learning disabilities.

Heart Disease

Heart disease is reported as a leading cause of death amongst people with learning disabilities. As people with learning disabilities live longer and individuals experience changing lifestyles, it is expected coronary heart disease will become even more prevalent. Making healthy lifestyle choices can reduce the risk of cardiovascular disease; therefore it is paramount that access to health screening and health improvement initiatives are available. In addition to age and lifestyle choice, genetics also contribute, with around half of all people with Down's syndrome being affected by congenital heart defects.

Diabetes

When a person is overweight, this increases their risk of diabetes. There is a high level of obesity amongst persons with learning disabilities and this is likely to be associated with an increased risk of diabetes. There is also a reported link between diabetes and inactivity. Individuals who take certain types of medicines, such as some antipsychotic medicines can also be more at risk of having diabetes. There is no evidence of the prevalence of diabetes in the UK population of people with learning disabilities, although a study in the Netherlands has reported higher levels. This is an area requiring further research.

Respiratory Disease

Respiratory disease is the leading cause of death for people with learning disabilities and is responsible for around half of all deaths among people with learning disabilities; these rates are much higher than for the general population. Pneumonia and aspiration are more common which may be linked to the prevalence of swallowing and eating problems and gastro-intestinal disease amongst people who have profound and multiple needs.

People with learning disabilities are less likely to die of lung cancer; this may be due to lower levels of smoking. However those people with

¹⁴² Allan, L, Brown, J, Brown, M and Stevenson T (2012). *The same as you? Evidence Scoping Exercise Health Report*, Glasgow: Scottish Consortium for Learning Disability, Scottish Government

learning disabilities who do smoke are twice as likely to have asthma. More than half of women with learning disabilities and asthma also have associated problems with obesity.

Cancer

Cancer is one of the main causes of death amongst people with learning disabilities, although the general population are more likely to die of cancer than a person with learning disabilities. People with learning disabilities experience different types of cancers than the general population but, as people with learning disabilities are increasingly living longer this pattern is constantly changing. In particular, for people with learning disabilities there appears to be reduced rates of prostate, lung and urinary tract cancers which are prevalent in the general population, but an increased risk of tumours of the oesophagus, stomach and gallbladder.

Evidence also indicates that gastrointestinal cancer is more prevalent. People with learning disabilities are often affected by helicobacter pylori which is linked directly to stomach cancer, gastric ulcers and lymphomas.

People with Down's syndrome are at higher risk of leukaemia compared to the general population, especially during early childhood, whilst there is a reduced risk of solid tumours, including breast cancer. Evidence also highlights that there is an increased risk of myeloid leukaemia for people with Prader Willi syndrome.

Dementia

People with learning disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age. Life expectancy of people with Down's syndrome has increased significantly. The incidence and prevalence of Down's syndrome is not decreasing. As many individuals who experience dementia, people with learning disabilities may also display challenging behaviours and other health issues. People with Down's syndrome, who are at greater risk, are more likely to first experience symptoms in their mid to later life. The Scottish Government dementia strategy specifically highlights the increasing need of people who have learning disabilities and dementia and highlights that dementia care is a national priority for the government. The national care standards for dementia and the skills and knowledge framework for all people working with people with dementia is also applicable to individuals who have learning disabilities

Epilepsy

People with learning disabilities are over twenty times more likely to have epilepsy than the general population and epilepsy is more prevalent amongst those with severe learning disabilities. Seizures can be complex and multiple in presentation which can significantly affect an individual's quality of life. Epilepsy can also be resistant to medication, leading to epilepsy being uncontrolled. Seizures can lead to injury and unexpected, sudden death.

Hearing and Vision

People with learning disabilities are more likely to have difficulties with hearing and vision than the general population. Visual impairment has been reported as up to 200 times more prevalent and around 40% of people who have learning disabilities have a hearing impairment. Many people will have a hearing impairment due to impacted ear wax, which is often easily corrected. Sensory impairments can be present at birth due to genetic causes or acquired through a life span due to environmental causes and aging.

People with Down's syndrome are more liable to develop vision and hearing loss. Sensory impairments are often not recognised by carers, therefore regular screening is required to detect any changes.

Oral health

Many people with learning disabilities experience dental disease; with some reports suggesting that this affects one in three adults. This prevalence is higher for adults with Down's syndrome where dental disease can affect four out of five people. Dental health needs are often not met. Contributory factors to dental disease include anticholinergic medication and gastrointestinal reflux disorder. Dental health improvement strategies for individuals, family carers and paid care workers are of key importance to address dental disease.

Physical disabilities

People with learning disabilities may also experience physical disabilities. These can often be related to cerebral palsy as well as to severe or profound levels of learning disability. The prevalence of mobility problems increases with the age of the person. Decreased mobility can affect the individual's social functioning and wellbeing, as can secondary conditions like constipation, respiratory disease, osteoporosis and gastro-oesophageal reflux disease.

Evidence highlights that having a physical disabilities greatly increases the risk of death.

Dysphagia

The term dysphagia is used to describe problems with swallowing, eating and drinking. This is often experienced by people with learning disabilities and in particular people with profound and multiple disabilities and cerebral palsy. It is reported that about 40% of individuals with dysphagia frequently have respiratory tract infections. Other conditions associated with dysphagia are choking, asphyxia, dehydration and poor nutritional state.

Gastro-oesophageal Reflux Disease (GORD)

GORD is the name given to a very common condition which happens when the acid in the stomach washes back into the bottom of the oesophagus (the tube leading from the mouth to the top of the stomach which carries food and fluids into the stomach when someone swallows). Common names for this condition would include 'heartburn' or 'dyspepsia'. This 'backwashing' of the acid is called 'reflux'. As a consequence, the lining of the oesophagus becomes chemically 'burnt' which can lead on to other problems.

A Dutch study evidences that up to 50% of people with learning disabilities with severe and profound needs experience GORD. GORD, although common, is often undiagnosed. Symptoms of GORD include pain leading to behaviours that challenge, sleep disruption, anaemia and increases the risk of oesophageal cancer compared to the general population. GORD is a treatable condition when identified.

Constipation

Constipation is a common problem for many people with learning disabilities. A Dutch study identified 69% of people with moderate and severe learning disabilities living in an institution to be constipated. People who were non-ambulatory, had cerebral palsy, refused food, or who were taking antiepileptic drugs or prescriptions for other gastrointestinal disorders were more likely to experience constipation.

Osteoporosis

Studies have indicated that there is an increased prevalence of osteoporosis and lower bone density amongst people with learning disabilities than the general population. Reasons for this include lack of weight bearing activity, genetic factors leading to late puberty and early onset menopause, poor nutrition and being underweight. Osteoporosis is asymptomatic and may only present after injury causing a fracture.

Endocrine problems

People with Down's syndrome are more likely to experience hypothyroidism and its prevalence increases with age. An individual with untreated hypothyroidism will present with lethargy, general malaise and a decrease in their own abilities. Symptoms of thyroid disease can go undetected until a late stage and can impact on an individual's functioning. A simple blood test can detect the disease and annual screening is recommended for individuals with Down's syndrome. From 2011, annual screening for people who have Down's syndrome has become part of the General Medical Services Quality Outcome Framework for General Practitioners.

Accidents and Falls

Several studies state that there are high levels of accidents and injuries and in Denmark and Australia deaths from accidents in the learning disabled population is more common than the general population. Rationale for this could include individuals also experiencing epilepsy, mental ill health, medication use, sensory and neurological impairments and balance problems. Behaviours that challenge like self-injury, pica and destructive behaviours can be linked to injuries, therefore with robust risk assessment and management the morbidity from accidents and injuries could be greatly reduced.

Mental Health

Both children and adults with learning disabilities are more likely to experience mental ill-health than those without learning disabilities. There is an increased prevalence of psychiatric disorder for people with autism, ADHD or conduct disorders. Studies have reported that some people are three times more likely to have schizophrenia, experience depression and delirium. Evidence suggests that prevalence rates for depression and anxiety are higher for people with Down's syndrome.

Appendix 5

An example of a layout with essential equipment of a Changing Places toilet

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Glossary

Meaning of words

Advocate/Advocacy Someone who helps people with learning disabilities to say what it is they need and to make their own decisions. See citizen advocate and self-advocate.

Allied Health Professionals These are physiotherapy, occupational medicine (PAMs) therapy, chiropody, radiography, dietetics, remedial gymnastics, orthoptics, art, music and drama therapies.

Alternative and Augmentative Communication (AAC) AAC is any method of communication that supplements the ordinary methods of speech and handwriting, where these are impaired. AAC equipment can range from high tech dedicated computer equipment with specialist software to simple low tech picture communication books or mats.

Asperger's syndrome This is a type of autism (see below) that some people of average intelligence and language ability have. They find it particularly difficult to understand what other people think and this makes it hard for them to communicate and act appropriately.

Attention Deficit Hyperactivity Disorder (ADHD) ADHD is thought to be caused by a chemical imbalance in the brain that affects the parts controlling attention, concentration and impulsivity.

Autism This is a lifelong developmental disability that affects the way a person communicates and relates to people around them. People with autism can often have learning disabilities but everyone with the condition shares a difficulty in making sense of the world.

Autistic spectrum disorder Autism can happen in people with different degrees of learning disability as well as in people of average intelligence, for example, those who have Asperger's syndrome. Because of this wide range, we talk about a spectrum of autistic disorder.

Behaviour analysis Looking into the cause and effect of behaviour based on what has happened in the past.

Benchmarking Working out how good a service is by comparing it to another service that has set a high standard.

Brokerage service Somewhere people with learning disabilities can go to get independent help in deciding on and buying the services they need.

Care at Home A form of health care service provided where a person lives.

Care Programme Approach A way of making sure that all those with serious mental health problems and complex needs have an assessment and care plan that all the different professionals agree on (for example, social workers and doctors). This is checked regularly to see how well the person is doing.

Challenging behaviour A term used to describe when someone is acting in a way that might do themselves or others harm. People who care for these people are 'challenged' to stop the harm.

Circles of support A group of people who care about change happening for the individual and choose to give their time and resources to working for a change.

Citizen advocate An 'unpaid' volunteer who is independent of the services, a person with learning disabilities receives. This advocate represents the needs of the person and supports them to make sure they get their rights.

Commissioning Deciding what services are needed and then getting someone to provide these by signing a contract.

Complex needs This describes the needs a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour.

Continence management Trying to help people who have problems with bladder and bowel control.

Continuing care Nursing or medical help or both of a level that cannot be provided in a care or nursing home.

Co-occurring conditions Where a person may have two or more conditions i.e. may have autism as well as a learning disability.

Co-ordinated Support Plan (CSP) (was Record of Need) This is a legal document which aims to make sure that the additional support a child receives is properly co-ordinated. A CSP describes the child's strengths, their additional support needs, and their educational objectives. It will also describe the support the child needs to meet these objectives and the types of professionals who will provide the support.

Deafblind There is no accepted definition of deafblindness to which everyone subscribes. However, the most commonly used is the European one: Persons are regarded as Deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems with communication, information and mobility. Deafblindness may also be referred to as dual sensory loss. There is no difference in the definition of Deafblind and dual sensory loss.

Detained patient Where someone is detained and treated on the ground of mental disorder under the Mental Health(Care and Treatment) (Scotland) Act 2003.

Diagnostic overshadowing Where an incorrect assumption is made that an individual's presentation or symptoms are due solely to their learning disability rather than a consideration of other attributable factors.

Direct payments Local authorities giving people money to buy their own social care services so that they have more say in how their needs are met.

Dementia Dementia is an umbrella term used to describe a range of brain diseases characterised by a progressive decline in intellectual and other mental functions. While Alzheimer's disease and vascular disease are the most common causes, there are a number of less common forms of dementia. Dementia is a terminal condition.

Early onset dementia A term used to describe people who get dementia at an earlier age than might be expected. This leads to a variety of problems, including difficulties in remembering, making decisions, and learning new skills. These difficulties get worse as time passes.

Demographics Demographics are the quantifiable statistics of a given population.

Foetal Alcohol Spectrum Disorder (FASD) This is an umbrella term which describes continuing permanent birth defects caused by maternal consumption of alcohol.

Forensic needs This relates to the support and services required by people who come into contact with the criminal justice system.

Guardian/guardianship A guardian for a child is someone appointed by a parent, or, where necessary, the sheriff, to take over parents' responsibilities and rights after a parent dies. The guardian's role applies until the child is 18. A guardian for an adult with a mental disorder is someone appointed by the sheriff who has the power to say where the person lives, gets education and training and also makes sure that doctors can see a person without difficulty.

Health and social care integration Where health and social care providers will work together to provide adult services.

Hearing impairment This covers any loss of hearing from mild hearing loss to profound deafness.

Invasive procedures This is procedure that is carried out by entering the body through the skin or body cavity.

Learning difficulty Pre-school and school-age children are usually described as having a learning difficulty rather than a disability when they have special educational needs that need extra or different approaches to the way they are taught.

Mainstream Generally available to all members of the community.

Managed clinical network Where healthcare professionals who have an interest in the same area of work share their knowledge and resources to get the best care for patients. A network can be local, regional or national depending on what the work is.

Mapping of services Finding out what services there are and what they are like.

Mobility Being able to move from one place to another with or without help.

Natural supports People who help those with learning disabilities like family and friends and are not paid to do this.

Out of area placements Where a person is placed out with their usual geographical area.

Palliative care Managing care for someone who is not going to get better. This is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering. (definition taken from Living and Dying Well)

Peripatetic support staff Staff who go from place to place to do their work rather than staying in a single centre.

Post school education The range of education that takes place after school leaving age. It may include further education, community education, higher education, adults going back to school, other kinds of informal education and vocational training.

Prevalence data A way of working out how many people in a population are likely to have a learning disability.

Psychotherapy A psychological treatment based on talking and usually designed to help the person understand what is happening now and how to change it.

Rectal diazepam This is a drug inserted up a person's bottom to stop severe epileptic fits.

Self-advocacy Where people with learning disabilities promote their needs and wishes for themselves.

Self-directed Support This describes the ways in which individuals and families can have informed choice about the way support is provided to them.

Sensory impairment This covers people with varying degrees of hearing loss, sight loss and also the loss of both senses. This loss can be present from birth or occur during the life time of a person.

Social inclusion Helping people to feel and be part of the society in which they live.

Transitions When a person moves from children's to adult services.

Visual impairment This covers any loss of vision that cannot be corrected by wearing glasses or contact lenses. Conditions that can cause a visual impairment include, but not only, cataracts, glaucoma, macular degeneration and diabetes-related eye conditions.

Signposting

Action on Hearing Loss Scotland represents the 850,000 people who are deaf or have a hearing loss in Scotland.

<http://www.actiononhearingloss.org.uk/>

Association of Directors of Social Work (ADSW) The professional association of senior social work managers in Scotland.

<http://www.adsw.org.uk/>

Association of Local Authority Chief Housing Officers aim to shape, inform national policy and guidance and legislation to the benefit of local authorities in particular strategic housing policy.

<http://www.alacho.org/>

Camphill Scotland One of the largest support networks for children, young people and adults with learning disabilities, mental health problems and other support needs.

<http://www.camphillscotland.org.uk/>

C-Change Scotland provides individually tailored support for people to make choices about where they live and who they live with.

<http://www.c-change.org.uk/>

Citizens' Advice Scotland The national umbrella body that provides support services for the Scottish citizens bureaux and collates client case evidence to shape policy in Scotland.

<http://www.cas.org.uk/>

Cornerstone cares and supports over 1700 people each year through a wide range of services.

<http://www.cornerstone.org.uk/>

Convention of Scottish Local Authorities (COSLA) The representative voice of Scottish local government.

<http://www.cosla.gov.uk/>

Dates and Mates Scotland's national dating and friendship agency run by and for people with learning disabilities.

<http://www.dates-n-mates.co.uk/>

Deafblind Scotland aims to help Deafblind people in Scotland live as rightful members of their own communities, where they have the permanent support and recognition necessary to be equal citizens.

<http://www.deafblindscotland.org.uk/>

ELCAP provides housing support and care at home services for people with a learning disability; physical or sensory impairment; mental health issues; drug and alcohol misuse problems; older people and people with acquired brain injury.

<http://www.elcap.org/>

ENABLE Scotland support people with learning disabilities and their families to live, work and take part in their communities.

<http://www.enable.org.uk/>

Equal Futures Led by families who have taken the initiative to plan and support their relative who has a disability to enjoy a good life.

<http://www.equalfutures.org.uk/>

Heartfelt is a training and consultancy organisation based in Scotland but working through UK. Most of the people who work for Heartfelt are people who have experience of using social work or social care services or care for someone who does.

Housing Options Scotland Helping disabled people to find the right housing in the right place.

<http://www.housingoptionsscotland.org.uk/>

Indepen-dance An inclusive dance development company offering creative movement classes to people with diverse abilities, their carers, family members and volunteers.

<http://indepn-dance.org.uk/>

Institute of Public Care committed to improving the quality and performance of services across health and social care, education, housing and welfare.

<http://www.ipc.brookes.ac.uk/>

Interest Link Borders run befriending services that link people with learning disabilities and volunteers so they can meet up and do activities they both enjoy.

<http://www.interestlink.org.uk/>

Kingdom Abuse Survivors Project (KASP) aims to enable adult survivors of childhood sexual abuse to eliminate the debilitating effects that the abuse has on their lives.

<http://www.kasp.org.uk/>

Link Housing Association One of Scotland's leading housing, regeneration and support organisations.

<http://linkhousing.org.uk/>

PAMIS The only organisation working with people with profound and multiple learning disabilities and their families in Scotland.

<http://www.pamis.org.uk/>

People First Scotland Works to support people with learning disabilities to have more choice and control over their lives.

<http://www.peoplefirstscotland.org/>

RNIB Scotland Leading charity working with blind and partially sighted people in Scotland, supporting children and adults with sight loss to live full and independent lives.

<http://www.rnib.org.uk/>

Scottish Consortium for Learning Disability (SCLD) A consortium of partner organisations who work together to encourage best practice in the support of people with learning disabilities through training, information, consultancy, research and public education.

<http://www.sclld.org.uk/>

Scottish Human Rights Commission (SHRC) promotes and protects the human rights of everyone in Scotland and is dedicated to helping everyone understand their rights and shared responsibilities they have to each other and their community.

<http://www.scottishhumanrights.com/>

Scottish Independent Advocacy Alliance (SIAA) promotes, supports and defends the principles and practice of Independent Advocacy across Scotland.

<http://www.siaa.org.uk/>

Scottish Learning Disability Observatory University of Glasgow have been funded by the Scottish Government to create a Scottish Learning Disability Observatory which will be dedicated to underpinning health improvement and to addressing health inequalities.

Self-directed Support Scotland The Scottish Government's Self-directed support website – a one-stop shop for information on Self-directed Support in Scotland.

<http://www.selfdirectedsupportscotland.org.uk/>

Share Scotland provides practical, emotional and physical support to people with learning and physical disabilities.

<http://www.sharescotland.org.uk/>

SurvivorScotland Developed by the Scottish Government aims to raise awareness of childhood abuse and its long-term consequences, improve services and enhance the health and well-being of survivors.

<http://www.survivorscotland.org.uk/>



**The Scottish
Government**
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