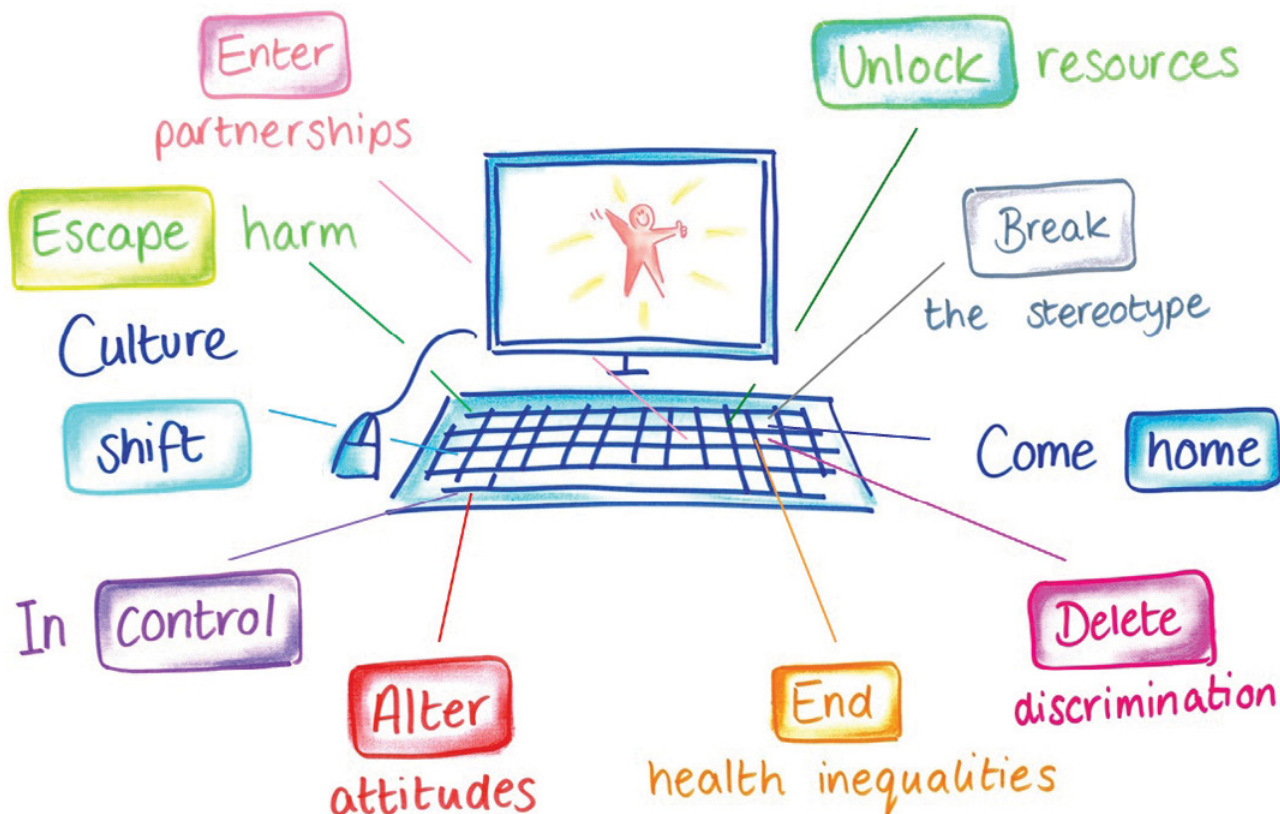


The keys to life

Unlocking Futures for People with Learning Disabilities
Implementation framework and priorities 2019-2021





CLARE HAUGHEY MSP
MINISTER FOR MENTAL
HEALTH



CHRISTINA MCKELVIE MSP
MINISTER FOR OLDER PEOPLE AND
EQUALITIES

Ministerial Foreword

The lives of people with learning disabilities have changed. People with learning disabilities are citizens who want to play a full part in their communities across Scotland.

At the heart of this framework is a

commitment that recognises that people with learning disabilities have the same aspirations and expectations as everyone else. We cannot focus only on health and social care needs or believe that if we get that right, we are doing all we can.

This framework reflects what people with learning disabilities, their families and people who provide support and services have told us about their lived experiences, including the challenges and barriers they face. It takes their expectations and aspirations for the future as its starting point.

It builds on what we have done since the previous framework was published in 2015 and reflects the broader priorities of the Scottish Government, local authorities, NHS Boards and integration authorities.

For the Scottish Government, this includes our commitment to equality through the Fairer Scotland Disability Delivery Plan – to halving the disability employment gap, getting it right for every child and tackling the impact of social isolation, and recognising the capacity that self-directed support can offer people with learning disabilities to have greater choice and control in their lives.

It is vital that we provide support from an early age. Young people have told us about the challenges they can sometimes face in education, in forming relationships, in finding jobs and in their journey to leading a more independent life.

We know that how people with learning disabilities are perceived has a significant impact on both their choices and their life experiences. We must address this – building on Scotland's reputation as an open and inclusive society. We have a moral imperative to understand and embrace difference.

People with learning disabilities including those with complex needs, have many skills and talents to offer to friends and family, teachers and employers. They can and do contribute to vibrant and diverse communities across Scotland.

Scotland is making its presence felt on the global stage too. In 2018, Down's Syndrome Scotland brought the World Down's Syndrome Congress to Glasgow. In 2019, the University of Glasgow will host the IASSID (International Association for the Scientific Study of Intellectual and Developmental Disabilities) Conference.

We need to make a step change if we are to truly deliver fair opportunities for everyone in Scotland with a learning disability to live happy, healthy, fulfilling lives – for "The keys to life" to unlock the future.



COUNCILLOR STUART CURRIE
COSLA SPOKESPERSON FOR HEALTH AND
SOCIAL CARE

COSLA Foreword

As COSLA's Spokesperson for Health and Social Care, I am delighted to endorse this updated framework. The keys to life in its original form focused on improving quality of life for people with learning disabilities, specifically around health outcomes.

The Implementation Framework and Priorities update, which was published in 2015 further developed the vision around a healthy life, choice and control, independence and active citizenship.

I am pleased to see that meaningful progress has been made against these priorities with the support of our third sector partners.

This latest update of The keys to life identifies what we will do to support people throughout their whole life journey. We need to raise expectations, enhance opportunities

and deliver better outcomes around the themes that were identified following extensive engagement with people with learning disabilities.

Despite the current financial climate, Local Government remains committed to improving the lives of people with learning disabilities and supporting the whole-system improvements required to make the change. COSLA is very much committed to improving people's whole life journey and will continue to show leadership in driving forward The keys to life.

Our vision

Our vision for people with learning disabilities is shaped by the Scottish Government's ambition for all citizens and by everything we have heard from people with learning disabilities.

Everyone – including people with learning disabilities - should be able to contribute to a fairer Scotland where we tackle inequalities and people are supported to flourish and succeed.

People with learning disabilities should be treated with dignity, respect and understanding. They should be able to play a full part in their communities and live independent lives free from bullying, fear and harassment.

Our vision is for a creative, open and connected nation in which people with learning disabilities are empowered to:

- ✓ live healthy and active lives
- ✓ learn to reach their full potential
- ✓ participate in an inclusive economy
- ✓ contribute to a fair, equal and safe Scotland

Strategic Ambitions - A Fairer Scotland for Disabled People

Our priorities for delivery in the next phase of The keys to life will continue to be guided by our four rights-based strategic outcomes. They are closely aligned to the strategic ambitions in Scotland's disability delivery plan, A Fairer Scotland for Disabled People.

- **Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation.**

Health and social care support services are designed to meet - and do meet - the individual needs and outcomes of disabled people.

- **Decent incomes and fairer working lives.**

Making sure disabled people can enjoy full participation with an adequate income to participate in learning, in education, voluntary work or paid employment and retirement.

- **Places that are accessible to everyone.**

Housing and transport and the wider environment are fully accessible to enable disabled people to participate as full and equal citizens.

- **Protected rights.**

The rights of disabled people are fully protected and they receive fair treatment from justice systems at all times.

- **Active participation.**

Disabled people can participate as active citizens in all aspects of daily and public life in Scotland.

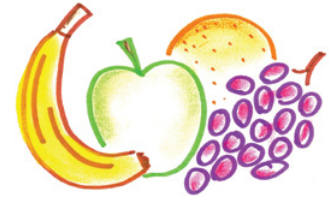


Strategic Outcomes

The keys to life

A Healthy Life:

People with learning disabilities enjoy the highest attainable standard of living, health and family life.



Choice and Control:

People with learning disabilities are treated with dignity and respect, and are protected from neglect, exploitation and abuse.



Independence:

People with learning disabilities are able to live independently in the community with equal access to all aspects of society.



Active Citizenship:

People with learning disabilities are able to participate in all aspects of community and society.

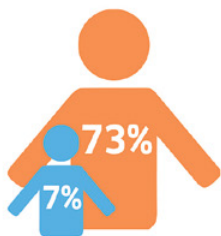


Who are people with learning disabilities in Scotland today?

Our definition of a learning disability was developed in consultation with people with learning disabilities themselves:

A learning disability is significant and lifelong. It starts before adulthood and affects the person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate.

Scotland's Census, 2011, reported 26,349 people to have learning disabilities, which is 0.5% of Scotland's population. Statistics show that people with learning disabilities do not yet enjoy the same life chances as others.

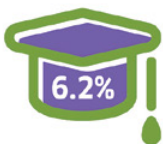


People with learning disabilities die on average, **20 years earlier** than the general population.¹



The estimated employment rate for people with a learning disability is **7%** compared to Scotland's national employment rate of **73%**.²

There are **14,200 children with a learning disability** registered as receiving additional support in Scotland's schools.³



There were **1,434 (6.2%) adults with learning disabilities** known to local authorities enrolled in further education in 2017.⁴

52% of people recorded as having 'a learning disability' lived in social housing, compared with **21%** of the population as a whole.⁵



39% of people with learning disabilities live in owner occupied property, compared with **66%** of the population as a whole.⁶

Robust data is vital to underpinning the work we do. In order to better understand the lived experiences of people with learning disabilities, we will commission further research and analysis to:



Link data to understand the number of women in Scotland who become mothers, their children who are adopted or looked after, and the household and community supports of mothers with learning disabilities.



Understand the impact on the health outcomes of parents, and older parents, caring for their children with learning disabilities, to help inform support decisions.



Gain a more comprehensive understanding of the factors that improve educational outcomes, and destinations, of all children and young people with learning disabilities.



Better understand the impact of employment schemes on opportunities for people with learning disabilities.

People with learning disabilities experience barriers caused by attitudes as well as physical barriers. But we know that when they are given the right support, people with learning disabilities can achieve their potential.

The case studies in this document show that people with learning disabilities have many talents. But more than that – they are leaders and role models who strive to contribute to Scottish society.

Case Studies



Alexander Warren

When Alexander Warren first heard about dreams he decided he wanted to spread the word about how these could support young people. After an internship at Edinburgh Development Group, he realised the best way to do this was to set up his own business, AJP Dreams. AJP Dreams provides training and consultancy to encourage families and parents, and social work and social care professionals to work hard to listen to the dreams of young people and help them to follow and achieve them.



The National Involvement Network (NIN)

ARC Scotland's National Involvement Network (NIN) is a network of people who receive social care support who meet to promote involvement and share ideas about things that matter to them the most. The NIN has developed the Charter for Involvement, which shows how people who use support services want to be involved in the services they receive, in the organisations that provide them and in the community. Over 70 organisations have since made a commitment to put the Charter into practice, and improve how they listen to and respect those they support.



COPE Ltd

COPE Ltd is a social enterprise and charity which provides employment and skills development for adults with learning disabilities or autism spectrum disorders. They are committed to giving people with disabilities the opportunity to participate in a supportive and inclusive work environment, free from stigma and discrimination. COPE Ltd's ongoing success is supported by its team of people with learning disabilities who every day produce, promote and sell a wide range of items through different business outlets.



Leeanne Clark

Leeanne Clark is a writer from Fife, and an RSA Fellow. Leeanne is writing a book documenting her life to share with health and social care professionals, academics and other people with learning disabilities. Leeanne hopes that her book will influence future practice and provide a source of inspiration for people in a similar situation to hers.



Neil Price

Neil Price is a dancer, choreographer and professional Dance Artist with Indepen-dance. He is a member of Indepen-dance's flagship inclusive dance ensemble, which delivers a range of innovative and high quality productions, touring across the UK and Europe. He was named Best Dance Performer at the Sunday Herald's Culture Awards in 2017. Neil recently choreographed and performed a dance which was part of the Keynote programme at the World Down's Syndrome Congress held in Glasgow, in 2018.



Lucy McKee

Lucy McKee is an ENABLE Scotland Youth Change Champion who plays a leading role in the organisation's campaigning work, which has benefited greatly from her real life experience. Over the years, Lucy's confidence has grown tremendously, and she has spoken publicly about her personal experience of bullying during her time at school. She has become a role model for many young people in Scotland, acting as a positive voice to the media, politicians and a variety of different organisations across Scotland.



Eddie McGinlay

Eddie McGinlay works as a Kitchen Porter at Haggs Castle Golf Club. Eddie secured his position through a work trial, which he found more accessible and comfortable than an interview process. The work trial was negotiated by his job coach at the Glasgow Supported Employment Service, who provided subsequent support.

Eddie's job has allowed him to make new friends, do more socialising and improve his confidence. His employers have spoken positively of the experience and would encourage other businesses of their type to employ people with learning disabilities.



Liam

Liam is a very active 22-year-old young man, who happens to have Profound and Multiple Learning Disabilities, due to the very rare Emanuel Syndrome, but he doesn't let that interfere with him enjoying his life like any other 22-year-old. He has a full week of activities,

including music, dance, and sport. Liam attends college and has shown incredible improvement over a 3 year period in his sporting achievements, culminating in him winning 2 Gold Medals in the Special Olympic Commemorative Games in 2018. Liam believes he has more medals to win, and wishes to continue his lifelong learning opportunities.

The keys to lifethe story so far

A lot has been done since The keys to life was first launched in 2013. In 2015, an implementation framework was published which focused delivery in a number of key areas across our four strategic outcomes. Our work since then includes:

A Healthy Life

- The Scottish Commission for Learning Disability (SCLD) commissioned a scoping report on effective interventions for parents with learning disabilities.
- SCLD published a report with examples of good practice around Relationships, Sexual Health and Parenting Education for children and young people with learning disabilities.
- The Scottish Learning Disabilities Observatory worked with primary health care services to understand access and improvements to care for people with learning disabilities and long term conditions.
- The Observatory has undertaken research on physical activity, mental and physical health, and its wider

determinants, in the lives of adults with learning disabilities.

- The Scottish Government has included people with learning disabilities in the new Mental Health Quality Indicators, so that people's experiences can be improved.
- The Observatory undertook a comprehensive survey of people with learning disabilities using mental health hospital beds.
- SCLD and ISD are incorporating Learning Disability Statistics Scotland (LDSS) into national routinely collected health and social care data.



Choice and Control

- SCLD mapped the activity of Third Party Reporting centres, which are safe and private spaces for people to report hate crimes, and this was then used to inform practice, in partnership with Police Scotland.
- The Observatory identified the impact of hate crime on the everyday lives and health of people with learning disabilities.
- IRISS and the University of Dundee explored the challenges in hate crime data recording and made recommendations on how to increase reporting.
- Glasgow and Strathclyde Universities developed resources to help tackle bullying and increase understanding and acceptance of people with learning disabilities. These are used in schools based lessons as part of the personal and social education curriculum.
- SCLD commissioned the Centre for Public Scrutiny to better understand how scrutiny bodies are impacting the lives of people with learning disabilities across Scotland and explore its potential to drive positive outcomes for people with learning disabilities.
- SCLD carried out a scoping of advocacy provision for adults with learning disabilities, identifying good practice and areas for improvement.



Independence

- People First (Scotland), PAMIS, SCLD and other learning disability organisations, contributed to the Accessible Transport Framework and Action Plan.
- We added the measurement of out of area placements to the Learning Disability Statistics Scotland dataset.
- Dr Anne MacDonald led a two year project reporting on delayed discharge, out of area placements and positive behavioural support for people with learning disabilities and challenging behaviour.
- SCLD commissioned a scoping study to assess the role of housing in contributing to positive outcomes for people with learning disabilities.
- We have supported access to the creative arts by funding delivery organisations including musicALL.

Active Citizenship

- SCLD commissioned a mapping and scoping project to identify areas of asset based practice across Scotland and to determine its efficacy for people with learning disabilities.
- SCLD commissioned a scoping study to map the employability landscape for people with learning disabilities in Scotland and an SCLD employment task group was formed to carry forward the recommendations of this report. The task group reported in 2018.
- Using The keys to life development fund, we invested in local projects across four themes – employment, hate crime, parenting and social connectedness. SCLD helped us to support those projects to maximise learning, including the production of a series of 'How to' Guides.

Our approach

The central ambition in The keys to life to tackle health inequalities – in access to healthcare and life expectancy remains critical. Social care will continue to play an important role in the lives of many people with learning disabilities.

However, unlocking futures and enabling people with learning disabilities to realise their full potential is about more than that. The vast majority of people with learning disabilities now live in the community and want to play their full part in it. Young people with learning disabilities today have vastly different expectations than they did just a generation ago.

Our refreshed approach acknowledges these changes and challenges. It will take a **whole system**, **whole population** and **whole person** approach.

Whole system

Our approach stretches across local and national Government, the third and private sectors. Within Government we are working hard to ensure that the needs of people with learning disabilities are discussed across a wide range of Scottish Government policies and are properly embedded in some of our key strategies:

Within health and social care, the Scottish Government's 2020 Vision emphasises integrated care and prevention, anticipation and supported self-management; the Health and Social Care Delivery Plan reinforces the equal importance of mental and physical health. We are tackling loneliness caused by social isolation, which can significantly affect mental wellbeing. We recognise people with learning disabilities within our approach to Getting it Right for Every Child, Curriculum for Excellence (CfE) and Developing the Young Workforce. Children and young people with a learning disability have a right to have the same opportunities to succeed as anyone else and we are working with colleagues to recognise and address barriers in education and employment. This means consistent support through additional support for learning, closing the attainment gap and ensuring there are positive choices available for young people to progress to further education and employment.

Whole population

Our approach is about the whole life journey from childhood to older age and addresses key elements of that journey from health and social care support to education, housing and employment – and beyond.

Whole person

Our approach is about the whole person, recognising the capabilities and talents of people with learning disabilities as well as the challenges they face. We also understand how important relationships and communication are for the wellbeing of people with learning disabilities, both personal and professional.

A rights based approach

Human rights belong to everybody and our approach continues to be rooted in recognising those rights and embedding them at the heart of everything we do. We are committed to meeting our international obligations in full, including the UN Convention on the Rights of Persons with Disabilities. We take a human

rights approach and our policies are grounded in the principles of Participation, Accountability, Non-discrimination, Empowerment and Legality.

A Fairer Scotland

The Scottish Government's National Performance Framework commits us to being a society that treats all of our people with kindness, dignity and compassion and to working with local government to deliver a fairer Scotland. The 11 National Outcomes include an explicit human rights outcome: "We respect, protect and fulfil human rights and live free from discrimination".

Collaboration

We will continue to work with our strategic partners, the Scottish Commission for Learning Disability and the Scottish Learning Disabilities Observatory and with a wide range of delivery partners across the third, public and private sectors, including Disabled Persons Organisations (DPOs).

How we got here

We worked with SCLD and policy advisers with the support of the Royal Society of the Arts' Action and Research Centre. We explored how best to deliver the vision of The keys to life and A Fairer Scotland for Disabled People into sustained improvement in the lives of people with learning disabilities.

Our key themes – wellbeing, living, working and learning - started to emerge from this work.

This approach was developed by engagement with people with learning disabilities and their supporters:

- The whole system approach was discussed with The Scottish Government's The keys to life expert group of people with learning disabilities who provided valuable early feedback.
- A range of third sector experts were invited by the Minister for Mental Health to take part in a Policy Reference Group to provide advice on the next phase of delivery.
- A series of stakeholder events were held in Glasgow, Inverness, Dumfries and Edinburgh. The events attracted policy professionals, service providers, family carers and people with learning disabilities, and gave everyone an opportunity to share their thoughts about what the next implementation priorities should be.
- A series of events were held with young people with learning disabilities who told us about their aspirations and expectations for the future.
- We heard from people with learning disabilities through ARC Scotland's National Involvement Network, People First (Scotland), PAMIS family carers, ENABLE Scotland, Down's Syndrome Scotland and the Thistle Foundation.

We have used the feedback from this engagement alongside learning from a range of other activities.

We heard often that attitudes to people with learning disabilities need to change and that this means focusing on capabilities not challenges. In particular, we were also reminded of the need to shape what we do to meet the legitimate aspirations of a new generation who expect a different future.

People with learning disabilities want to be part of the change by acting as leaders, supporting their peers and promoting understanding as positive role models.

As part of our work moving forward, we will work with people with learning disabilities, SCLD and stakeholders to promote awareness, through investing in targeted activities about the contributions that people with learning disabilities can and do make.

Priorities 2018 – 2021

Living

What we have heard

- People with learning disabilities lack meaningful choice and control about where to live.
- People with learning disabilities feel they are placed in houses far away from their family and friends.
- Parents with learning disabilities are not provided with adequate support.
- Transport links, particularly bus services, are hugely important if people with learning disabilities are to live active and independent lives.
- People with learning disabilities should be able to have safe and healthy relationships.
- Women with learning disabilities should have their sexual health and reproductive rights ensured and should have access to appropriate services if they experience gender based violence.

What we will do next

- Ensure that the needs of people with learning disabilities are reflected in decision making about housing provision, and that there is greater transparency and accountability in how these decisions are made. This will include reflecting these needs in the refresh of local housing strategies, new Scottish Government Housing Allocations Guidance by working with the Association of Chief Housing Officers, housing associations, local authorities and other providers.

- Support people with learning disabilities to become more connected to their local communities through public transport, by ensuring their needs are considered by providers, particularly bus services.
- Protect the rights of people with learning disabilities to become parents, addressing the need to provide effective, early and on-going support to keep families together, including producing an easy read version of NHS Health Scotland's Parenting Guide 'Ready Steady Baby', commissioning the Scottish Learning Disabilities Observatory to produce better data on women who become mothers and their children who become adopted or looked after, and working collaboratively with health and social care partnerships to address stigma and discrimination associated with the rights of people with a learning disability to have children.
- Recognise the rights of people with learning disabilities to enjoy and maintain healthy relationships, including sexual relationships. Address the discrimination around the reproductive rights of women and girls with a learning disability to be given appropriate relationship, sexual health and parenting education, to be empowered around their own reproductive health and to have access to advice and services. This will include working collaboratively with health and social care partnerships to address stigma and discrimination and including advice and guidance on learning disability in the redraft of the sexual health framework in 2019.
- Recognise and promote the rights of people with learning disabilities to be protected against gender based violence by working with the NHS Health Scotland Advisory Group on their Gender Based Violence programme including the publication of guidelines for frontline staff in 2019.

Learning

What we have heard

- Teachers have a pivotal role in securing positive experiences for people with learning disabilities.
- Many teachers do not have the skills and resources they need to support pupils with learning disabilities.
- Testing and attainment structures do not reflect the potential of children with learning disabilities and how they can succeed.
- Transition periods are particularly challenging for people with learning disabilities.
- There are a lack of appropriate choices for people with learning disabilities at school and college.

What we will do next

- Support the early years development of children with learning disabilities, including ensuring the needs of young children with learning disabilities are reflected in the implementation of The Scottish Government's Play Strategy.
- Work with local government to improve the consistency of additional support for learning across Scotland, through improved guidance, building further capacity to deliver effective additional support and improving career pathways and professional development (including new free training resources for schools on inclusive practices).

- Work in partnership with Education Scotland, the Association of Directors of Education, local authorities, and other leaders on awareness raising to stimulate cultural change within our schools to improve the experiences of pupils with learning disabilities.
- Work with students, colleges, Colleges Scotland, College Development Network and the Scottish Funding Council to identify examples of best practice within the further education sector, with a particular focus on activity that supports progression to employment and promote the adoption of these across Scotland.
- Help to promote the Independent Living Fund (ILF) Scotland's Transition Fund, to ensure that young people with learning disabilities are aware of and encouraged to access support to enhance their independent living, including access to further education and employment.



Working

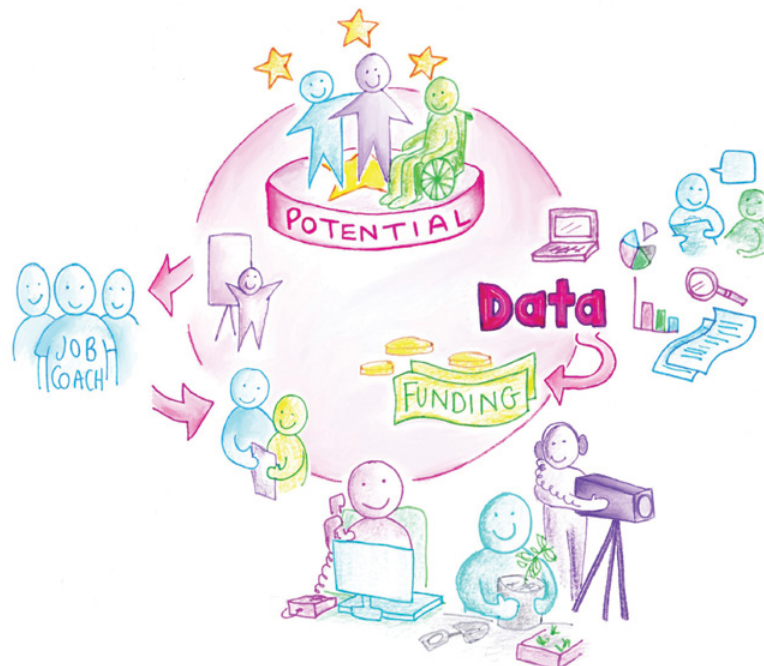
What we have heard

- It is important to raise awareness and challenge attitudes amongst employers of what people with learning disabilities can do within the workplace.
- Job coaches provide valuable support for people with learning disabilities and their work should be better recognised and supported.
- Recruitment processes are not accessible for people with learning disabilities and the support provided is often unhelpful.
- Support the provision of supported employment services and ensure the needs of people with learning disabilities are considered when the effectiveness of these services are being evaluated.

What we will do next

- Challenge attitudes amongst parents, schools, colleges and employers about supported employment services and the potential of people with learning disabilities to succeed in the workplace with targeted awareness raising activity.
- Gather data more effectively and invest funding where people with learning disabilities in Scotland can secure both employment and support to develop in their job. This should include ensuring that people with learning disabilities are visible in data collected by employment programmes in Scotland.

- Ensure that the needs of people with learning disabilities are reflected within the new models of support being delivered by the Disability Employment Action Plan, including support to employers through the new Public Social Partnership and in awareness raising to promote the positive business case for employing disabled people.
- Undertake a review in 2019 of Supported Employment provision across Scotland, and consider the need to build on the existing service offer through local authorities and Fair Start Scotland, the devolved employment service.
- Building on the Seven Principles of Good Transitions, and broader recommendations received from sector experts, disabled young people and their families and carers, work across government to improve transitions into education, learning and work for young people with learning disabilities.



Wellbeing

What you told us

- People with learning disabilities have problems accessing and using primary care services.
- Health care information is not accessible and understandable for people with learning disabilities.
- Experiences of self-directed support are uneven and people with learning disabilities are not being supported in making the right choices.

What we will do next

- Develop effective interventions to improve the life expectancy of people with learning disabilities by improving access to support for general healthcare needs through primary care, annual health checks and screening services. This will include: working with Healthcare Improvement Scotland to gather case studies for best practice for treating patients with learning disabilities to be uploaded onto the Improving Together Interactive. This will allow GP clusters to carry out quality improvement work on this area to find and share examples of best practice.
- Monitor and evaluate the effectiveness of screening interventions which have been funded through the cancer strategy, to improve access to screening services for people with learning disabilities. This will be taken forward by the Screening Inequalities Network which is currently being established.

- Invest in the development of positive behavioural support through the creation of a University post and provide direct support to Health and Social Care Partnerships to consider the findings of the 'Coming home: complex care needs and out of area placements' report, including the need for different models of care to bring home people identified as priority to return.
- Work in partnership to ensure that people with learning disabilities are able to gain greater choice and control over their lives through self-directed support, including through The Scottish Government's development of a new Implementation Plan for self-directed support for 2019-2021 and the associated funding of organisations offering advice, advocacy and support.
- Ensure the rights based approach of the new social security system in Scotland reflects the needs of those with learning disabilities with a focus on the design and testing phase of the new system.
- Develop guidance to support Health and Social Care Partnerships in building local learning disability strategies, to drive the delivery of The keys to life strategic outcomes and embed a human rights approach.



Data sources for info-graphic on page ten:

1. The keys to life 2013
2. SCLD report 'Mapping the employability landscape for people with learning disabilities in Scotland' 2016
3. Pupil's census 2017
4. LDSS 2017
5. Scotland's Census 2011
6. Scotland's Census 2011

Published by SCLD on behalf of The Scottish Government, March 2019,
Available for download at keystolife.info.

