

14th September, 2021

Agenda Item No. 4 - Appendix 3

Learning/Intellectual Disability and Autism – Towards Transformation

Purpose

We want this plan to shape supports, services and attitudes to ensure that the human rights of people with learning/intellectual disabilities and autistic people are respected and protected and that they are empowered to live their lives, the same as everyone else.

This plan is a partnership document with COSLA and a range of stakeholders. The Scottish Government and COSLA currently work in partnership with the third sector and others on our existing [Keys to Life Strategy](#) and the [Scottish Strategy for Autism](#) which end in 2023 and 2021.

However, our work over the last few months has been about sustaining and introducing additional ways to help autistic people and people with a learning disability manage the changes and challenges brought by the pandemic. Throughout those months we have also learnt more about what has worked, what has been most difficult, about how people have managed and what they need. Some things remain the same and some have changed.

We don't know everything now. It will take time to fully understand the longer lasting impacts of the pandemic. We need to take some actions now based on what we have already learned and what people have already told us. We also need to think about the future – we have come a long way over the last 20 years but there is more to do to ensure that autistic people and people with a learning disability can live their lives to the full and be a rightly valued and integrated part of our communities.

This has led us to this plan, which will run for two years, and:

- Describes the huge impact of the pandemic, including that some people feel alone, anxious, and vulnerable.
- Takes on board what we have learned already from your experiences of life during the pandemic.
- Sets out what we have done to provide additional support during the pandemic.
- Sets out the outcomes people want as we understand them now, and actions we are taking or will take.
- Reinforces our shared human rights based and person-centred approach; and
- Starts the journey towards new strategies, as we promise to continue the conversations.

This plan talks about WHAT we need to do but we need to work together on HOW this will be achieved.

We will start to tackle this with new leadership groups that will embed at their heart the voices and experiences of the people who face these challenges every day.

Who is this plan for?

This plan is for autistic people and people who have a learning/intellectual disability, and their family and carers. It is also for local authorities, integration authorities, NHS and third sector support providers. Therefore, this plan is for anyone with a role to play in implementing changes that improve outcomes for autistic people and people who have a learning/intellectual disability, and their family and carers.

Why a Joint plan?

This joint plan recognises that although the issues and solutions can and will be different there is also often common ground, including around the challenges and barriers people face. This has been demonstrated clearly during the pandemic and stakeholders working together has been a strength.

We have brought our actions together into one plan, but we are maintaining clearly separate actions for both groups that reflect their differences.

Our strategies remain separate.

We will take our lead from autistic people and people with a learning disability about whether and how they want to join up this work as we move forward. We know that there are lots of different and strong views about this. We will seek to reconcile and respect those views.

What is the population?

- Scotland's Census 2011 reported 26,349 people to have learning/intellectual disabilities, which is 0.5% of Scotland population¹. Statistics show that people with learning disabilities do not yet enjoy the same life chances as others.
- The Micro segmentation² report established a robust national Scottish autism prevalence rate of 1.035% (103.5 per 10,000). This means there are approximately 44,133 autistic people in Scotland.
- 32.7%³ of autistic people also have a learning/intellectual disability.

How we have engaged and what people told us

We held 10 virtual events that engaged directly with 107 organisations or individuals. We sought their views, experiences, and responses to the draft plan. In addition, a dedicated email address was available in which 5 organisations or individuals responded. As part of this process, we ran engagement sessions with the National Strategy Groups across learning disabilities and autism. The plan has also been considered by COSLA's Health and

¹ <https://www.sldo.ac.uk/census-2011-information/learning-disabilities/topics/population/>

² <https://www.gov.scot/publications/microsegmentation-autism-spectrum/>

³ [00533382.pdf](#)

Social Care Board. Quotes which run through this plan are drawn from this engagement process.

How have people managed during the pandemic?

The COVID-19 pandemic has affected everyone in Scotland. Autistic people and people with learning/intellectual disability have faced a wide range of challenges because of the pandemic. Their response to these challenges has been remarkable. Many people have experienced the sudden loss of social and other supports and have had to adjust to new routines that have often been challenging. Carers and families have had to bear the weight of full-time care without some or all the usual levels of external support. Equally remarkable has been the pace at which services which support people have adapted to the circumstances we have faced and continue to face. We now face the reality of a situation which is likely to have long lasting economic, social and health impacts. This has tested everyone's resilience and will continue to do so.

Evidence from the last few months has shaped this plan

As we move forward, we must be ambitious and rebuild our services to better achieve the human rights of autistic people and people with learning/intellectual disabilities to live as equal and valued members of Scottish society. We must also ensure that those ambitions are matched with what we can achieve and with practical steps that will make a difference daily.

Many organisations rapidly adapted services to continue essential social care support to the most vulnerable in our society. There is a commitment to holding onto that innovation and good practice developed during the restrictions. Beyond service provision, there has also been an amazing community spirit and sense of unity across Scotland. We must build on this.

We have listened to the experiences we have heard about the changes in the lives of autistic people and/or people with a learning/intellectual disability and their family and carers during the pandemic. This plan reflects these voices and the consistent priorities raised.

Learning Disabilities

Further erosion of Human Rights

Healthcare and Social Care

- Procedures cancelled
- Fear of going to GP
- Loss of services and respite

Mental Health

- Isolation, lack of anything meaningful to do
- Loss of support

Fear of COVID Unemployment

- Lost job and no income
- Fear about finding new work

Education

- Little contact
- No support for transition

Digital Exclusion

- Lack of money, no data/ broadband, fear of how to use the technology

Communication

- Confusion of the rules, and how many different types of information published

Autism

Further erosion of Human Rights

Health and Social Care/Support

Diagnosis

- **People crying out for diagnosis and post-diagnosis care/ support**
- **gap in provision of services**

Mental Health

- **Isolation**
- **Anxiety**
- **Lack of autism informed mental health services, or understanding from professionals**
- **Fear of Covid**

Employment

- **Fear of furlough/ redundancy**
- **Fear of asking for reasonable adjustments**

Education

- **Home-schooling - some flourished while it has/had serious negative impact for others**
- **Lack of understanding/ support of autistic children's needs**

Responding to the Pandemic – What we have done since March 2020

Since the start of lockdown, the Scottish Government and COSLA have been working with our partners to understand how the pandemic is affecting people and to provide support. The Scottish Government, Local Government, Health and Social Care Partnerships, NHS Boards and the third and voluntary sectors all provide critical support to both individuals and organisations who deliver services and have continued to do so during the pandemic.

- SG has provided additional social care pandemic funding and commissioned the independent review of adult social care.
- SG has funded organisations through the Third Sector Wellbeing Fund to deliver essential support services throughout the height of lockdown.

- Financial support is available for social care provider sustainability.
- Health and Social Care Partnerships and Local Authorities have supported social care providers and implemented payment arrangements for the guidance on financial support arrangements for social care providers ([link](#))
- SG established a £500,000 fund to help local carer organisations transition to remote working so that they can continue to provide advice and emotional support, such as telephone counselling and online sessions.
- Additional Winter Funding of approx. £90k has been provided to third sector organisations providing national support.
- Scotland's National Wellbeing Hub for the health and social care workforce, now has a specific section with wellbeing resources for unpaid carers.
- Inspiring Scotland has supported our portfolio of third sector organisations to build resilience.
- Scottish Autism's helpline handled calls with Covid and mental health related issues being among the top issues. Contact calls were made to isolated autistic people and families and live chats with people via the website.
- NAS virtual social groups – over 200 people a week were supported through national online social groups, tackling social isolation. People also received health and wellbeing support.
- ENABLE Scotland launched ACE Connect and Family Connect in response to the pandemic as places where members could stay connected, get access to the most up to date information related to the pandemic, and access emotional support through new dedicated helpline.
- The Scottish Commission for Learning Disabilities (SCLD) produced [easy to read information on the Covid-19 pandemic](#) about how people could protect themselves.
- PAMIS have supported families to cope with their caring responsibilities during the disruption caused by the pandemic.
- SG provided additional resource to Downs Syndrome Scotland for their family helpline
- ARC Scotland Provider Forums produced a report [We're all in this together: the impact of Covid-19 on the future of social care](#). National and Local Involvement Networks have supported people to connect virtually with peers. Scottish Transition Forum has produced guidance and held webinars to support parents and carers of young people leaving school at this challenging time.

Human Rights

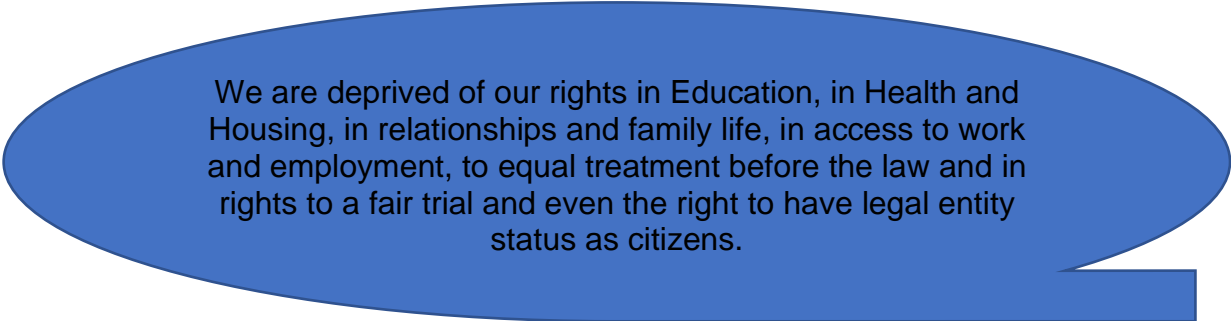
It is important to acknowledge that the rights of autistic people and people with learning/intellectual disabilities were infringed prior to Covid-19 and have been significantly highlighted and exacerbated by the pandemic. People's social care support has been affected by the pandemic and they have not been fully supported and for many their quality of life will have decreased. Fulfilling human rights is a legal duty. In practice, for people with an intellectual/learning disability or autistic people it is about being able to make decisions, have choices and live the way that they want to and access services without a struggle. The [PANEL Principles](#) breaks down what a human rights based approach means in practice.

The Scottish Government is committed to deliver a UNCRC Bill which will incorporate the United Nations Convention on the Rights of Children into Scots' law. This will deliver a proactive culture of everyday accountability for children's rights across public services and protect the rights of children and young people in Scotland.

There is a strength of feeling of people who have an intellectual/learning disability and or autism that a similar focus is needed to uphold their human rights, in line with the UN Convention on the Rights of People with Disabilities. This issue has been discussed at the Learning Disabilities Cross-Party Group and highlighted by People First and ENABLE Scotland who have been advocating for a possible Bill of Rights.

Included in the recent report by the Cross Party Group on Autism at the Scottish Parliament and the Independent Review of the Mental Health Act⁴, a Commission or Commissioner has been proposed to safeguard rights and could be a way of delivering accountability for autistic people's rights and those with an intellectual/learning disability.

The Scottish Government commissioned an independent review of the inclusion of learning disability and autism in the definition of mental disorder within the Mental Health Act. The Rome Review of the Mental Health Act recommended in January 2020 that: *"in future, autism and learning disability should not be defined as forms of 'mental disorder' under the Mental Health (Care and Treatment) (Scotland) Act 2003 or in other mental health law. We recommend that autism and learning disability should be defined in a new law. A new law should also be created which aims to protect human rights on the same basis for everyone, to protect the rights of people who are at risk of serious adverse effects to their human rights."*⁵



We are deprived of our rights in Education, in Health and Housing, in relationships and family life, in access to work and employment, to equal treatment before the law and in rights to a fair trial and even the right to have legal entity status as citizens.

Human Rights - What we will do:

Action 1 - The Scottish Government is clear that the needs of autistic people and people with learning/intellectual disabilities and their carers are to be actively considered as part of the ongoing independent review of the Mental Health Act. This legislative reform⁶ work will help inform the shape of our future legislation.

Action 2 - The Scottish Government will explore further the proposals for a commission or commissioner to help protect people's rights.

⁴ <https://webarchive.nrscotland.gov.uk/20200313213229/https://www.irmha.scot/wp->

⁵ <https://webarchive.nrscotland.gov.uk/20200313213229/https://www.irmha.scot/wp-content/uploads/2020/01/IRMHA-Final-report-18-12-19-2.pdf>

⁶ [Independent Review of Mental Health](#)

Working towards Transforming Lives

Autistic people and people with a learning/intellectual disability want us to work with them to recognise and address the things that will transform their lives as well as the things we have recognised because of the pandemic. They also want to be empowered to make change in their own lives and to be leaders in their communities.

People have a clear vision about what they want from their lives. In people's day to day lives this means:

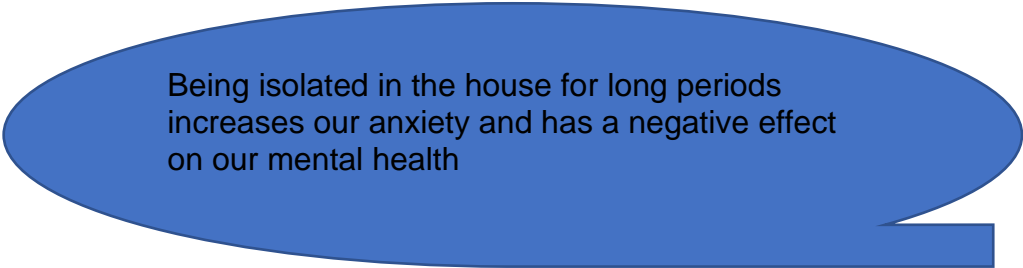
- **To have and be supported to keep good health**
- **To have a good experience at school and for education to give us opportunities and choices for our futures**
- **To be able to work**
- **To be able to live independently but connect with our families and friends**
- **To choose to have a family of our own.**

These things are also the human right of every autistic person and/or person with a learning/intellectual disability but the evidence we have so far tells us that people still struggle to achieve their basic rights and often do not feel valued or respected.

Mental Health, Health and Social Care

Mental Health

Autistic people and people with a learning/intellectual disability have told us that their mental health has been severely affected by the pandemic and that they can be denied mental health services as a direct result of being autistic or having a learning disability. They feel they are not understood by professionals and are more likely to have had a negative experience in mental health services.



Being isolated in the house for long periods increases our anxiety and has a negative effect on our mental health

What we will do

Action 3 - The delivery of the Mental Health Transition and Recovery Plan will support improvement in population-level mental health services. We will explore how these services can better meet the needs of autistic people and people with a learning/intellectual disability.

Action 4 - We will promote the [Mental Health resources](#) being developed by PAMIS to better support people with Profound and multiple learning disability (PMLD) to explore their emotions and a resource developed by Glasgow University to better support people with learning/intellectual disabilities to cope with anxiety.

Health

People with learning/intellectual disabilities have some of the poorest health of any group in Scotland and die on average twenty years earlier than the rest of the population.⁷ This year, new evidence was published by the Scottish Learning Disabilities Observatory that tells us children with learning disabilities are at least 12 times more likely than other children to die in childhood and adults with learning disabilities are twice as likely to die from preventable illnesses.⁸

It is not acceptable for people with a learning/intellectual disability to suffer poorer health and shorter lives and in some cases be delayed in hospital. We must do everything we can together to change this.

There is an urgent need to understand and address the inequalities that lead to preventable deaths in the population with learning/intellectual disabilities

What we will do

Action 5 - We will ensure that the recommendations of the [Coming Home Report](#) are fully considered in the implementation of the work of the SLWG set up to improve delayed discharge and reduce inappropriate out of area placements for people with complex needs. The findings of this work will be reported on and published soon, and mechanisms will be put in place to deliver on its recommendations.

Action 6 - We will pilot a Nurse/AHP Consultant for Autism/learning/intellectual disabilities (learning from best practice from Alzheimer's Scotland Nurse Consultants) aimed at improving both mental health and hospital care of autistic people and/or people with learning/intellectual disabilities.

Action 7 - We will work with the Scottish Learning Disability Observatory⁹ to further understand health inequalities and to identify specific predictors of mortality and actions that will improve health outcomes for people with learning disabilities of all ages.

Action 8 - The Scottish Government, Aberdeenshire Health & Social Care Partnership and partners will take forward a pilot of health checks for people with learning/intellectual disabilities to address health inequalities and early deaths.

Action 9 - The Scottish Government and partners including NHS Boards, the Scottish Commission for Learning Disability and the Scottish Learning Disability Observatory will deliver improvements in data collection and access to data to improve the visibility of these

⁷ O'Leary, L., Hughes-McCormack, L., Cooper, S-A. (2017) Life expectancy and causes of death of people with intellectual disabilities: a systematic review. Journal of Applied Research in Intellectual Disabilities, DOI: 10.1111/jar.12417

⁸ <https://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/mortality-rates-for-children-and-young-people-with-learning-disabilities/> and <https://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/causes-and-rates-of-death-in-adults-with-learning-disabilities/>

⁹ <https://www.sldo.ac.uk/>

populations and consider the development of a Key Performance Indicator to monitor improvements.

Action 10 -We and our partners have established a Gender Based Violence Steering Group and will develop an action plan to reduce incidence of violence and empower women with learning/intellectual disabilities and/or autistic women to have safe and loving relationships.

Action 11 - We will continue to work with the National Autism Improvement Team (NAIT) to support autism and ADHD diagnostic services through improvement practice and explore with Healthcare Improvement Scotland (HIS) the development of a Key Performance Indicator to monitor diagnostic services across Scotland.

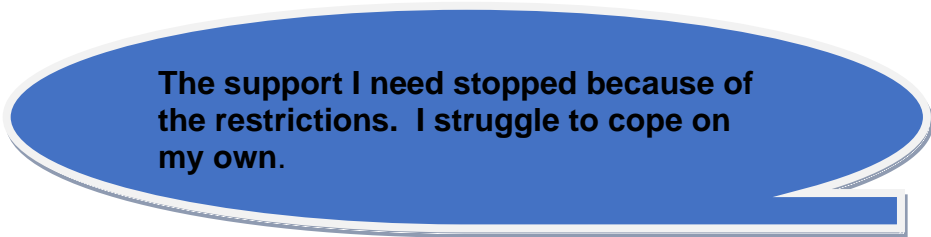
Action 12 - We will explore establishing mandatory autism and learning/intellectual disability training for all NHS staff.

Covid has highlighted the need for Autism Post diagnostic support which is focussed on the kind of social and community support people need. We want to ensure that autistic people have equality in access to post diagnostic support. The Scottish Government has worked with autism charities to put together and pilot post diagnostic support and this was announced in October 2020.

Action 13 - As committed to in the Programme for Government we will deliver a 6-month pilot national post diagnostic support service for autistic people from December 2020. We will work collaboratively with national autism charities and autistic people's organisations and evaluate the outcomes of the pilot post May 2021.

Social Care and Support

It is important to have support to live your daily lives in your communities. People who have learning/intellectual disabilities and autistic people have told us about the importance of having support at times to make their voices heard and being part of networks, which empower independent living by nurturing supportive communities. The support people are offered can vary considerably.



The support I need stopped because of the restrictions. I struggle to cope on my own.

What we will do

Action 14 -The Scottish Government will ensure that people with lived experience are listened to and better supported to influence programmes and initiatives which will impact on their lives. This will include helping to support engagement with the review of adult social care, the Social Renewal Advisory Board and National Taskforce on Human Rights. This provides opportunities to ensure that social care reform and the transformation of

social care services are focussed on reducing inequalities and better meet the needs of our population.

Action 15 - The Scottish Government continues to work with Inspiring Scotland ‘*Support in the Right Direction*’ and other partners to ensure that more people who have a learning/intellectual disability or autism access their rights under the Social Work (Self Directed Support) (Scotland) Act 2013 to direct their own support.


Action 16 - In May 2020, the Scottish Government, Social Work Scotland and COSLA produced COVID-19: Guidance on Self-Directed Support Option 1 and Option 2. The guidance is for Local Authority and Health and Social Care Partnership staff who assess, approve and administer social work and social care and support (including carer support), and approve Self-directed Support (SDS) budgets and is relevant only for the duration of the COVID-19 pandemic period. It aims to support local social care systems and services to continue to respond appropriately and flexibly, to enable service users to meet their outcomes during the pandemic. We will work with partners and individuals to understand the impact of this change. The Scottish Government is also working with Healthcare Improvement Scotland (iHub) and H&SCPs on a learning disability collaborative to maximise partnership working on community led solutions to new models of day support for people with learning disabilities.

Action 17 - The Scottish Government has launched a national carers marketing campaign to help more people recognise when they are in a caring role and to access the support available to under the Carers (Scotland) Act 2016.

Action 18 - The Scottish Government will explore asset based community development models to create better outcomes for autistic people and/or people who have learning/intellectual disabilities and their family carers.

Employment

Employment helps people to feel valued - opportunities and choices to work are important for everyone. It is estimated that the employment rate for people with learning/intellectual disabilities is 7% and 16% for autistic people compared with Scotland’s national employment rate of 73%. The pandemic will have made this worse. The Scottish Government is reviewing the current schemes that help autistic people and people with a learning/intellectual disability to successfully obtain and keep a job.



We are excluded from the world of work. We want support to find work and hold down a job so we can contribute to society, just like everyone else.


What we will do

Action 19 - The Scottish Government will continue to work towards our ambition to at least halve the disability employment gap as stated in A Fairer Scotland for Disabled People and [A Fairer Scotland for Disabled People: Employment Action Plan](#).

Action 20 - The Scottish Government will ensure that the voices of autistic people and people with learning/intellectual disabilities are heard and part of the decision making in the review of supported employment provision across Scotland. Supported Employment plays an important part in helping people into work who would otherwise struggle to gain employment in the open labour market. As such, it is a model that can make an important contribution to the ambition to at least halve the disability employment gap in Scotland, and will be more important than ever as part of our COVID-19 recovery efforts. The review is taking place in the first quarter of 2021 with the final report due in the summer of 2021.

Education

“Excellence and equity for all” is the Scottish Government’s vision for education in Scotland. This aspiration fits with Scotland’s inclusive and forward-thinking approach to education policy, and there is an extensive programme of work happening to make this a reality. Yet for some children with additional support needs this is not their experience.



Autistic children find home schooling stressful bringing additional pressures on families already struggling to cope.

What we will do

Action 21 - The Scottish Government and COSLA will work with partners to support the implementation of the action plan on the recommendations of the [Additional Support for Learning Review](#), improving educational experiences and outcomes for all children and young people who need support with their learning.

Action 22 - We will action the Deputy First Minister’s Working Group Implementation Plan following the [Not Included, Not Engaged, Not involved Report](#). This will include building better autism awareness in Initial Teacher Education, working with the General Teaching Council Scotland and Universities to develop training resources and deliver training in autism to all trainee teachers.

Action 23 - We will build better learning/intellectual disability awareness by promoting the Talking about Learning Disability resources¹⁰ through the General Teaching Council and Association of Directors of Education in Scotland.

Action 24 - The Scottish Government will work to develop meaningful Additional Support for Learning outcome measures which capture indicators of the achievements and progress

¹⁰.www.talkingabout.org.uk

of autistic children and/or children who have learning/intellectual disabilities beyond solely academic and destination data.

Action 25 - The Scottish Government will produce new standalone guidance on the use of physical intervention and seclusion in Scotland's schools. This will provide a clear human rights based policy on physical intervention and seclusion and will be presented as part of the *Included, Engaged and Involved* suite of guidance. We will also introduce a standard data set and oversee subsequent implementation, including a review one year from publication of the revised guidance to ensure its effectiveness.

Action 26 - As part of our joint action plan in response to the Additional Support for Learning implementation review, we will explore how to support more parents to have access to the information, skills, support, and advocacy they need to be active and equal participants in their child's education.

Digital Exclusion

It is important to stay connected with family, friends, and our communities. The pandemic has made this even more important.

Digital exclusion is a barrier to all citizens with learning disabilities, many do not fit the current Connecting Scotland Criteria.

What we will do

The Scottish Government wants to end digital exclusion in Scotland through our Connecting Scotland programme. This means providing technology and connectivity to those that need it to open up access to education, health care and employment as well as help us to feel less isolated and keep us connected to family and friends.

Action 27 - We will improve digital access for people with learning/intellectual disabilities so that they can stay connected to their family, and communities.

Communication

People with learning/intellectual disabilities have told us that they need accessible public health messaging to help them understand what to do to stay safe and healthy.

The places where hard copies of these documents could previously be found are closed. Web versions of easy read are only available to those with access online.

What we will do

Action 28 - In partnership with Scottish Commission for Learning Disabilities (SCLD) and People First we will build on the Covid-19 experience of providing access to accessible information, using SCLD's website as an accessible information hub and linking into Disability Equality Scotland's Inclusive Communication Hub.

Autistic people and people with learning/intellectual disabilities are, like all other groups, not all the same. Some people identify with other protected characteristics too. We want to support people to learn from each other and develop their ability to speak up and have their voice heard in decisions about their lives, services and communities through self-advocacy and peer support.

What we will do

Action 29 - We want to empower people to have their voices heard as active citizens. Our new autism campaign – [Different minds. One Scotland.](#) – is part of trying to change the way that autistic people are understood.

Action 30 - In partnership with Inspiring Scotland and the Scottish Commission for Learning Disability (SCLD), we will encourage people with lived experience to participate in a Future Leaders Programme to empower people to be active and involved in their own community. We also want to support self-advocacy initiatives like the National Involvement Network, Autistic People's Organisation, People First and People's Assembly.

Action 31 -The Scottish Government will take specific action to engage with autistic people and people with a learning/intellectual disability from Black, Asian and Minority Ethnic Communities to hear about their experiences and identify how we can best support and work with them.

WHAT HAPPENS NEXT?

- **People want this plan to start conversations about how we can really change lives. We know this isn't easy – people with a learning/intellectual disability and autistic people have to be really valued for what they can contribute.**
- **We want to help people achieve this. So, this also means working to change attitudes.**
- **We will put in place arrangements for everyone to work together through new leadership arrangements and for this work to be led by autistic people and people with a learning disability.**
- **We will be led by people with a learning/intellectual disability and autistic people about how much of this they want to do together.**
- **We will start working out how to achieve the vision people have for their lives.**
- **We will start (and continue) delivering the actions set out here.**

ANNEX A

Equality Impact Assessment

An Equality Impact Assessment (EQIA) is being carried out as part of the development of this to ensure that best practice is implemented. It is important that we recognise that autistic people and people with learning/intellectual disabilities are not a homogenous group and that there will be those who identify with other protected characteristics within these groups. The EQIA will help us to identify areas of multiple discrimination.

An EQIA involves assessing the impact of new or revised policies, practices or services against the requirements of the public sector equality duty. The duty requires all Scottish public authorities to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. It covers people in respect of all aspects of equality (age, disability, sex, race, religion or belief, sexual orientation, gender reassignment and pregnancy and maternity). It helps to ensure that the needs of people are taken into account during the development and implementation of a new policy or service or when a change is made to a current policy or service.