

# Learning/Intellectual Disability and Autism Towards Transformation

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## **Foreword by the Minister for Mental Health**

Unprecedented. It is a word we will forever associate with 2020 – and rightly so. In March, we heard for the first time that message of ‘Stay home. Save lives. Protect the NHS.’ We are still in the depth of dealing with the Coronavirus pandemic, and we will be for some time yet. We remain in response mode, but the recent positive developments around a vaccine mean it is only responsible that we start planning ahead for Scotland’s recovery.

I saw first-hand how Scotland changed to deal with the crisis. Everything that we had come to know as ‘normal’ changed. But what I saw most was the human qualities of compassion and care come through loud and clear from all areas of society. People, organisations and individuals responded to the crisis, supported by those around them who displayed those Scottish values of compassion and care. This was Scotland’s response to coronavirus.

What became clear was how vital the third sector and local authorities were in protecting the NHS. The rapid transition to provide critical mental health support to people and families at home, and social care providers supporting people in their homes and in the community, protected the NHS when it needed it most. Allowing people to stay indoors, be safe, healthy, and out of hospital is only due to the heroic commitment and dedication of Scotland’s health and social care staff and volunteers.

Similarly, the resilience of individuals and their ability to adapt was also unprecedented. It exposed how much our ‘normal’ needs to change, so that people enjoy choice and control and are supported to be independent and active citizens.

I am delighted to introduce this ‘Towards Transformation’ document which looks at the particular needs of Scotland’s autistic people, people with learning/Intellectual disabilities, and people who are both autistic and have a learning/Intellectual disability.

In the immediate coronavirus response, I saw how leaders worked together to address issues together. The provisions we made during Covid for third sector organisations with our investment of £450k to combat social isolation and to support national helplines, specifically for the benefit of autistic people, and/or people with learning/Intellectual disabilities demonstrates this. We know that coming together to tackle big issues works.

But I also know how important identity is. Our work on post-diagnostic support for autistic people, and the efforts of Connecting Scotland to reach digitally excluded people with learning/intellectual disabilities proves that our commitment to each of your individual communities continues.

The situation remains unprecedented and significant challenges remain. Mental Health will stay high on the agenda, with the full extent of the impact of the collective trauma of coronavirus still unknown. We cannot predict how our response to the virus may need to change, but we can think about Scotland’s transformation. We need to use this opportunity as we rebuild Scotland to decide – what will Scotland’s new normal look like?

I hope you will see this plan as the beginning of the conversation about how we change Scotland for the benefit of autistic people, people with learning/Intellectual disabilities, and people who are both autistic and have a learning/Intellectual

disability. Transformation is a joint responsibility, only possible with your help – whether you are an individual or part of our third, public or private sector.

Let this be the start of our work together to transform Scotland into a place where the human rights of autistic people, and/or people with learning/intellectual disabilities are respected and protected and that they are empowered to live their lives, the same as everyone else.

A handwritten signature in black ink that reads "Clare Haughey". The script is cursive and fluid, with the first letters of each word being capitalized and prominent.

Clare Haughey

**Minister for Mental Health**

## **Foreword by Councillor Currie, COSLA**

Like the Minister I too would like to thank all staff working in the NHS, local authorities, other public services, the third and independent sector and all the people of Scotland for their commitment and forbearance in the face of the pandemic. These have been, and at the time of writing continue to be, very challenging times for everyone with restrictions in place limiting everyday pursuits, activities and the ability to engage with our usual support networks, friends and families. The rollout of vaccinations offers us a way out of this.

COSLA and the Scottish Government have engaged with local authority staff group representatives, third sector organisations and with disabled people's organisations and individuals in developing this joint Learning/Intellectual Disability and Autism Towards Transformation Plan”.

We have heard the concerns raised by some that having a joint learning/intellectual disability and autism plan will result in the diluting of different approaches where they exist in the existing Keys to Life Strategy and Scottish Strategy for Autism. I want to reassure anyone with such concerns that is not the aim, the intention and that it will not be the outcome of having a joint plan.

The plan is the start of considering the impact of the Scottish Strategy for Autism 2011 – 2021 and the Keys to Life 2013 – 2023 and what comes next. It highlights the impact of Covid-19 on both groups, how services to support people have adapted in light of restrictions to movement and opportunity and highlights actions which local government and Scottish Government will take individually and jointly with partners to mitigate these restrictions. The intention is that the plan articulates actions to improve things for people with lived experience and fully involves them in the leadership and scrutiny of the plan.



Councillor Stuart Currie

**COSLA Spokesperson Health and Social Care**

## 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 autistic people and people with learning/intellectual disabilities 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/intellectual 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 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 also people with a learning/intellectual 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 also 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 includes things like stereotyping. 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 clear separate actions for both groups that reflect their differences. We are not advocating for joint actions or services at local level. We need to be clear this joint plan is not about treating this group as one population. We are very clear that person centred approaches need to be taken at all levels.**

**Our strategies remain separate.**

**We will take our lead from autistic people and people with a learning/intellectual 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 have engaged extensively with People First and Autistic led organisations to listen and hear their views about this. We have assured them we will seek to reconcile and respect those views. We commit to always listen, hear and respect people's views and for those voices to be at the centre of decision making going forward.**

## **What is the population?**

- Scotland's Census 2011 reported 26,349 people to have learning/intellectual disabilities, which is 0.5% of Scotland's population<sup>1</sup>.
- The Micro segmentation<sup>2</sup> 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%<sup>3</sup> of autistic people also have a learning/intellectual disability.

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

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

<sup>3</sup> [00533382.pdf](#)

## **How we have engaged and what people told us?**

We held 12 virtual events that engaged directly with 225 individuals or organisations. 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/intellectual disabilities and autism. The plan has also been considered by COSLA's Health and 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 of the usual levels of external support. Equally remarkable has been the pace at which services which support people locally have adapted to the circumstances we have faced and continue to face. There has also been significant pressure on the people providing services. We have all had to 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 to better secure the human rights of autistic people and also people with learning/intellectual disabilities to live as equal and valued members of Scottish society. We must ensure that those ambitions are matched with what we can achieve and with practical steps that will make a difference on a daily basis.

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 people with a learning/intellectual disability and their family and carers during the pandemic. This plan reflects those voices and the consistent priorities raised. Here is some of what we heard:

## Learning/Intellectual Disabilities

### Further erosion of Human Rights

#### Healthcare and Social Care

➤ **Procedures and regular physio cancelled**

“my physio stopped, and nobody can be trained to do it with or for me because of rules - really frustrating (as live 2mins from hospital), so I’m getting physically weaker”

➤ **Fear of going to GP, or GP not providing a service**

“ I can't get in touch with GP despite several ear infections, and now detrimental effect on hearing. My hearing aid is broken, and I can't get it fixed.”

“I don't like video calling with GP as they can't see everything”

“We are too afraid to go to GP or hospital during COVID”

➤ **Loss of services and respite**

“I can't get carers or train any new ones up because of restrictions”

“Citizens Advice is so busy that it can't pick up the calls, so we're missing benefit or grant deadline”

#### Mental Health

➤ **Isolation, lack of anything meaningful to do**

“Losing independence and having to move back in with family, being a prisoner in own home – and being told what to do

➤ **Loss of support**

“I can't access the counselling support that I used to get”

#### Fear of COVID Unemployment

➤ **Lost job and no income**

“I'm furloughed and feeling very isolated”

➤ **Fear about finding new work**

“There is too much competition, people with LD don't stand a chance”

#### Education

➤ **Little contact**

➤ **No support for transition**

“I didn't get to finish school to go to college”

“Shielding and sickness meant that I couldn't get the support I needed, new people didn't know me or what I needed

### **Digital Exclusion**

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

“The gap between the people who are learning digital skills and the ones who are excluded is widening. This is going to be a problem.”

### **Communication**

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

“There are so many rules, I find them so confusing” “we need a consistent Easy Read format that people with LD can understand”

## **Autism**

### **Further erosion of Human Rights**

#### **Health and Social Care/Support**

“Support is only provided when crises point is reached”

#### **Diagnosis**

- **People crying out for diagnosis and post-diagnosis care/ support**
- **gap in provision of services<sup>4</sup>**

#### **Mental Health**

- **Fear of Covid**
- **Isolation**

“My biggest fear during this Pandemic is being arrested for having an Autistic meltdown. I used to be very active doing Munroe’s, going to Uni and when the Pandemic hit I have been completely reclusive. I haven’t been exercising because I don’t want to go out in public.”

“Friends ...(They’re) losing skills they’ve gained over years like using public transport and going to a familiar place.”

- **Anxiety**

“It’s the biggest issue with people I interact with. We are seeing significant depression spikes in a community which is routinely depressed anyway so it’s a bad thing.”

- **Lack of autism informed mental health services, or understanding from professionals**

“Autistic people are being taken to hospital in handcuffs when distressed”

“GPs blaming the mental health of people on their autism and so not providing support.”

#### **Employment**

- **Fear of furlough/ redundancy**

“The Autistic community seems the easiest to let go because they are the most challenging in the workplace.”

- **Fear of asking for reasonable adjustments**

“I struggle to ask for adjustments because I know I’m going to have to self-advocate. Support is lacking and I don’t have the energy to fight for it.”

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<sup>4</sup> [cpg on autism report - the accountability gap 06.10.2020.pdf](https://www.scottishautism.org/cpg_on_autism_report_-_the_accountability_gap_06.10.2020.pdf)  
([scottishautism.org](https://www.scottishautism.org))

## **Education**

### ➤ **Home-schooling - some flourished whilst it has/had serious negative impact for others**

“I have 2 Autistic kids both at Secondary school. During the pandemic one wasn’t engaged with school but the other one thrived because he could work to his own timetable. The other one just couldn’t get working at home, now back at school working but there has been no help to catch up on what was missed.”

### ➤ **Lack of understanding/ support of autistic children’s needs**

“The school just thinks I’m being over-dramatic, they don’t take me seriously, very patronising. They know I’m Autistic and they just use it as an excuse.”

### ➤ **No support for transitions**

“Covid-19 has removed transition support for children between primary and high school”

## **Communication**

### ➤ **Constant changing of rules**

“At the beginning all the changes and uncertainty, all the different rules all the time and it’s happening again now. For a while I wasn’t sure what was going on and then I’d get the hang of it and then it changes. On the radio, I’m not even sure what is English or Scottish advice.”

## **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.

- We have provided additional social care pandemic funding and commissioned the [independent review of adult social care](#).
- We have 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
- We 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.

- We provided third sector investment of £450k to combat social isolation and to support national helplines, specifically for the benefit of autistic people, and/or people with learning/intellectual disabilities.
- Scotland's National Wellbeing Hub for the health and social care workforce, now has a specific section with [wellbeing resources for unpaid carers](#).
- The Scottish Commission for people with Learning Disabilities, in collaboration with the University of Glasgow, the University of Warwick, the University of Oxford and Lancaster University, developed [a suite of guided self-help resources](#) for people with learning/intellectual disabilities to support their mental health and well-being during the pandemic.
- We collaborated with the Scottish Learning Disabilities Observatory, National Records of Scotland and Public Health Scotland to access and analyse data on the [impact of COVID-19 on people with learning/intellectual disabilities](#).
- Inspiring Scotland has supported our portfolio of third sector organisations to build resilience.
- Scottish Autism's helpline handled calls with coronavirus 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.
- National Autistic Society 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.
- Triple A's have run social groups supporting over a hundred people a week through online Discord groups. In addition, they provided ongoing mental health support, counselling, and advice.
- 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 people with 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.
- The Scottish Government 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. The Scottish Transition Forum has produced guidance and held webinars to support parents and carers of young people leaving school at this challenging time.
- A [Community Living Change Fund of £20m](#) was announced to facilitate the discharge of long-stay hospital patients who have been delayed in their discharge; to bring home people with learning/intellectual disabilities who have been inappropriately placed outside of Scotland; and to redesign current service provision to ensure such people do not face prolonged hospitalisation or unnecessary placement outside of Scotland going forward.

## Human Rights

It is important to acknowledge that there is a widely held view that the rights of autistic people and people with learning/intellectual disabilities were infringed prior to coronavirus and have been significantly highlighted and exacerbated by the pandemic. People's social care support has been affected by the pandemic and when they have not been fully supported, for many their quality of life will have decreased. Fulfilling human rights is a legal duty. In practice, for autistic people and people with learning/intellectual disability 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 autistic people and people with learning/intellectual disability 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 Act<sup>5</sup>, 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 a learning/intellectual 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."<sup>6</sup>

*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.*

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

<sup>6</sup> <https://webarchive.nrsotland.gov.uk/20200313213229/https://www.irmha.scot/wp-content/uploads/2020/01/IRMHA-Final-report-18-12-19-2.pdf>

## **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 reform<sup>7</sup> 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.**

## **Equality Impact Assessment**

An Equality Impact Assessment (EQIA) is being carried out as part of the development of this plan 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.

A total of eighteen workshops are being undertaken to ensure that the needs and experiences of autistic people and also people with learning/intellectual disabilities are understood and taken into account. The findings from the EQIA will be incorporated into the implementation of the plan going forward.

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<sup>7</sup> [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 as a result of the pandemic. They also want to be empowered to make change in their own lives and to be leaders in their communities.

This needs to happen at all levels nationally and locally for change to happen.

People have a clear vision about what they want from their lives. In their 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 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/intellectual 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

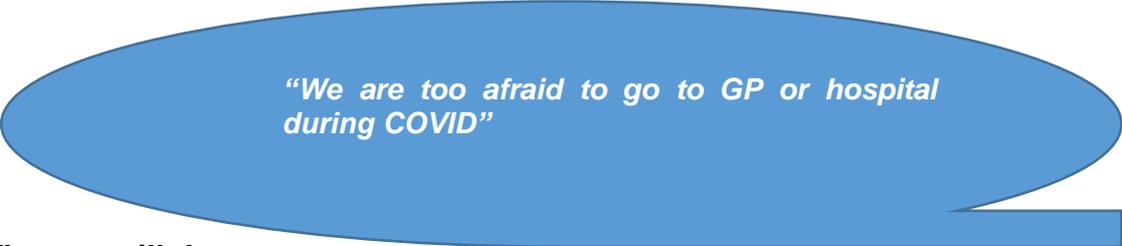
explore their emotions and a resource developed by Glasgow University to better support people with learning/intellectual disabilities to cope with anxiety.

## 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.<sup>8</sup> This year, new evidence was published by the Scottish Learning Disabilities Observatory that tells us children with learning/intellectual disabilities are at least 12 times more likely than other children to die in childhood and adults with learning/intellectual disabilities are twice as likely to die from preventable illnesses.<sup>9</sup>

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.

We are also told that autistic people have poorer health outcomes. We know less about their health needs and need to learn more about how their health needs can be improved.



*“We are too afraid to go to GP or hospital during COVID”*

## What we will do

**Action 5** - We have ensured that the recommendations of the [Coming Home Report](#) have been fully considered in the work of the short life working group (SLWG) set up to improve delayed discharge and reduce inappropriate out of area placements for people with complex needs. A final report of the SLWG is currently being drafted and mechanisms will be put in place to deliver on its recommendations. One of the groups' early recommendations on a “Community Living Change Fund” of £20m has been announced and allocated to Integration Authorities. There are three main expectations from the Community Living Change Fund: to facilitate the discharge of long-stay hospital patients who have been delayed in their discharge; to bring home people with learning/intellectual disabilities who have been inappropriately placed outside of Scotland; and, to redesign current service provision to ensure such people do not face prolonged hospitalisation or unnecessary placement outside of Scotland going forward. Recognising the complexity of designing, commissioning and

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<sup>8</sup> 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/>

arranging services, and often bespoke newly built accommodation, we have allowed three years for the funding to be used and the outcomes to be achieved.

**Action 6** - We will pilot a Nurse/AHP Consultant for Autism and 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 Observatory<sup>10</sup> to further understand health inequalities and to identify specific predictors of mortality and actions that will improve health outcomes for people with learning/intellectual 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 people with Learning Disabilities and the Scottish Learning Disability Observatory will deliver improvements in data collection and access to data to improve the visibility of these 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:

**A** - mandatory autism training for all NHS staff.

**B** - mandatory 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, autistic led charities and organisations and evaluate the outcomes of the pilot post May 2021.

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<sup>10</sup> <https://www.sldo.ac.uk/>

**Action 14** – We will explore the barriers to autistic people living a healthier life.

### **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 to make their own decisions and to make their voices heard. Being part of networks which empower independent living can help them to do that. 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 15** - The Scottish Government will ensure that people with lived experience are listened to and better supported to initiate and influence programmes and initiatives which will impact on their lives. We want to ensure that those voices are part of discussions from the outset. This will include helping to support engagement with the issues set out in 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 16** - The Scottish Government continues to work with Inspiring Scotland 'Support in the Right Direction' and other partners to ensure that more autistic people and people with learning/intellectual disabilities access their rights under the Social Work (Self Directed Support) (Scotland) Act 2013 to direct their own support.

**Action 17** - 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 HSCPs on a learning disability collaborative to maximise partnership working on community led solutions to new models of day support for people with learning/intellectual disabilities.

**Action 18** - 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 under the Carers (Scotland) Act 2016. We will help make sure that people know about this support.

**Action 19** - The Scottish Government will explore asset based community development models to create better outcomes for autistic people and 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 20** - 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 21** - The Scottish Government will ensure that the voices of autistic people and people with learning/intellectual disabilities are heard and a meaningful and important 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.

*Some autistic children find home schooling stressful bringing additional pressures on families already struggling to cope. Some have flourished.*

### What we will do

**Action 22** - 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 23** - 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 understanding 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 24** - We will build better learning/intellectual disability understanding by promoting the Talking about Learning Disability resources<sup>11</sup> through the General Teaching Council and Association of Directors of Education in Scotland.

**Action 25** - The Scottish Government will work to develop meaningful Additional Support for Learning outcome measures which capture indicators of the achievements and progress of autistic children and/or children who have learning/intellectual disabilities beyond solely academic and destination data.

**Action 26**- 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 27**- 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

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<sup>11</sup>.[www.talkingabout.org.uk](http://www.talkingabout.org.uk)

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 critical.



*Digital exclusion is a barrier to all citizens with learning disabilities*

## **What we will do**

The Scottish Government wants to end digital exclusion in Scotland. 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. Part of our current response includes providing devices through our Connecting Scotland programme, however we can continue to build on the work undertaken during the pandemic to promote digital inclusion.

### **Action 28 –**

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

B - We will improve digital access for autistic people so that they can stay connected to their friends, family, and communities.

## Communication

Both autistic people and 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 29** - In partnership with the Scottish Commission for people with Learning Disabilities (SCLD) and People First we will build on the Covid-19 experience of providing access to accessible information. This will include 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 groups who, like other groups, are 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 30** - 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 and was built on early and successful involvement from autistic people. We will continue our work on this.

**Action 31** - In partnership with Inspiring Scotland and the Scottish Commission for people with 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 led charities and organisations, People First and the People's Assembly.

**Action 32** -The Scottish Government will take specific action to engage with autistic people and also 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 have told us that they want this plan to start conversations about how we can really change lives. We know this isn't easy – autistic people and people with a learning/intellectual disability have to be valued for what they can and do contribute.
- We want to help people achieve this. So this also means working together to change attitudes, including our own.
- We will put in place plans for everyone to work together through new leadership arrangements and for this work to be led by autistic people and people with a learning/intellectual disability. National and local organisations need to be involved in this.
- We want the voice of autistic people, people with a learning/intellectual disability, and unpaid carers to be at the centre of work going forward.
- We will also be led by autistic people and people with a learning/intellectual disability 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.

## List of actions

### Human Rights

**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 reform<sup>12</sup> 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.

### Both learning/intellectual disability and autism

**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 6** - We will pilot a Nurse/AHP Consultant for Autism and 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 people with learning/intellectual disabilities.

**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 autistic women to have safe and loving relationships.

**Action 12** - We will explore establishing:

**A** - mandatory autism training for all NHS staff.

**B** - mandatory learning/intellectual disability training for all NHS staff.

**Action 15** - The Scottish Government will ensure that people with lived experience are listened to and better supported to initiate and influence programmes and initiatives which will impact on their lives. We want to ensure that those voices are part of discussions from the outset. This will include helping to support engagement with the issues set out in 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.

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<sup>12</sup> [Independent Review of Mental Health](#)

**Action 17** - 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/intellectual disability collaborative to maximise partnership working on community led solutions to new models of day support for people with learning/intellectual disabilities.

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<sup>13</sup>[www.talkingabout.org.uk](http://www.talkingabout.org.uk)

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**Action 32** -The Scottish Government will take specific action to engage with autistic people and also 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.

### **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.

**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 in the near future and mechanisms will be put in place to deliver on its recommendations.

**Action 7** - We will work with the Scottish Learning Disability Observatory<sup>14</sup> to further understand health inequalities and to identify specific predictors of mortality and actions that will improve health outcomes for people with learning/intellectual 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 people with Learning Disability and the Scottish Learning Disability Observatory will deliver improvements in data collection and access to data to improve the visibility of these populations and consider the development of a Key Performance Indicator to monitor improvements.

**Action 29** - In partnership with the Scottish Commission for people with Learning Disabilities (SCLD) and People First we will build on the Covid-19 experience of providing access to accessible information. This will include using SCLD's website as an accessible information hub and linking into Disability Equality Scotland's Inclusive Communication Hub.

## **Autism**

**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 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, autistic led charities and organisations and evaluate the outcomes of the pilot post May 2021.

**Action 14** – We will explore the barriers to autistic people living a healthier life.

**Action 23** - 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 understanding 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.

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<sup>14</sup> <https://www.sldo.ac.uk/>



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