



The Scottish Strategy for Autism

Outcomes and
Priorities
2018-2021



Scottish Government
Riaghaltas na h-Alba
gov.scot

Joint Ministerial and COSLA Foreword

In 2011 the *Scottish Strategy for Autism* was published and the then Minister for Public Health, Michael Matheson, and Councillor Douglas Yates at COSLA stated our commitment to improving the lives of autistic people in Scotland. We believe significant strides have been taken towards realising the strategy's vision in the intervening seven years, but we know challenges remain and that much work is still to be done. Much has changed in Scotland since 2011, not least the introduction of health and social care integration and the establishment of the new bodies called Integration Authorities. These new bodies bring health and social care services into new local single structures which have responsibility for planning and making decisions about how best to meet the needs of their local population, using the combined resources available. This requires close working with professionals and local communities to deliver sustainable new models of care and support that are focused on improving outcomes for people.

Our commitment to the strategy's vision is undiminished. To gather the views on its final phase, we undertook an engagement exercise in which more than 1,200 people participated through either our online questionnaire or engagement events. This engagement helped to inform this updated set of priorities, which we hope will take us closer to our vision for all autistic people living in Scotland.

Staff education, training and development remain at the heart of the *Scottish Strategy for Autism*. We are committed to supporting the on-going implementation of the Optimising Outcomes framework, led by NHS Education for Scotland, and will work with the Scottish Social Services Council to improve understanding of autism across the social care workforce. This activity complements Integration Authorities delivery of autism services and support. Of course, all Integration Authorities have developed autism action plans to improve local services, and we will continue to support their implementation.

It is important that autistic people and their families are understood and welcomed within their own communities and supported to be as independent and active as they wish to be. That is why we have committed to supporting national autism public awareness campaigns.

Autistic people contribute much to Scottish society and with the right support many could contribute much more. We want to recognise this contribution. We are delighted therefore to announce the development of new national autism awards, which will highlight and promote the successes of autistic people in Scotland and recognise innovation and best practice in autism services.

In 2011 we said the realisation of the *Scottish Strategy for Autism's* vision will require concerted effort across all sectors and by all those involved. This remains the case. Only through collaboration will we be able to truly improve the lives of autistic people and create the kind of Scotland we all want to see and live in – a fairer Scotland, a more equal Scotland, a Scotland for everyone.



Maureen Watt



Peter Johnston

Introduction

The *Scottish Strategy for Autism* was published jointly by Scottish Government and COSLA in 2011. The Scottish Government originally committed £13.4 million over four years to improve the lives of autistic people and their families and carers and to build on improvement to autism services and access to them. The original document set out 26 recommendations and the vision that by 2021 ‘individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives’.¹

In 2014 the Scottish Government published a report on the progress made by the autism strategy during its first two years entitled - *The Foundation Phase*.² Significant progress was made during this phase. Key developments included the development of a Menu of Interventions – a guide to help people on the autism spectrum and their families and carers identify available advice and support.³ A mapping exercise was also conducted, which sought to ‘map out’ local autism services and to improve their coordination.⁴ This exercise coincided with the one-off investment of £35,000 for each local authority in Scotland to develop local autism strategies and action plans. Alongside this investment, £4.5 million was set aside for Autism Development Funds, the purpose of which was to encourage local and national organisations to develop projects to improve the delivery of local autism services.⁵

In the year following the publication of the Foundation Phase Progress Report, Scottish Government and COSLA refreshed the autism strategy and reframed it into an outcomes approach for the period 2015 to 2017. These new outcomes – healthier life, choice and control, independence and active citizenship – and their attendant priorities ensured the *Scottish Strategy for Autism* was better placed to drive forward the realisation of the strategy’s vision for autistic people and their families.

- 1 Scottish Government, ‘Scottish Strategy for Autism’, <http://www.gov.scot/Publications/2011/11/01120340/0> [date accessed 21 February 2018].
- 2 Scottish Government, ‘Scottish Strategy for Autism: Progress Report – Foundation Stage (0-2 Years)’, <http://www.gov.scot/Resource/0046/00462295.pdf> [date accessed 21 February 2018].
- 3 Scottish Government, ‘Scottish Strategy for Autism – Menu of Interventions’, http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=187&lang=en&task=doc_download [date accessed 12 February 2018=]
- 4 Scottish Government, ‘Scottish Strategy for Autism – Mapping Report’, http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=191&lang=en&task=doc_download [date accessed 21 February 2018]
- 5 In the period March 2012 - March 2015

Now, after passing the strategy's halfway point, and conscious of the significant shifts that have taken place in Scotland since 2011, including the devolution of new powers, the Scottish Government sought to engage with autistic people, their families and carers and those with a professional interest on the development of the strategy's next and final phase.

Progress and achievements

Our achievements since 2015 include:

- Supported the development and promotion of the Autism Training Framework – Optimising Outcomes – for those working in health and social care, as well as other resources including a learning space to inform workforce development.⁶
- Invested over £2m in more than 40 autism charities and projects which have reached and delivered positive outcomes for some 6,000 autistic people, their families and carers.⁷
- Invested in Autism Network Scotland to promote the work of the strategy and share good practice with autism professionals, third sector, autistic adults and family carers in Scotland.
- Invested in the National Coordination Project which supported the development of local autism strategies and action plans.
- Invested in a pilot of six One Stop Shops to provide early intervention post diagnostic support to autistic adults, children and their families.⁸
- Invested in a diagnostic improvement programme, which has shared good autism practice across services.
- Launched a Knowledge Hub to support networking, collaboration and informing sharing among the professionals working with autistic people.
- Supported the development of Scottish Autism's Right Click programme for Women and Girls.
- Supported the development and promotion of the Principles of Good Transitions 3 and the autism supplement as guides to good practice for transitioning young people with additional needs.
- Continued to promote the Autism Toolbox for teachers and school support staff.
- Showcased the strategy at Autism-Europe's 11th International Congress in Edinburgh 2016.⁹
- Developed a number of employment resources, led by the strategy's Employment Network.¹⁰

6 NHS Education for Scotland, 'The NHS Education for Scotland Autism Training Framework - Optimising Outcomes: A framework for all staff working with people with Autism Spectrum Disorders, their families and carers', http://www.knowledge.scot.nhs.uk/media/12392691/sct0117216030-3%20asd%20training%20framework%20cov_final.pdf [date accessed 21 February 2018].

7 In the period March 2015 - March 2018

8 Of the six locations piloted with Scottish Government seed funding only Fife, Perth, Ayrshire and Highland remain.

9 <https://www.youtube.com/watch?v=TaMWSHnFrZ8>

10 <http://employment.autismnetworkscotland.org.uk/>

Purpose of this document

This document sets out priorities for action through to 2021 to improve outcomes for autistic people living in Scotland.¹¹

These priorities attempt to reflect the key issues raised during a short period of engagement with autistic people and their families, practitioners working with autistic people and members of the Scottish Strategy for Autism Governance Group. Our analysis of the issues raised during our engagement activity has been published separately, and can be accessed [here](#).

As well as our direct engagement with autistic people and their families and practitioners working in the field, we have taken account of national evidence to inform our actions, in particular the newly published [Micro segmentation report](#) on the economic costs of autism in Scotland, which establishes 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.

Data

The collection of information and data on the health and healthcare of autistic people is important. This information and data can then be turned into meaningful health intelligence for practitioners, commissioners, policymakers and the wider community. To achieve this we need to increase the visibility of autistic people within Scotland's routinely collected data and generate high quality evidence to build the understanding of the health and health inequalities experienced by autistic people. There are a number of routinely collected data sources for example GP, Health and Social Care, Mental Health, Housing and Education. Statutory bodies need to work together to link this data into meaningful intelligence that will inform policy and change practice.

Who is the audience for this document?

Integration Authorities (IAs) are responsible for the strategic planning and decision making for all functions delegated to them, including diagnostic services for autistic adults in line with their statutory responsibilities under the Public Bodies (Scotland) Act (2014).¹² This means they have a major role to play in designing and delivery of local autism strategies and action plans, alongside NHS Boards and local authority colleagues in housing, education, and other relevant local services which may not be delegated to the IA, and services delivered by other community planning partners. Therefore, this document should be read by anyone with a role to play in leading and implementing changes that improve outcomes for autistic people and their families.

11 Throughout this document we have used the terms 'autistic people' to describe people on the autistic spectrum. We understand there is still some disagreement about the best descriptor to use, but we believe the phrase 'autistic people' has more significance for those on the autism spectrum.

12 Scottish Government, 'Health and Social Care', LINK, [date accessed 21 February 2018]. <http://www.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration>

While most of the actions detailed in this document will be led by delivery partners, the contribution of autistic people, their families and carers, and professionals in the field is essential. We would encourage autistic people, their families and carers to engage both at national and local level in the planning of autism services.

As in the original *Scottish Strategy for Autism* published in 2011 this document recognises that the autism spectrum is wide and autistic people are diverse. This document recognises that autistic people are represented within the protected characteristics under the Equality Act 2010. It also recognises that autism is lifelong and that autistic people will require support across their lifespan.

Graphic Artist

In an effort to provide a graphic depiction of our engagement events we commissioned graphic artists. The cartoon graphics used in this document were produced during our engagement exercises by graphics artist, Graham Ogilvie - graham@ogilviedesign.co.uk. These depict the conversations that took place.

Strategic Outcomes

Our strategic outcomes relate to the vision, values and goals of the *Scottish Strategy for Autism*, contribute to all of the National Health and Wellbeing Outcomes and resonate strongly with the ambitions set out in *A Fairer Scotland for Disabled People*. Our outcomes are unchanged from the outcomes framework launched in 2015.

Strategic Outcome One: A Healthy Life

Autistic people enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services.

Strategic Outcome Two: Choice and Control

Autistic people are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs.

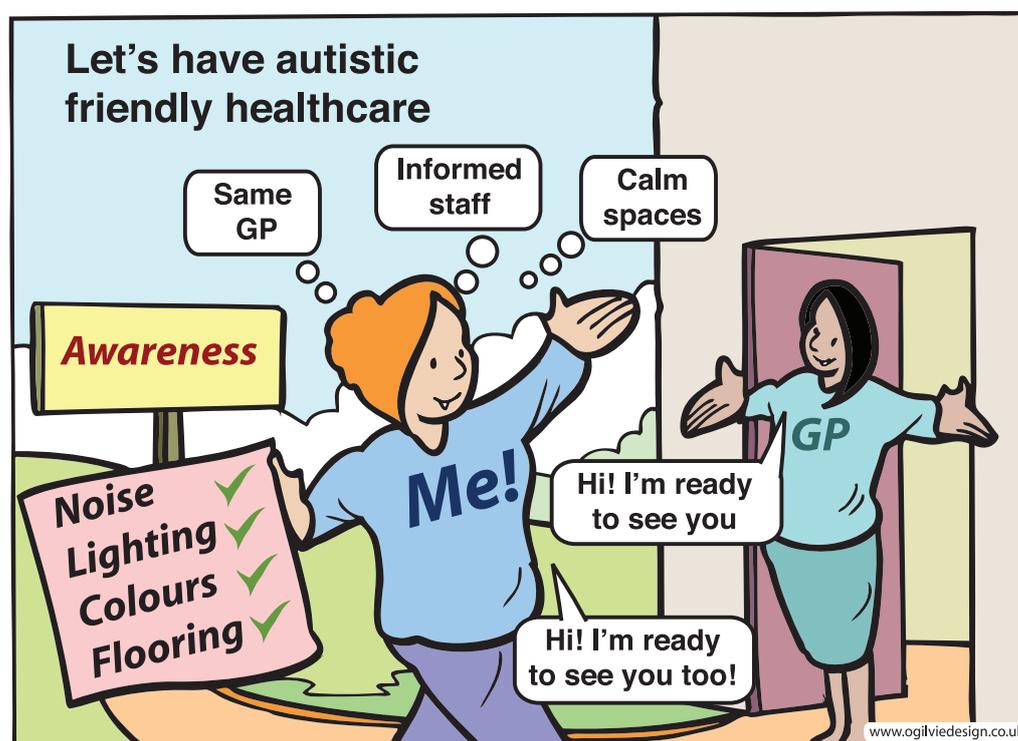
Strategic Outcome Three: Independence

Autistic people are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding.

Strategic Outcome Four: Active Citizenship

Autistic people are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities.

A Healthy Life



WHAT YOU TOLD US:

- That autistic people need early access to a clear diagnostic pathway.
- That support services need to be in place for autistic people and their families both during and after diagnosis.
- That information on the support available to autistic people, their families and carers needs to be consistent, relevant and up-to-date.
- That good mental health is of critical importance to autistic people and that more support is needed in this area.

WHAT WE WILL DO NEXT:

- Scottish Government will continue to facilitate improvement for autism assessment and diagnosis for all age groups and genders through Improvement Programmes and the Autism Knowledge Hub.¹³
- Scottish Government will work with partners to develop a National Post-Diagnostic Support Toolbox which pulls together information on all the local resources available to autistic people and their families.
- Scottish Government will continue to support Integration Authorities to contribute to achieving the national autism strategic outcomes.
- The Mental Health Strategy 2017-2027 sets a vision for Scotland that applies to everyone.¹⁴ Its themes of parity of esteem, improved early intervention, access, physical health improvement and rights and recovery apply regardless of diagnosis. People with autism have higher incidence of comorbid anxiety, depression and other mental disorders. General improvement work as described in the Mental Health Strategy therefore needs to equally apply to people with autism as other mental health disorders where appropriate. Action 33 of the Mental Health strategy commits to a review of how the provisions in the Mental Health (Care and Treatment) (Scotland) Act 2003 fulfil the needs of people with learning disability and autism, taking forward new legislative measures if necessary. This review is underway.¹⁵
- We will continue to explore alternative solutions to out of area placements for people with complex care needs and autism. Scottish Government will engage with Health Improvement Scotland on improvement programmes designed to improve how autistic people in Scotland are met and understood within all services, including the Living Well in Communities work.¹⁶

13 The Autism Knowledge Hub enables a network of professionals across health and social care with an interest in autism to learn about and share good autism practice.

14 Scottish Government, 'Review of learning disability and autism in the Mental Health (Scotland) Act 2003: Findings from a scoping exercise', <http://www.gov.scot/Publications/2017/01/8102> [date accessed 21 February 2018].

15 Scottish Government, 'Review of learning disability and autism in the Mental Health (Scotland) Act 2003: Findings from a scoping exercise', <http://www.gov.scot/Publications/2017/01/8102> [date accessed 21 February 2018].

16 'Living Well in Communities', <http://ihub.scot/a-z-programmes/living-well-in-communities/> [date accessed 21 February 2018].

Choice and Control



WHAT YOU TOLD US:

- That awareness of autism needs to be raised among professionals and services that encounter or work with autistic people.
- That professionals across various areas need more training in autism and in understanding how autism impacts upon a person's life.
- That more needs to be done to support teachers and school staff to support autistic pupils.
- That more needs to be done to support families.
- That older autistic people face a number of challenges and barriers that increase as they age.

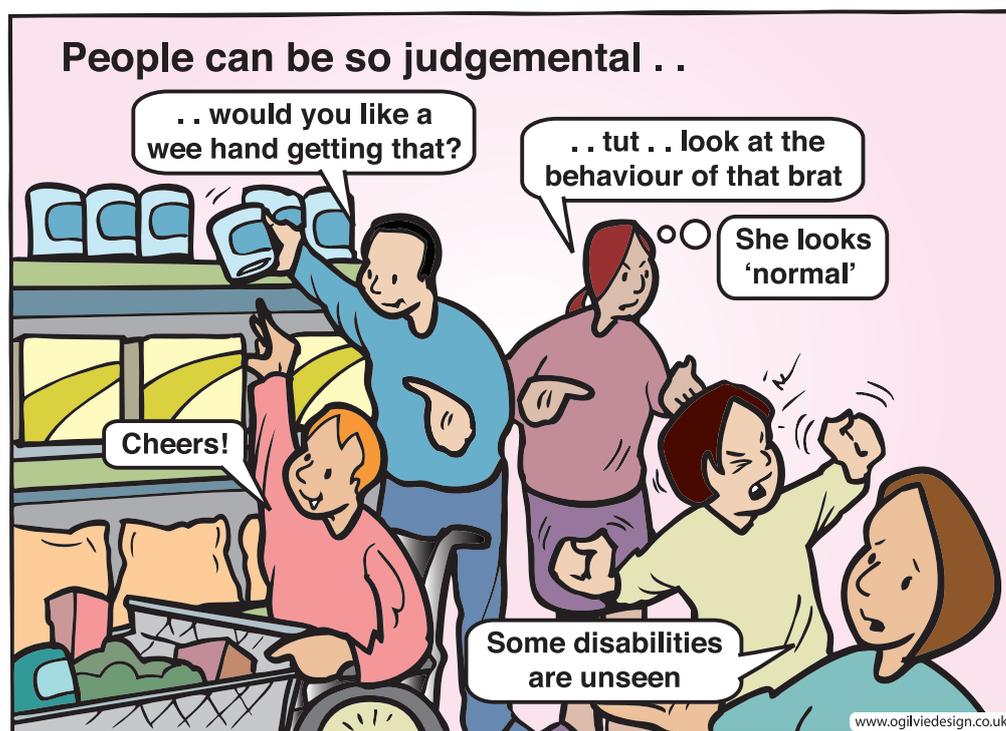
WHAT WE WILL DO NEXT:

- We will increase investment and build on the work done by NHS Education for Scotland (NES) on the autism training framework. We will work with NES, the Scottish Social Services Council, Health Boards, Local Authorities and Integration Authorities to analyse gaps in training across Scotland's health and social care workforce and deliver targeted training to improve the understanding of autism across the workforce.
- Scottish Government will continue to support the work of Scottish Autism and the SWAN Network in the promotion of the Right Click resource for women and girls to improve the understanding of autism in females across professionals.¹⁷
- Scottish Government will work with the Care Inspectorate to improve services for autistic people. The Care Inspectorate will appoint an autism champion and involve autistic people in service inspections.
- We will work with the Scottish Offenders with Learning Disabilities Network (SOLD) to improve autism awareness across the Criminal Justice System.
- We will build on education resources, such as the Autism Toolbox, to ensure teachers and the education workforce have access to resources designed to help them better support autistic children.
- We will work with universities who deliver teacher education to explore how we can increase awareness of autism in teacher education.
- We will explore what needs to be done to ensure autistic parents are better supported.
- We will establish what needs to be done to support the aging autistic population.
- Scottish Government will work with partners to consider how autism research is translated into practice, and explore the introduction of a Scottish Autism Research Consortium.¹⁸

17 Scottish Autism, 'Online Support for Women and Girls', <https://www.scottishautism.org/services-support/support-families/women-and-girls-online-support> [date accessed 21 February 2018].

18 <http://eprints.gla.ac.uk/132866/1/132866.pdf>

Independence



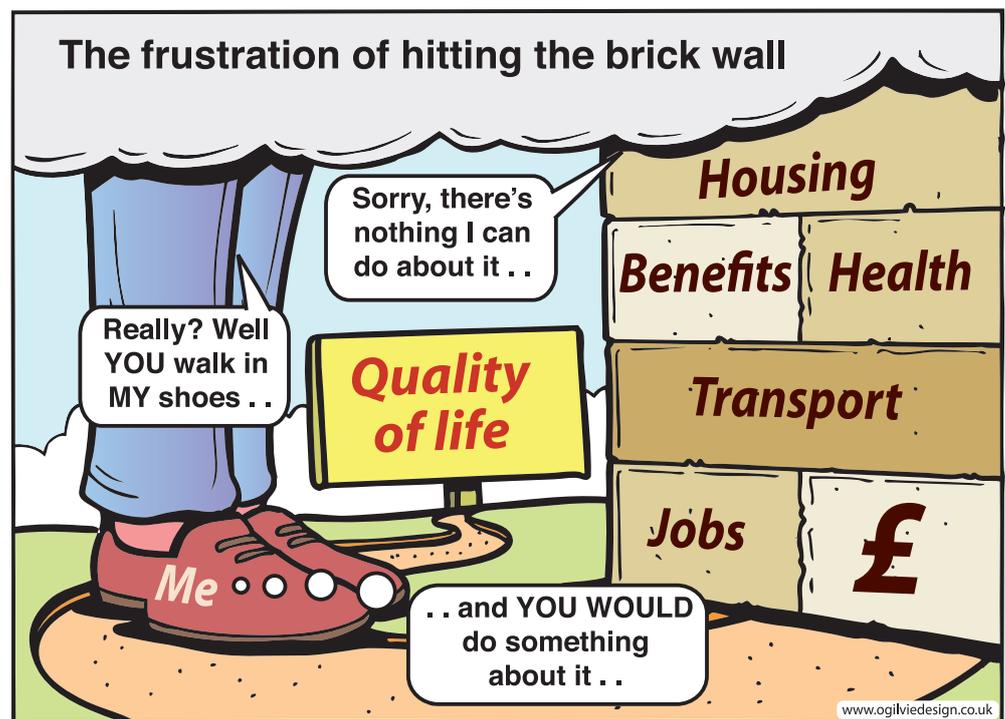
WHAT YOU TOLD US:

- That more needs to be done to raise awareness and acceptance of autism among the general public.
- That we need to adopt a strengths-based approach to autism, focusing on individuals' strengths, skills and abilities.
- That autistic people should be able to access community facilities like any other citizen.
- That autonomy and peer support are important to autistic people.
- That housing has a major role to play in delivering positive outcomes for autistic people.

WHAT WE WILL DO NEXT:

- We will support national autism public awareness campaigns to improve how autistic people and their families' needs are met and understood within their communities and across all aspects their lives.
- Scottish Government will develop national autism awards to highlight and promote the successes of autistic people in Scotland as well as innovation and best practice in autism services.
- We acknowledge the growing number of autism friendly places in Scotland including airports and shopping centres, and encourage organisations to consider making their facilities autism friendly and enabling.
- We will promote the extension of the Blue Badge Scheme, which now covers carers of people with dementia, autism and Down's syndrome, meaning carers and relatives of people who pose a risk to themselves or others in traffic can apply for a badge.
- We will share the best practice from assisted travel training work nationally and explore with Integration Authorities how assisted travel training can lead to better outcomes for young autistic people to travel independently and access their community.
- The Scottish Government will explore the role of advocacy services in supporting autistic people across Scotland.
- The Scottish Government wants everyone to have a home that is the right size, in the right location and able to meet their needs and to ensure people are able to live independently. Local authorities have a key role in planning for the housing needs of everyone within their local community including people on the autistic spectrum. We have also put collaboration with the housing sector at the Integration Authorities thinking and planning by requiring them to produce a Housing Contribution Statement as an integral part of their Strategic Commissioning Plans.
- Scottish Government will ensure flexibility in the housing grant subsidy arrangements within the Affordable Housing Supply Programme (AHSP), so that social landlords are supported to build specialist housing in accordance with local need. Appropriate adaptations can also help disabled people stay in their own home. We are working with Integration Authorities, disabled people's organisations and the housing sector to improve access to these services for those who need them.
- We will work with local housing partners to pilot an autism housing project to inform housing practice and awareness of autism to ensure the housing needs of autistic people are well understood across the housing sector.

Active Citizenship



WHAT YOU TOLD US:

- That autistic people should have more opportunities to work and should be supported into work and while in work.
- That autistic people should be supported on a strengths-based approach.
- That the current social security system is difficult for autistic people, their families and carers to access and navigate, and does not fully recognise the nature of autism and how it affects a person.
- That autistic people, their families and carers should be able to access cultural and social activities like any other citizens.
- That well-planned transitions are important to ensuring autistic people are properly supported throughout their lives.
- That social isolation is an issue for many autistic people and their families and that steps need to be taken to reduce this.

WHAT WE WILL DO NEXT:

- Scottish Government will deliver on the commitments in *A Fairer Scotland for Disabled People*.¹⁹ We have engaged with stakeholders, including disabled people with learning disabilities and autism, on how to halve the disability employment gap – and will continue doing this during 2018 and beyond. In the Spring of 2018 we will set out next steps for taking forward action to reduce by more than half the disability employment gap, and on 30 April 2018 we will hold a national congress on disability, employment and the workplace.
- We will consult with public sector bodies and disabled people's organisations about how to increase the disability employment rate in the public sector. During this process we will engage with autistic people and their representative bodies.
- The Scottish Government recognise that autistic people have much to give but still face very specific challenges in securing sustained employment. Our new employment programme, Fair Start Scotland will commence in April 2018.²⁰ Fair Start Scotland will reflect the need for effective person-centred services and in-work support and will include tailored and personalised provision for all customers.
- The Scottish Government will expect Fair Start Scotland providers to have specialist support in place for people with additional support needs, including autism, to help them secure sustained employment. They will be expected to work closely with employers and have a proven track record of achieving positive results for their clients.
- Fair Start Scotland will gather data on the autistic people that we support into work. For our own programmes and initiatives we will improve data collections and break downs of disability data into meaningful categories in order to establish base line and to be able to measure progress.
- We will work with our partners in Skills Development Scotland (SDS) to support autistic people in Modern Apprenticeships. SDS will focus their efforts on measures to increase the number of individuals starting apprenticeships who have a learning disability, including autism. Emphasis will also be placed on strategies to enable disabled people to sustain and achieve their apprenticeship including using additional funding to deliver supported employment models and support in making reasonable adjustment for delivery and assessment.

19 <http://www.gov.scot/Publications/2016/12/3778>

20 Employability in Scotland, 'Employment Support 2018', <http://www.employabilityinscotland.com/devolved-employment-services/employment-support-2018/> [date accessed 21 February 2018].

- The Scottish Government is responsible for designing the new social security system for Scotland and one of the guiding principles for social security is that we will put the user experience first, and design our new system with people who have experience of using the current system.²¹ We want to ensure Scotland's newly devolved social security arrangements are fully responsive to the needs of autistic people.
- Scottish Government will work to promote and facilitate participation in activities that have meaning for individuals. We will work across government to ensure people with autism are able to enjoy Scotland's rich cultural heritage, vibrant creative arts sector, inclusive sport opportunities and built and natural environments.
- Scottish Government will work with partners to promote the *Principles of Good Transitions 3* and its autism supplement as guides of best practice in transitions for young people with additional needs.²²
- We will work with national agencies to explore the findings of the report - *Facing the Future Together* - on availability of transitions planning and support, and develop plans for improvement.²³
- We will work with partners and the Scottish Funding Council to deliver training – Enhancing Inclusive Practice: Transitions and Autism – to staff in Scotland's Further Education colleges and universities.
- We will work with partners to promote the new *Transitions across the lifespan* resources.
- We recognise that social isolation is an issue for many autistic people and their families. We want everyone to have the opportunity to develop meaningful relationships regardless of age, status, circumstance or identity, and we will work with partners to reduce social isolation in the autistic population.²⁴

21 <http://www.gov.scot/Topics/Statistics/Browse/Social-Welfare/SocialSecurityforScotland>

22 Scottish Government, 'Social Security for Scotland', <http://www.gov.scot/Topics/Statistics/Browse/Social-Welfare/SocialSecurityforScotland> [date accessed 21 February 2018].

23 Ibid, "Facing the Future Together: A national survey of young people with additional support needs and their parents and carers about their experiences of leaving school" [date accessed 21 February 2018].

24 Scottish Government, 'A Connected Scotland: Tackling social isolation and loneliness and building stronger communities', <http://www.gov.scot/Publications/2018/01/2761> [date accessed 21 February 2018].

How will we know the Scottish Strategy for Autism has made a difference?

- An Autism Strategy Review Group will be established to review and monitor progress in achieving the priorities and outcomes set out in this document.
- We will report regularly to the newly formed Cross Party Group on Autism.
- We will publish a report on our progress towards the priorities set out in this document during 2020.
- In 2021 we will review the evidence and evaluate the impact of the strategy across Scotland and report to the Scottish Parliament.



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