

The National Autistic Society Scotland's Response to the Scottish Government's consultation on the final stage of the Scottish Strategy for Autism

About Autism

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while there are certain difficulties that everyone with autism shares, the condition affects them in different ways. Some autistic people are able to live relatively independent lives, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK¹.

About The National Autistic Society Scotland

The National Autistic Society Scotland is a leading charity for autistic people in Scotland and their families. There are around 58,000 autistic people in Scotland, both children and adults, plus their more than 174,000 family members and carers. We provide local specialist help, information and care across Scotland to children, adults and families affected by autism. We offer a wide range of personalised quality support at home and in the community, both in groups and one-to-one. Our branches in Scotland offer families and autistic people help and mutual support, and our employment team support autistic people in work and their employers.

Introduction

The National Autistic Society Scotland welcomes the opportunity to respond to the Scottish Government's consultation on the final phase of the Scottish Strategy for Autism. In our view, which is informed by the experiences of the people we support and our staff, it has not yet had the impact that was intended or expected. We also believe that too few of the initiatives that have been brought about by the Strategy have had real lasting change. With four years left until the end of the Strategy, significant measurable change is needed and data needs to be gathered and shared on the impact and outcomes of the initiatives it has brought about.

To ensure the Strategy has a real impact on the lives of autistic people and their families in Scotland, it is important for there to be clarity as to how its actions will be delivered, and by whom. It is also vital to have measurable outcomes. There must be a shared and effective process of monitoring the Strategy and measuring its effectiveness. This is particularly important in relation to monitoring local autism plans, but applies to many parts of the Strategy and needs to be addressed if we are going to be able to evaluate its effectiveness.

Question 1: How can we ensure autistic people and their families enjoy healthier lives?

Being able to live a healthy, fulfilling and rewarding life is important for everyone. However, too many autistic people currently struggle to unlock the support they need to lead the healthy life they would choose. Below, we have outlined some of the main obstacles that autistic people face in accessing health services.

¹ Baird, G. et al. (2006) *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. The Lancet, 368 (9531), pp. 210-215, and Brugha, T. et al (2009) *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007*. Leeds: NHS Information Centre for Health and Social Care. Available to download at <http://www.hscic.gov.uk/catalogue/PUB01131>

Diagnosis Waiting Times

Getting a diagnosis is a critical milestone for autistic people and key to them living healthier lives. It can offer a gateway to accessing the right support as well as providing an explanation for years of feeling 'different' or helping a parent to understand their child better. Delays in diagnosis mean delays in getting the right support and all the associated problems that entails: 60% of local authorities agree that having a diagnosis means someone is more likely to get support² and for those autistic adults who don't receive support, 73% told us they would feel less isolated if they were able to access it³.

Research from Goldsmith's University suggests that, on average, children wait 3.6 years to receive an autism diagnosis after first seeking professional help, while adults wait an average of two years.⁴

In addition, our 2013 *Count Us In; It Pays to Listen* report found that:

- 42% of respondents said the process was too stressful.
- 27% of respondents said they had been misdiagnosed.
- 6% of respondents had paid to access diagnosis.

Currently in Scotland there are no autism-specific diagnosis waiting times targets. In 2011, the Scottish Strategy for Autism recommended that an assessment of national waiting lists be undertaken to clarify the extent of delays. The Autism Achieve Alliance (AAA) published their findings in 2014, using a recommended maximum waiting time of 119 days from having an initial referral to sharing a diagnosis as a target to measure performance against (from recommendations issued in National Autism Plan for Children (2003)). The AAA report in Scotland identified that 59% of adults and 74% of children took longer than 119 days to receive a diagnosis and that the average diagnosis waiting time for children was 331 days, with the longest individual case in their study taking over five years. This underlines a wide variation diagnosis waiting times across the country.

We welcome the steps that the Government have taken since the strategy was last refreshed in 2015 to address this issue, particularly the improvement programme which is underway across NHS Boards to improve diagnostic services and increase diagnostic capacity. We also welcome the publication of new guidelines on 'Assessment, diagnosis and interventions for autism spectrum disorders' by the Scottish Intercollegiate Guidelines Network (SIGN). We have long been campaigning for better recognition of autism among adults and for many years have called for action to improve the diagnostic process for autistic adults. We therefore particularly welcome that the new guidelines cover all ages and replace previous guidelines that only covered children and young people.

However, there is still a lot of work to do if we are going to address this issue. Our *Count Us In* report made a key recommendation in 2013 that there should be an NHS HEAT target for post-diagnostic support which hasn't been met.

In England, the Government has recently committed to collecting and publishing the average waiting time for an autism diagnosis assessment. It is expected that this data will be recorded from April 2018. While collecting this information is just one element of what is

² Daly, J. (2008). *I Exist: the message from adults with autism in Scotland*. London: The National Autistic Society

³ NAS Scotland (2013), *Count Us In*.

⁴ <http://www.autismdiagnosis.info>

needed for us to have a better understanding of the autistic population, it's a significant and positive step.

In light of this, we believe that as part of the final phase of the Strategy the Scottish Government should develop a Local Delivery Plan (LDP) standard for autism to join the many others that are currently in place, such as dementia post-diagnostic support and the treatment time guarantee. This would require local authorities and health boards to devise a local plan which would include how they would develop and maintain a diagnostic pathway.

Recommendation:

- The Scottish Government should record, publish and monitor autism diagnosis waiting times in every area.
- The Scottish Government should develop a Local Delivery Plan (LDP) standard for autism.

Data

The Strategy recommends that at a local/community planning level there is a process for data collection to improve the reporting of how autistic people many people receive services and inform the planning of those services.

Each local authority, as community planning lead, is asked to develop this through an area autism strategy. A number of approaches to data collection can be taken and we would recommend a range of data sources on autism be used, if possible, to form a picture of local need. We often find in local strategies that the prevalence rate is applied to the local population for both children and adults. This is a starting point but it cannot develop a picture of who requires services or support and what type of service they may require.

We believe the main issue concerning data collection and autism is that much of the adult population is hidden or invisible but the needs and support of children are much better recorded.

Data recorded on Additional Support Needs in School by the Scottish Government and local authorities has identified what appears to be most of the expected school age population who would be estimated to be on the autism spectrum. This suggests that most autistic children and young people are at least being identified.

For adults the picture is quite different. The Scottish Commission for Learning Disability (SCLD) collates the eSay data set which is focused on people receiving social work support who have a learning disability or are autistic. This data does not gather information on autistic adults who do not receive services and therefore does not address the whole population. It also varies significantly in how it is collected between local authorities and it may be the case that autism is still not recorded, particularly where an individual has other support needs and where their autism may not have been identified. Many adults, and in particular older adults, will therefore be 'invisible' and services are too often not available to support people on the autism spectrum.

Just as the presentation of autism varies across a spectrum, the needs of autistic people vary greatly. A greater understanding of the autistic population could significantly contribute to the planning of services and monitoring of the outcomes that the Strategy is seeking to achieve.

In addition, for the final phase of the Strategy, as stated above we believe that the Government must make a commitment to gathering diagnostic information, outlining exactly where autism is going to be recorded.

Recommendations:

We believe that the final phase of the Strategy should commit to the following, locally and nationally:

- Recording diagnosis waiting times
- Recording autism in social care records
- Collecting data on the employment rate for autistic people
- Ensuring autism is recorded in all newly devolved benefits systems.

Improving GP records

Linked to the above point, the Government should look to improve the recording of autism in primary care records. We have been calling on the Government and NHS England to improve the recording of autism in individuals' GP records, which was also reflected in the Government's Think Autism adult autism strategy. This will have two key benefits:

- GPs will be better able to make reasonable adjustments for autistic people, meaning the GP will be better equipped to support their autistic patients
- Anonymised data from GP records will give a picture of the health (including mental health) needs of autistic people.

This will be crucial to addressing mental health inequality, and help the right support to be put in place at the right time. Following campaigning from the National Autistic Society in England, the National Institute for Health and Clinical Excellence supported this recommendation in summer 2016.

Recommendations:

- The Government should use the Strategy to outline actions to ensure that autism is recorded in GP records.

Autism and Epilepsy

Autistic people appear more likely to have epilepsy than the general population. About [one in every 100](#) people has epilepsy and autistic people are thought to be at heightened risk, with between [20% and 40%](#) having epilepsy. This rate increases steadily with age.

In their 2016 report looking at premature mortality and autism, research charity Autistica highlighted evidence from Sweden that suggests autistic people are at greater risk of dying prematurely, often decades before their non-autistic peers⁵. The research behind this report suggested that across every major cause of death in Sweden, mortality risk is increased in autism, but early deaths due to epilepsy and suicide were found to be particularly high. Other research has shown that autistic adults who also have a learning disability have been found to be almost 40 times more likely to die from a neurological disorder relative to the general

⁵ Autistica (2016), *Personal tragedies, public crisis - The urgent need for a national response to early death in autism*

population – with the leading cause being epilepsy⁶. While we do not know what the situation is in Scotland, there is little reason to think that it would be substantially different.

In their report, Autistica called for a national response to this issue, including from the Scottish Government. They recommended that there should be increased investment in research and evidence gathering in order to gain a better understanding of the link between autism and epilepsy, using the emerging findings to develop better treatments. We echo this recommendation and believe that the final phase of the Strategy should commit the Government to undertake work on this issue to inform policy and practice. We also believe that the Scottish Government should launch a review into mortality and autism, to find out more about the health of autistic people. This should then be used to develop actions to tackle the key causes of premature mortality.

Recommendation:

- The Government should commission research into autism and epilepsy, as well as a review into mortality.

Question 2: How can we ensure autistic people have proper choice and control over the services they use and in their lives more generally?

Choice and Control

The respondents to our *Count Us In* consultation, autistic people who are experts in their own condition, told us very clearly that making choices was fundamentally important to maintaining a sense of control over their own lives, and that their self-esteem was affected when they couldn't take part in decisions affecting them. The report found that 91% of respondents want more say over their support.

Some autistic people will need significant support to make and communicate decisions. Not all autistic people have the capacity to make choices about every aspect of their lives, but everyone should be supported to take part in as many decisions as possible.

Many others need support to communicate their views, particularly those who cannot communicate using words and the availability of accessible information can be an issue for many autistic people.

It is therefore vitally important that autistic people are able to access advocacy services when they are needed. Respondents to our *Count Us In* consultation told us that:

- 37% wanted advocacy support.
- Only 16% had access to advocacy.
- 66% had not made use of an advocacy service.

In addition, of those responding to our survey:

- 49% said that a lack of understanding of autism has made it difficult to get the support they need.

⁶ 3 Hirvikoski, T. et al. (2015). *Premature mortality in autism spectrum disorder*, *The British Journal of Psychiatry*, 207(5)

- 45% hadn't been able to ask for support because of a lack of information.
- 48% wanted help with social skills.

In relation to 'choice and control', we also believe that there have been instances where commissioning or tendering processes have made it difficult for specialist autism providers to operate. Like many other organisations within the third sector, we were disappointed with the Scottish Government's announcement that the majority of the contracts for specialist employment services in the new Fair Start Scotland initiative are to be managed by generic providers who, in our experience, cannot provide the specialist service (based on good understanding) that autistic people need. It is vital that the strategic commissioning process ensures that autistic people have maximum choice of potential services available to them, including specialist autism providers.

Recommendations:

- Autistic people or their families should be empowered to advocate for themselves, through good transition planning and support after diagnosis.
- Autistic people or their families should have access to independent advocacy services from advocates who understand their needs, as a way to help them access services. Having access to advocacy services can provide the temporary but specific help that people need.
- Local autism strategies should map independent advocacy services that are available across all the services that autistic people need to access.
- Specialist autism providers, and the expertise that they can provide, should be enabled in the commissioning processes.

Criminal Justice System

It is our view that the Criminal Justice System (CJS) is failing autistic people and that this must be addressed. In our experience, autistic people are no more likely to commit a crime than anyone else. However, our research indicates that as many as a third of autistic adults may have been a victim of crime⁷. We know that autistic people can be vulnerable to exploitation from others due to their condition, leading to them either inadvertently committing a crime or becoming a victim.

The Strategy aims to ensure that mainstream services are better equipped to support autistic people. We believe that this ambition can only be met if further action is taken to make sure that the CJS is set up to support and understand them. Looking at the learnings of Keys to Life, we recommend that a task and finish group is established to identify the clear actions that need to be taken to ensure that autistic people are treated fairly and appropriately – whether they are a victim, witness, suspect or offender.

We also wish to highlight our charity's work with HMP Feltham, where for nearly two years we have worked to improve the way they support autistic offenders in custody, leading to them to becoming the first prison to receive Autism Accreditation, our internationally-recognised process of support and development for all those providing services to autistic people. This is important as a relative few adjustments can go a long way to providing a more suitable environment for autistic people, which will help ensure that prisons and our justice system are more effective in rehabilitating offenders whilst in custody. We would

⁷ Unpublished stat for *I Exist* research (Daley et al 2008 Glasgow: NAS)

encourage the Scottish Government to commit to ensuring that all criminal justice agencies are accredited by the end of the Strategy's lifespan.

Recommendations:

- The Strategy should commit to setting up a task and finish group looking at key actions needed to ensure there is a clear plan across the CJS, so that different agencies can meet the specific needs of autistic people.
- The Scottish Government should commit to ensuring that all criminal justice agencies receive Autism Accreditation by the end of the Strategy's lifespan.

Question 3: What can we do to ensure autistic people can live independently?

Mental Health

Autism is not a mental health condition and it is perfectly possible to be autistic and have good mental health just as this is possible for anybody else. However, all too often, due to a lack of recognition of their autism and because of a lack of appropriate support, many autistic children and adults develop mental health problems. This can prevent them from living the independent lives that the strategy aims to deliver for autistic people in Scotland.

Research has shown that more than 70% of autistic children have a mental health problem⁸. There is also a high prevalence of mental health problems in autistic adults. Research suggests that 16 – 35% of autistic adults have a comorbid psychiatric disorder⁹. In addition, our own research indicates that a third of autistic adults in Scotland have developed severe mental health problems due to a lack of support¹⁰.

Recommendations:

The National Autistic Society Scotland made a number of recommendations in our submission to the Scottish Government's consultation on the 2017-2027 Mental Health strategy. We believe that these recommendations need to be enacted upon if strategic outcome three is to be realised. They are:

- Identification and diagnosis of autism in both children and adults must become a priority for the NHS to help ensure early support for this 'at risk' group and prevent the development of mental health problems among the one in a 100 autistic people in Scotland.
- Where autistic people develop mental health problems, professionals need to ensure they can adapt their practice appropriately to meet their needs effectively
- Ensure that NHS workforce training strategies include appropriate levels of training in autism for all relevant professionals, especially GPs, health visitors, paediatricians, child and adult mental health professionals, speech and language therapists and occupational health professionals.
- Make sure that the prevention of mental health issues among autistic adults is prioritised.
- Make sure that local authorities are commissioning a range of provision at local level to meet the needs of their local population of autistic people. This will include

⁸ Simonoff E. et al, *Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample*, 2008, Journal of American Academy of Child and Adolescent Psychiatry 47: 4: 921-929

⁹ Royal College of Psychiatrists, *Good practice in the management of autism (Including Asperger Syndrome) in adults*, 2014, Royal College of Psychiatrists

¹⁰ Daly I *Exist: The Message from adults with autism in Scotland* 2008 The National Autistic Society Scotland

low level interventions like social groups, advocacy and counselling as well as more intensive support.

- Make sure that mental health professionals in Scotland are equipped to support autistic people who also have a mental health problem and are able to adapt mental health treatments effectively.
- Invest in research to identify how best to adapt mental health therapies for autistic people.
- Issue guidance for mental health services on the reasonable adjustments they could be making to mental health settings to meet the needs of autistic children and adults.

Question 4: How can we ensure autistic people are active citizens, fully integrated and able participate in their communities and society?

Education

Initial Teacher Education

Getting the right education and support is a top concern for many of our members and other people who contact us. Parents tell us they want a range of provision for their children, including access to support in mainstream schools, special schools, resource bases in mainstream schools and dual placements. But we know that parents often have to fight to get the support their children need. If we are to ensure that autistic people are able to live their lives as active citizens who are fully integrated and able to participate in their communities and society then this needs to be addressed.

In order to achieve this, we want to make sure that every new teacher in Scotland is trained to work with autistic pupils. While autism can present some challenges, we know that a child who is understood and supported can make excellent progress. Having teachers who are properly trained and have the necessary tools to support the inclusion of autistic children and young people in mainstream education services is a vital component of this.

Currently, there is no requirement for new teachers in Scotland to learn about autism. The 2016 *Pupil Census* figures show that of the 170,329 school pupils in Scotland with an Additional Support Need, 13,423 are autistic. The vast majority of these pupils are in mainstream schools and so every teacher will have autistic pupils in their classes throughout their careers. It is because of this prevalence that we believe that autism should be included as a specific topic in Initial Teacher Education in Scotland.

Autistic children and young people (and their parents) are clear about the need for teachers to have a better understanding of autism. In a survey we carried out in 2015 on what our charity's priorities should be, 70% of Scottish respondents identified teacher training as the most important change that needed to happen in our education system.

In addition, the Additional Support Needs Tribunals for Scotland's 11th Annual Report shows that cases involving autistic children and young people account for 65% of the references they received between April 2015 and March 2016. We often hear from the parents of autistic children and young people that they often have to go down this route of dispute resolution because a child's needs are not understood by education professionals and therefore, not being met appropriately.

From 2018, autism will be included in the Initial Teacher Training framework in England – meaning that all new teachers will learn about autism in their initial training. This framework

states clearly that all trainee teachers should learn how to adapt their teaching strategies so that autistic people are fully included and helped to succeed. This was a direct result of a campaign by the National Autistic Society, called *Every Teacher*, which called for all teachers to be trained in autism. Moreover, in England the Government fund the Autism Education Trust who provide continuous professional development for education staff. They have trained over 150,000 staff.

We believe that autistic pupils in Scotland should also be taught by teachers who have an understanding of autism.

Recommendation:

- The Scottish Government should commit to making autism a compulsory element of the initial teacher education framework in Scotland.

We also believe that at this stage of the Strategy it is important to identify what the national picture is in relation to education support, an issue that is addressed by local autism strategies. As part of the autism strategy funding package, the Scottish Government provided £35,000 to each Local Authority to develop a local autism strategy and associated action plans. There are no Local Authorities in Scotland without either a published (draft) strategy or action plan. However, there are significant variations within these strategies and action plans, with differing core outcomes. It is difficult to evaluate the progress being made across the entire country as the timescales for Local Authority strategies and action plans vary.

Recommendation:

- We recommend that a list of key indicators of success is devised to provide a standardised metric to measure the impact of local authority strategies in a number of areas, including education. These indicators could include whether or not a lead has been put in place, whether capacity building training has been developed and which services are offered. This information could be gathered in a similar way to the Department of Health's [autism self-assessment framework](#), which aims to enable local strategy groups in England to review their progress and support future planning with partners.

Importance of Continuing Professional Development

It's imperative that teachers, and the schools they work in, have the training and resources to meet the needs of autistic children and young people. That's why we believe that more needs to be done to ensure that teachers who are already qualified have access to training in autism as part of their continuing professional development. While we welcome the development of the Autism Toolbox for teachers, we believe that it is important to continue to explore the possible introduction of a programme, similar to the Autism Education Trust, in Scotland.

Recommendation:

- The Scottish Government should explore the possible introduction of a programme, similar to the Autism Education Trust, in Scotland.

Employment

Another aspect of life that autistic people tell us is particularly important is addressing the autism employment gap. Unfortunately, we know that autistic people are significantly under-represented in the labour market. According to a 2016 survey of over 2,000 autistic adults, or people responding on their behalf which was published in our *Autism Employment Gap Report*, under 16% are in full-time paid work, a figure has remained similar since 2007¹¹. Only 32% are in some kind of paid work (full and part time combined), compared to 47% of disabled people and 80% of non-disabled people¹². Crucially, four in 10 autistic people working part time told us that they want to work more hours.

We have already stated our disappointment in the Scottish Government's decision to award the majority of the contracts for specialist employment services in the new Fair Start Scotland initiative to non-specialist providers. We have heard from autistic people that generic providers delivering these services aren't always able to recognise when specialist support is needed, nor are they incentivised to procure it. It is vital that the Government now ensures that all organisations that have been awarded these contracts can offer appropriate specialist support, or commission it from other specialist providers if needed.

Recommendations:

Our *Autism Employment Gap Report* made a number of recommendations for both the Scottish Government and local authorities to consider in order to reduce the autism employment gap, and in turn ensure autistic people are able to live as active citizens.

During the last phase of the Strategy, the Scottish Government should:

- Make sure it is monitoring work outcomes for autistic people in the new Fair Start employment programme.
- Note the recommendations of the England 'Maynard' taskforce on apprenticeships and look at the scope for implementing them as part of the apprenticeships programmes in Scotland.
- Make sure that local autism strategy working groups include representatives from employment agencies (e.g. local Jobcentre Plus).
- Make sure that local autism plans include strategies for getting more autistic people into work.

One Stop Shops

We believe that the One Stop Shop model has worked well and have proved to be a valuable resource. Indeed, they continue to be impactful in areas where they have been kept open. However, we are disappointed that sustaining the One Stop Shops did not form part of local autism action plans. We believe that autistic people and their families who live in areas without One Stop Shops are disadvantaged by not having access to this type of service.

¹¹ A 2007 survey by the National Autistic Society (I Exist, NAS (2008) found that 15% of autistic people were in full time employment. The new survey was 15.5% and does not represent a statistically significant change

¹² Disabled people and non-disabled people figures from Office for National Statistics (2016) Dataset: A08: Labour market status of disabled people (20 July 2016).

Question 5: What one single thing could the Scottish Government do to improve autistic people's lives?

We share the Scottish Government's ambition for Scotland to be the best place in the world to grow up. For autistic children and young people, a vital part of this will be ensuring that they have an education that is suited to their needs. In a survey we carried out in 2015 on what our charity's priorities should be, 70% of Scottish respondents identified teacher training as the most important change that needed to happen in our education system.

As highlighted earlier, we also know that the Additional Support Needs Tribunals for Scotland's 11th Annual Report showed that cases involving autistic children and young people account for 65% of the references they received between April 2015 and March 2016. We often hear from the parents of autistic children and young people that they have to go down this route of dispute resolution because a child's needs are not understood by education professionals and therefore, not being met appropriately. The evidence received by the Scottish Parliament's Education and Skills Committee when undertaking research into how Additional Support for Learning is working in practice was clear in highlighting the pressure on the education system in relation to autism.

We believe that making sure that every new teacher is trained to work with autistic pupils will help address these problems. While autism can present some challenges, we know that a child who is understood and supported can make excellent progress. Having teachers who are properly trained and have the necessary tools to support the inclusion of autistic children and young people in mainstream education services is a vital component of this.