

## **PE1704/M**

National Autistic Society submission of 31 October 2018

### **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 UK<sup>1</sup>.

### **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**

We are pleased to have been invited by the Public Petitions Committee to give evidence in relation to the action being called for in petition PE1704. This petition highlights some important issues that have a real impact on the lives autistic people and their families, and we congratulate the petitioner on bringing these to the attention of the committee. These area issues which the National Autistic Society Scotland have been campaigning on for many years, and we agree that action must be taken now across many policy areas if we are going to see meaningful and lasting positive improvements in the lives of autistic people and their families in Scotland. In our evidence below, we address each of the targets and priorities suggested by the petitioner.

- 1. That every person in Scotland going through an autism diagnostic procedure will be assessed within a calendar year and receive a statutory services assessment from a qualified social worker as an integral part of this process, within twelve months from the date of their initial referral.**

### **Our Response**

#### **Diagnosis Waiting Times**

---

<sup>1</sup> 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>

Getting a diagnosis is a critical milestone for autistic people and is 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 support<sup>2</sup> and for those autistic adults who don't receive support, 73% told us they would feel less isolated if they were able to access it<sup>3</sup>.

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.<sup>4</sup>

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. The Scottish Intercollegiate Guidelines Network (SIGN), the body which develops clinical practice guidelines for the NHS in Scotland, do not include a recommendation on waiting time targets for diagnosis, as waiting times policies are set by the Scottish Government. The National Institute for Health and Care Excellence (NICE) performs a similar function to SIGN for England (and to some extent for Wales and Northern Ireland), and makes clear that no patient should have to wait longer than three months between a referral for diagnosis and first appointment.

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 the 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.

In July 2016, we welcomed the publication of the new SIGN guideline on 'Assessment, diagnosis and interventions for autism spectrum disorders'. 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 welcomed the new guidelines covering all ages and replace previous guidelines that only covered children and young people.

---

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

<sup>3</sup> NAS Scotland (2013), *Count Us In*.

<sup>4</sup> <http://www.autismdiagnosis.info>

**However, there is still a lot of work to do if this issue is going to be addressed.**

In September 2017, the UK Government announced that autism diagnosis waiting times in England would be recorded from April 2018. While collecting this information is just one element of what is needed for us to have a better understanding of the autistic population, it's a significant and positive step. We also believe that the Scottish Government should also commit to recording, publishing and monitoring autism diagnosis waiting times in every area.

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 light of this, we recommended that in the final phase of the Scottish Strategy for Autism, which was refreshed in March 2018, the Scottish Government should develop a Local Delivery Plan (these replaced the system of HEAT targets) 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. We believe it should contain a target that no patient should have to wait longer than three months between a referral for diagnosis and first appointment.

#### Statutory services assessments

We know that getting the right support at the right time can have a strong, positive effect on a person's quality of life. However, we also know autistic people and their families and carers often struggle to access the help and support that they need.

Children with disabilities have rights to an assessment under Section 23 of the Children (Scotland) Act 1995. This assessment allows social work departments to collect information about children and families and identify any needs for support that they may have. The local authority then has a duty to provide any services necessary to meet their needs. Indeed, children may be entitled to an assessment of their needs even if they do not yet have a formal diagnosis of autism. This is because Section 23 of the Children (Scotland) Act 1995 applies to all 'children in need'.

Adults in Scotland are entitled to an assessment of needs under Section 55 of the NHS and Community Care Act 1990 and section 12a of the Social Work (Scotland) Act 1968. However, our *Count Us In* report found that while 66% of autistic adults felt that they did not have enough support, 69% of autistic adults haven't had an assessment of their needs since turning 18.

We believe that autistic children, young people and adults should get an assessment as quickly as possible after this is requested, and that this assessment must be carried out by someone with sufficient training in autism. Our *Count Us In* report found that 50% of the autistic people we spoke to said that professional understanding of autism is poor or very poor. Ensuring that assessors have a good understanding of autism and are appropriately trained to develop person-centred plans for autistic people will help address some of the issues autistic people currently face when going through this process.

- 2. That children with autism in mainstream schools will have their assessed needs for classroom support met by an ASL assistant with a recognised autism qualification as part of a mandatory registration process for ASL professionals.**

### Supporting autistic children and young people in education

Getting the right education and support is a top concern for many of our members and other people who contact us. 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.

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.

According to the most recent figures, there are 14,973 autistic pupils in schools run by local authorities in Scotland . 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 12th Annual Report shows that cases involving autistic children and young people account for 52% of the references they received between April 2016 and March 2017. 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.

In September 2018, we published our Not Included, Not Engaged, Not Involved joint report in partnership with Children in Scotland and Scottish Autism which looked in to the experiences of autistic children who are missing school. Nearly three quarters (72%) of the parents of autistic children who responded to our survey felt that staff having a better understanding of how their child's autism affects them, including their communication needs, would have made a difference to their child.

This report contained a number of calls to action, including improving the availability of specialist teachers. This recommendation called on the Scottish Government to commission a short-term working group to develop a plan for the additional support for learning workforce published within one year of the publication of the report. We think that the plan should include a commitment to increase trained additional support for learning teachers to 2010 levels (as a minimum) within two years.

We also recommended that programmes of Initial Teacher Education and Continual Professional Development should be enhanced to improve understanding of autism. As part of this recommendation, we called on:

- The General Teaching Council for Scotland to ensure all trainee teachers receive training on additional support for learning which includes a compulsory element on supporting autistic children.
- The Scottish Government to implement a model of continuous professional development in autism understanding for education staff, similar to the Autism Education Trust which is funded in England by the Department for Education and has trained over 150,000 staff.
- Local authorities to actively promote the Autism Toolbox to education professionals in their schools, and the Scottish Government should explore how the Toolbox can be developed further in order for it to fully support the inclusion of autistic children and young people in mainstream education.

**3. That young adults with autism will have a statutory right to specialist support from their local authority up to the age of 25.**

In Scotland, Coordinated Support Plans (CSPs) outline the support needed from social work for children and young people to meet their educational objectives. They may also have a separate Child's Plan to detail their non-education care needs (the CSP may be part of this but not all children with a Child's Plan will have a CSP). Whilst a young person is in school education, their CSP should continue if needed (could be up to age 19). There are no further duties relating to education once a young person has left school.

In England, Education and Health Care Plans (EHCPs) are statutory plans for children and young people requiring additional support from both education and social work services. They last until the age of 25 while they remain in education and further education.

We believe that EHCPs have proven valuable in helping to ensure that the transition from one education setting to another are as smooth as possible for autistic young people, due to the fact that they can continue up until the age of 25. We know that transition can cause anxiety for autistic people, and therefore believe that anything that improves this process should be welcomed. We therefore support a move to replicate this in Scotland.

**4. That an Autism Act will be in place within the next 5 years to enshrine specific rights and services for autistic people in our legal system.**

In March 2018, the Scottish Government launched its refreshed Scottish Strategy for Autism for 2018-2021. This document set out the Government's priorities for action through to 2021, identifying what it will do to improve services and support for autistic people in Scotland. It is the final refresh of the Strategy before it comes to an end in 2021.

We have campaigned for many years to improve support and services for autistic people. Our campaigning led, in 2011, to the publication of the ten year Scottish Strategy for Autism, which was then updated in 2015.

During the life of the Strategy, our charity has been a key member of the Governance Group that oversees it. In November 2017, we responded to the Scottish Government's consultation on what its priorities should be. In this response, we stated our belief that the Strategy 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 three 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.

We believe it's vital that the Scottish Government carries out a thorough analysis of the Strategy and its impact, and that this evaluation is used to inform what comes next. We will be undertaking our own work in this area. We have previously campaigned for an Autism Act in Scotland, and recognise the positive change legislation has brought about in England, and will come to a view as to whether or not legislation is necessary once the all the available evidence is gathered.