



Briefing for the Public Petitions Committee

Petition Number: [PE01704](#)

Main Petitioner: Duncan MacGillivray

Subject: Improve targets and outcomes for autistic people in Scotland

Calls on the Parliament to urge the Scottish Government to ensure that an agenda of real and meaningful change for autistic people is pursued by introducing the following targets and outcomes by 2021:

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

Background

Autism Spectrum Disorder (ASD) is a lifelong developmental condition which affects social communication, social interaction and behaviour. Symptoms may include a range of difficulties with verbal and non-verbal communication and repetitive or very specific behaviour or interests. The term 'spectrum disorder' is used because the degree of impairment people with ASD experience varies greatly and affects people in different ways. It is estimated that there are over 50,000 people in Scotland with ASD¹.

¹ SPICe briefing 17/23 [Autism Spectrum Disorder](#)

Diagnosis

In June 2016, the [Scottish Intercollegiate Guidelines Network \(SIGN\)](#) published new clinical guidelines on assessment, diagnosis and interventions for ASD ([SIGN 145](#)). The guidelines follow the most recently published diagnostic criteria (the Diagnostic and Statistical Manual of Mental Disorders, [DSM-5](#) 2013).

Waiting Times

Information on waiting times for autism diagnosis is not held or collected by [ISD Scotland](#). ISD Scotland collects waiting time information on all referrals to Child and Adolescent Mental Health Services (CAMHS) but this is not broken down by condition².

In September 2018, ISD Scotland published [Child and Adolescent Mental Health Services in Scotland: Waiting Times, Service Demand, and Workforce](#) this reported that, during April to June 2018, 4,664 children and young people started treatment at CAMHS. It noted that 67.8%³ of children and young people seen by a CAMH service started their treatment within 18 weeks of being referred, compared to 71.1% in the previous quarter and 80.7% in the same period in 2017.

Rejected Referrals to Child and Adolescent Mental Health Services

A recent research report commissioned by the Scottish Government [Rejected Referrals Child and Adolescent Mental Health Services \(CAMHS\)](#) found some particular issues where the child or young person had been referred to CAMHS for possible ASD. It reported that some people had difficulty getting an appointment, while others were unhappy with the assessment process.

Once a diagnosis has been given, there was often no further support provided. Where the child or young person already had a diagnosis of ASD, it found that some parents were told that CAMHS could not help with an apparent behavioural, emotional or mental health issue because of the ASD diagnosis. This left families feeling that there was nowhere else for them to turn. It noted that there seems to be little consistency in what information is provided at the end of the assessment, so young people and their parents leave without a clear understanding of what will happen next.

In relation to being assessed, parents and young people wanted:

- Clarity around the assessment process, with a clearer triage process and how decisions are taken on whether to conduct a face to face assessment.
- An expectation that CAMHS will meet children and young people for assessment, in an environment in which they feel comfortable (particularly for those with an ASD diagnosis).
- The opportunity for parents and young people to meet CAMHS staff separately, where they feel it would be helpful.

² [PQ S5W-15380](#) answered by Maureen Watt on 03/04/2018.

³ Using adjusted waits where available.

- The involvement of a wider group of family and professionals who are working with the young person, to gain a more holistic picture.
- Better use to be made of multi-disciplinary child planning meetings where all those who are supporting the child or young person can gain a holistic picture.
- A more person-centred approach by staff who would listen more, create a welcoming atmosphere, speak in plain English and not be dismissive or patronising⁴.

In a [news release \(29 June 2018\)](#), the Cabinet Secretary for Health and Sport announced that she has accepted the recommendations in the report and will establish a new CAMHS taskforce, with £5 million of investment, to reshape and improve CAMHS.

Additional Support for Learning in schools

The [Education \(Additional Support for Learning\) \(Scotland\) Act 2004](#) places a duty on education authorities to “make adequate and efficient provision” of additional support to children who require it.

Unlike teachers, who must be registered with the [General Teaching Council Scotland](#), Additional Support for Learning support workers are not subject to professional regulation in a school setting. It is up to the employer - the individual education authority, to determine the recruitment requirements when filling these posts.

The Scottish Government consulted on plans to require Additional Support for Learning support workers to register in an expanded education professional register, which was to include teachers, CLD practitioners and others. On 26 June 2018, the Cabinet Secretary indicated that, rather than creating a new body, the Scottish Government would explore what could be done using existing legislation, “to provide the benefits of regulation and registration to a wider group of education professionals”.⁵

Support up to age 25 and transitions

In its [Strategy for Autism](#), the Scottish Government committed to, “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.”

The [Principles of Good Transitions 3](#) sets out seven principles⁶ and the duties of professionals in education, social work, health and the third sector in supporting young people with additional support needs between the ages of

⁴ Scottish Government (2018) [Rejected Referrals Child and Adolescent Mental Health Services \(CAMHS\)](#)

⁵ [Official Report 26 June 2018, Col. 14](#)

⁶ The seven principles are: Planning and decision making should be carried out in a person-centred way; Support should be co-ordinated across all services; Planning should start early and continue up to age 25; All young people should get the support they need; Young people, parents and carers must have access to the information they need; Families and carers need support; and A continued focus on transitions across Scotland.

14 and 25. These duties include a requirement for social work services to be involved in a child's support planning in the later years of school and planning for a transition to how the required support will continue after school.

The [autism supplement](#) gives specific guidance on how to apply the seven principles of good transitions when supporting children and young people with autism.

Scottish Parliament Action

The [Autism \(Scotland\) Bill](#) was introduced to the Scottish Parliament in May 2010. At the Stage 1 debate on 12 January 2011, the Parliament disagreed to the general principles of the Bill and the Bill fell.

SPICe has published a subject profile on [Autism Spectrum Disorders](#) which provides an overview of policies, strategies and legislation guiding care and support for people with ASD.

There is also a [Cross Party Group on Autism](#). A number of relevant parliamentary questions and motions have been lodged, including: [S5W-17778](#), [S5W-16515](#), [S5W-16514](#), [S5W-15380](#).

Scottish Government Action

The Scottish Government published its [Mental Health Strategy 2017-2027](#) in March 2017. Following this, the [Scottish Autism Strategy Outcomes and Priorities 2018 -2021](#) was published in March 2018. This updated the [Scottish Strategy for Autism](#) (2011) to focus on specific priorities for the next three years to achieve the four strategic outcomes intended to ensure people with autism live healthier lives, have choice and control over the services they use, and are supported to be independent and active citizens. The Scottish Government hopes that, by aligning these aims with the wider ambitions for [A Fairer Scotland](#), it will be able to improve and transform people's lives⁷.

The Scottish Government seeks to work with NHS Boards and special boards to build knowledge of autism amongst staff, to improve access to services for autistic people, and to reduce waiting times by sharing improvement initiatives and sharing best practice through Improvement Programmes and the Autism Knowledge Hub⁷.

A number of Proposals in relation to CAMHS were announced in the [Programme for Government 2018-19](#) these included:

- investment in school counselling services
- additional school nurses
- support and professional learning materials for teachers
- services for community mental wellbeing for 5-24 year olds and their parents
- training and awareness of people working with vulnerable families
- a new website with information for young people and their families

⁷ Scottish Government personal correspondence 28 August 2018.

The Scottish Government has no current plans to introduce an Autism Bill⁸.

Lizzy Burgess and Ned Sharratt

SPICe

5 September 2018

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