

Briefing for the Public Petitions Committee

Petition Number: [PE01837](#)

Main Petitioner: Stephen Leighton

Subject: Provide clear direction and investment for autism support

Calls on the Scottish Parliament to urge the Scottish Government to:

- clarify how autistic people, who do not have a learning disability and/or mental disorder, can access support and;
- allocate investment for autism support teams in every local authority or health and social care partnership in Scotland.

Background

The petitioner is calling for a network of support teams for autistic people in each local authority or health and social care partnership in Scotland. The petitioner [explains in detail](#) why he thinks this is required.

He identifies the problems as partly stemming from the definition (or non-definition) of autism in legislation and in diagnostic manuals as well as the changing understanding of the condition over recent years.

Autism and legislation

Autism has been described as a learning disability, but the petitioner points out that 67% of people who are autistic do not have a [learning disability](#) in a form commonly understood by the term. The petitioner says that autism is better described as a neurodevelopmental disposition, and that this is now broadly accepted.

The petitioner also explains that mental health legislation has been used in relation to autistic people when it might have been inappropriate, in the criminal justice system for example.

The petitioner argues that the legislation requires amendment and proper acknowledgement of autism; that it is neither, necessarily, a mental disorder¹ or a learning disability as these are defined in the legislation. However, an autistic person might have a mental disorder, in the same way as anyone who

¹ [Section 328](#) of the 2003 Act provides that "mental disorder" means any mental illness, personality disorder, or learning disability, however caused or manifested

is '[neurotypical](#)'. There is widespread awareness of these issues (see below: Scottish Government Action).

Autism and diagnostic manuals and the challenge of definition

The petitioner refers to the diagnostic manual, [DSM-5. The Diagnostic and Statistical Manual of Mental Health Disorders, fifth edition](#). This is published by the American Psychiatric Association (APA), but is used internationally as a standard guide that defines and classifies mental health disorders. As the petitioner states, DSM-5 includes 'autism spectrum disorder', and considers and discusses it as a condition with symptoms that can be diagnosed. The APA has produced a [fact sheet on the changes in the updated manual](#) about autism. It states:

“People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Again, the symptoms of people with ASD will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms. This spectrum will allow clinicians to account for the variations in symptoms and behaviors from person to person.”

NICE, the UK National Institute for Health and Care Excellence, have published [guidelines about diagnosis of children and adults](#). The guidance reflects the complexity of diagnosis and its implications, but does not refer to autism as a neurodevelopmental disposition.

The Scottish Intercollegiate Guidelines Network (SIGN) also published guidance, '[Assessment, diagnosis and interventions for autism spectrum disorders A national clinical guideline](#)' in June 2016. This too notes caution in relation to diagnosis, terminology and assumptions about social and educational needs:

“Diagnostic classification in itself should not be the basis for decisions about provision within education, or need for social care and support. Some affected individuals advocate that it is inappropriate to describe them as having a disorder and consider that autism spectrum condition (ASC) is a more appropriate term.”

[Autism UK](#) refer to autism as a neurodevelopmental disability, but acknowledge the breadth of experience and range of needs for autistic people defies easy categorisation.

“The definition of autism has changed over the decades and could change in future years as we understand more. Some people feel the spectrum is too broad, arguing an autistic person with 24/7 support needs cannot be compared with a person who finds supermarket lights too bright. We often find that autistic people and their families with

different support needs share many of the same challenges, whether that's getting enough support from mental health, education and social care services or being misunderstood by people close to them.”

It would appear that in many cases, a 'diagnosis' might be appropriate for autistic people so that they can access support that they need. The petitioner argues that this is usually through mental health services, which is not always the most appropriate service for someone's specific needs. Referral to mental health services could also 'categorise' and 'medicalise' someone who does not have a mental illness/disorder.

Scottish Government Action

The Scottish Government appears to be aware of the issues outlined by the petitioner. An [overview of their focus in this area is summarised via this link](#).

The Scottish Government [updated its Autism Strategy in 2018, highlighting outcomes and priorities up till 2021](#).

In 2017 the Government published a report following a review and scoping exercise: [Review of learning disability and autism in the Mental Health \(Scotland\) Act 2003](#). This describes the conflicts and issues that arise and refers to the [Millan Committee that was set up in 1999 to review](#) mental health law in Scotland. The Committee did not reach a consensus on whether learning disability and autism should be included in the new legislation (the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#)).

There has been further mental health legislation: the [Mental Health \(Scotland\) Act 2015](#). The matter was not resolved in this later legislation. The [Review outlines the arguments in its introduction](#), for and against the inclusion of learning disability and autism in the mental health legislation.

In October 2019, the [Mental Welfare Commission \(MWC\) published a report](#) following visits and monitoring of settings where people with learning disabilities and autism were being treated under mental health or adults with incapacity legislation, which can mean that people can receive medical treatment against their will, and be detained without time limit.

The report made a set of recommendations about support that health boards and health and social care partnerships should provide. It also found that autistic people might be receiving psychotropic (such as anti-depressants or anti-psychotic) medication to control behaviour seen as challenging. The MWC recommended that the [Scottish Patient Safety Programme](#) should develop and lead an initiative to reduce the use of psychotropic medication with autistic people for the management of behaviours perceived as challenging as well as reducing the use of restraint and seclusion.

The MWC also recommended that: “Integration Authorities should ensure that autistic people with complex needs in community settings have a **dedicated co-ordinator** to oversee the full range of provision to meet their needs”

An independent review, '[Learning Disability and Autism in the Mental Health Act](#)' published its findings and recommendations in December 2019.

The petitioner provides a link to and an analysis of the [microsegmentation of the autism spectrum research report](#). Economic research was carried out about autism and implications for Scotland, including how the economic cost of autism can inform strategy and planning. The research investigated the many potential outcomes and manifestations of people on the autistic spectrum.

Scottish Parliament Action

In Session 4, the Health and Sport Committee was the lead committee scrutinising the Mental Health Bill. In their [Stage 1 Report](#), the debate about the inclusion of learning disability and autism in the Bill was addressed (pp 31-33), but made no firm recommendations, acknowledging that the Bill was not a wholesale review of the 2003 Act.

A [search of Parliamentary Questions and Motions](#) relating to autism found many more than can be included in this briefing.

See also [SPICe briefings](#) on [Autism Spectrum Disorder and Mental Health legislation and policy](#).

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