



The Scottish Parliament  
Pàrlamaid na h-Alba

**PUBLIC PETITION NO.**

**PE01837**

### **Name of petitioner**

Stephen Leighton

### **Petition title**

Provide clear direction and investment for autism support

### **Petition summary**

Calling 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.

### **Action taken to resolve issues of concern before submitting the petition**

I have raised the issue with Clare Haughey MSP, Minister for Mental Health and Stuart McMillan MSP.

### **Petition background information**

Learning disability services will not provide support to autistic people if they do not have a learning disability. Only 33% of autistic people have a learning disability, this means that 67% of autistic people do not. It is easier for the 33% of autistic people to access support through learning disability services than it is for the other 67% of autistic people to access any support. This is caused by confusion between the legal and clinical interpretation of autism.

It is clinically understood that autism is not a mental disorder, rather it is a lifelong neurodevelopmental disposition. So, if autism is not a mental disorder, then why are autistic people referred to adult mental health teams and Children Adolescent Mental Health Teams (CAMHS) for support?

There is a perception in Scotland that autism is covered within the Mental Health (Care and Treatment) (Scotland) Act 2003. However, the word autism (autistic spectrum/Asperger's) is not mentioned or referenced in any part of the Act or

spectrum disorder, by is not mentioned or referenced in any part of the Act or accompanying guidance. If it is not referenced, how can it be covered within the legalisation?

Autism was initially misunderstood as a mental illness. Fortunately, clinical opinion now understands that autism is a neurodevelopmental disposition. In 1908 it was first recorded that autism was used to describe schizophrenic patients. In 1987 the Statistical Manual of Mental Disorders (DSM) -III-R replaces "infantile autism" with a more expansive definition of "autism disorder," and includes a checklist of diagnostic criteria: finally removing autism from schizophrenia. Between 1994-2000 the DSM and the International Classification of Diseases (ICD) expand the definition of autism and include Asperger's syndrome, highlighting autism isn't a mental disorder, rather a social communication difficulty.

In 2013 the DSM-5 folds all autism subcategories into one umbrella diagnosis of 'Autism Spectrum Disorder' (ASD), it is defined by two categories:

- impaired social communication and/or interaction and
- restricted and/or repetitive behaviours (including sensory).

Under devolution, the Scottish Government had responsibility to create specific legislation for mental health law in Scotland. The Millan Committee was set up by the Scottish Executive in 1999 to make proposals for mental health legislation for the newly devolved Parliament.

The Millan Committee made various recommendations for the new Mental Health Act for Scotland. In relation to autism it was debated whether it should be included in the new Act. The Committee recommended that autism should be covered in the new Act under the definition of learning disability. This recommendation clearly did not reflect the clinical developments of autism since 1983: that autism is a neurodevelopmental disposition and not a learning disability or mental disorder. Thankfully, Recommendation 4.9 (Learning disability should include autistic spectrum disorders' under a wider definition within the Act & guidance), was never enacted into the Mental Health (Care and Treatment) (Scotland) Act 2003.

Why was autism not considered under the definition of learning disability of the Act?

As early as the 1990's it was understood that roughly 60-70% of the autistic population had average or above average intelligence, therefore meaning, autism could not be considered under the definition of learning disability. Some people believe that autism is covered within mental health legislation because autism is mentioned in the DSM and ICD. Therefore, if this logic is correct it would mean other dispositions highlighted within these manuals would also be covered within mental health legislation. Some of these other dispositions are 'walking into a lamppost', 'problems in relationship with in-laws' 'spelling disorder' and 'erectile dysfunction'. This hopefully highlights the fallacy that just because something is mentioned in the DSM or ICD does not automatically mean the person is subject to mental health legislation.

People then say, "*but you would not use the Act if the autistic person did not have a mental disorder or learning disability*". If this is the case, then why does autism have to be perceived as being covered in the Act if the Act can only be used when the autistic person either has a mental disorder or learning disability? Does this not mean that autism is not covered in the Act, if it can only be used if there is a mental disorder and or learning disability present? Is this not the same as every other person in Scotland? As you will understand, autism on its own is not covered within the Act.

There is a widespread belief that autism is covered within the Act as it protects autistic people, however, this is not evidently true. There may be some autistic people who have been, or will be, involved within the Criminal Justice System. Some autistic people may have been guilty of criminal intent and will have therefore been subject to prosecution. However, some autistic people may have been (or will be) involved in criminal behaviour without criminal intent.

It may be difficult for a subset of autistic people to understand some social norms, therefore limiting their understanding to comply within certain laws. If the nature of the behaviour (perceived criminal behaviour) met the 'serious harm test' (this is not harm to

self but harm to others), and it was believed that the person's 'mental disorder' would mean they would not understand the criminal prosecution against them, they may then be put through the mental health route instead of the Criminal Justice System.

This is when an autistic person could be subject to the Mental Health Act under the definition of 'mental disorder' within the context of The Criminal Procedure (Scotland) Act 1995. This is when an autistic person may be held on an Interim Order and subsequent Restriction Order without time limit. This may seem harsh, but is this a better option than being processed through the Criminal Justice System? Some autistic people and their families do not think so. There has been media coverage about some autistic people being detained without time limit even though they have never committed a crime.

Access to specific autism support is not available within the forensic system in Scotland (low, medium or high secure units in Scotland for people on such Restriction Orders although there is this provision in England), therefore, it is often hard for autistic people to learn life skills, develop the experience and awareness needed to be successfully supported back into their community.

This is why it is important to have autism support teams in every area of Scotland, as these support teams would have hopefully prevented such scenarios from happening to begin with. Also, these teams would help by providing the support needed to help autistic people be discharged from a secure facility and supported back into their communities safely.

Autism being covered within the Act was probably a result of good intentions, however, sadly it has caused harm for two reasons:

- The confusion between the legal and clinical definition of autism prevents autistic people without a learning disability accessing support.
- Lack of autism support in the community and within some forensic prevents a successful discharge from Restriction Orders.

The Convention on the Rights of Persons with Disabilities (CPRD) was effective from the 3rd May 2008. As highlighted in the CPRD, to state someone has a mental disorder as a result of a disability is unlawful, therefore, the definition of autism as a mental disorder breaches CPRD.

Just because you are autistic should not mean you are automatically subject to mental health legislation, yet that is fallacy we have in Scotland which is preventing autistic people getting access to support. This undermines the Human Rights of autistic people. Also, the Mental Health Act is also referenced in 25 other Acts within Scottish legislation which could impact on an autistic person for no other reason than simply being autistic.

There was a review concluded in Scotland (December 2019) as to whether autism should be removed from the 2003 Act. This review was called 'The Independent Review of Learning Disability and Autism in the Mental Health Act'. The review team have recommended that in future autism should not be defined as a 'mental disorder' under the Mental Health (Care and Treatment) (Scotland) Act 2003, or in other mental health law.

This review has forwarded their proposals to the Scottish Government and wider Scottish Mental Health Review chaired by John Scott QC. The review may take several years before changes will be realised. Therefore, until then the status quo will result in continued years of no support for autistic people who do not have a learning disability.

Mental health services will support people with a mental disorder, but not solely autism because autism is not viewed as a mental disorder. This was highlighted in the recent [Rejected Referrals Child and Adolescent Mental Health Services \(CAMHS\): A qualitative and quantitative audit](#).

All of what is highlighted in the CAMHS report is mirrored in adult mental health. When autistic people and families go to other services for support (Social Work, GP's) they are re-directed back to mental health services. This explains why there is so much frustration with mental health services within Scotland in relation to autism. The

problem is not mental health services: it is the lack of ongoing practical social support for autistic people.

Autistic people cannot wait years on reform through the Scottish Mental Health Law Review and subsequent Parliamentary process. This is why this petition requests the Scottish Government to invest in autism support teams for every local authority or Health & Care Partnership.

The [microsegmentation of the autism spectrum: research project](#) was funded by the Scottish Government as a result of the Scottish Strategy for Autism: Recommendation 5, "*on (what) the economic costs of autism is*". The Report looked at the costs of autism and concluded that some of the costs were 'escapable', explaining with the right support local authorities and NHS boards could save money.

The Report states 10 recommendations be implemented for every area in Scotland to promote the best outcomes for autistic people while also saving money.

I believe the bigger the investment in local autism support teams, the bigger the efficiency savings will be. If the 10 recommendations were implemented with 1% efficiency, this would save the Scottish Economy £22 million annually. If there was a 10% efficiency this would result in £220 million being saved annually, 30% efficiency would result in £440 million being saved annually and so on.

There is a big focus to create world class mental health support in Scotland, this is reflected in the budget for mental health currently at £1.1 billion (This is a spend of one thousand one hundred million per year). What if some of this budget was used to create autism support teams?

Spending some of this money on autism support teams would create a care pathway for autistic people out of mental health services. If mental health services have historically been the services to provide support, then some of this budget was always allocated for autism support anyway. Could there not be an audit undertaken to determine how much money is escapable costs within the mental health system, and therefore, could some of this money be used to create support teams, autistic people would get the right support at the time they needed it and it would also free up much needed capacity within the mental health system.

Having these support teams within Health and Social Care Partnerships would make much more sense than mental health services using the allocated money to support autism needs. This is because of the clinical governance of such mental health teams. Autism support usually requires a 'Systems approach' (social situations, education, relationships, employment, social care, housing and primary care). Mental health services would not have the capacity to engage with all these different services, this is probably why clinicians have told autistic people that they are too difficult to treat with psychological interventions only. This is why I believe the creation of specific autism teams working within the Health and Social Care Partnerships would be successful in implementing the 10 Recommendations of the Report - realising the savings that could be made while autistic people get the support when they need it.

These autism teams would be the automatic referral route for education, social work teams, police, GP's and mental health teams. It would also be open for self-referral from autistic people. This would guarantee that every autistic person/family would be offered tailored support at the time they needed it the most.

Any additional monies would create a National Autistic Commission Board for autistic representation based on a human rights approach. This Commission would oversee the network of these support teams, share best practice and be a leading movement globally based on research and support. The Commission would be able to advocate for changes for things such as additional support needs, respite, assessments, adequate housing needs and anything else that was needed. The additionally money could be used to develop new models, raise awareness and provide opportunities to make Scotland the leading country in supporting autistic people and families.

Scotland has a lot of rural communities which can be very problematic for services to get the expertise & professionals to help local autistic residents. Having the Commission with a vast network covering all of Scotland. could provide rural areas with

access to professionals at the times they needed it the most, therefore meaning autistic people in these rural areas are still getting access to expertise regardless of their geographical area.

Another issue is diagnosis, assessment, waiting lists and access to basic autism training. In some areas of Scotland people have complained that it has taken years to get a diagnosis. Evidence-based practice tells us that early intervention is essential in supporting autistic people. There are sensitive periods of development within a child's life, the earlier the intervention the better chance the child will have in life. Having these teams in place will be able to fast track diagnosis and provide support to children for these sensitive periods of development.

Another issue for autistic people is the financial burden of accessing good autism advice and training. An NHS diagnosis can take a long time, however a private diagnosis can be provided in one day at the cost £1500. This approach goes against the standards of assessment the Scottish Government is trying to impose. Autistic people and families should have access to diagnosis, post diagnostic support and training free of charge at the time of need.

The 'Independent review of Learning Disability and Autism' recognises that there is a need for some immediate action. The review identifies where action could begin. Some of the review's recommendations will need to take effect after the current independent review of mental health and incapacity legislation. There will need to be a process of transition which must include clear deadlines for change in law and for human rights issues to be resolved, therefore we should start the process of change before the end of the Scottish Mental Health Review.

#### Unique web address

<https://www.parliament.scot/GettingInvolved/Petitions/supportingautism>

#### Related information for petition

<http://chng.it/pM5VCYf2tk>

<https://youtu.be/1SsBf-Be4iA>

#### Do you wish your petition to be hosted on the Parliament's website to collect signatures online?

YES

#### How many signatures have you collected so far?

0

#### Closing date for collecting signatures online

08 / 12 / 2020

#### Comments to stimulate online discussion

Do you agree dedicated autism support would save hundreds of millions of pounds?  
Could there be an audit of escapable costs within mental health to identify funding for autism support teams?

autism support teams?

How much is needed to fund autism support teams?