

Citizen Participation and Public Petitions Committee

7th Meeting, 2022 (Session 6), Wednesday 4
May 2022

PE1837: Provide clear direction and
investment for autism support

Note by the Clerk

Lodged on	9 December 2020
Petitioner	Stephen Leighton
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to: <ul style="list-style-type: none">• 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.
Webpage	https://petitions.parliament.scot/petitions/PE1837

Introduction

1. The Committee last considered this petition at its meeting on [17 November 2021](#). At that meeting, the Committee agreed to write to the Minister for Mental Wellbeing and Social Care.
2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
3. The Committee has received new responses from the Minister for Mental Wellbeing and Social Care and the Petitioner which are set out in **Annexe C**.
4. Written submissions received prior to the Committee's last consideration can be found on the [petition's webpage](#). All written submissions received on the

petition before May 2021 can be viewed on the petition on the [archive webpage](#).

5. Further background information about this petition can be found in the [SPICe briefing](#) for this petition.
6. The Scottish Government's initial position on this petition can be found on the [petition's webpage](#).

Action

The Committee is invited to consider what action it wishes to take.

Clerk to the Committee

Annexe A

PE1837: Provide clear direction and investment for autism support

Petitioner

Stephen Leighton

Date lodged

09/12/2020

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.

Previous action

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

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 legal 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 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 micro-segmentation 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.

Annexe B

Extract from Official Report of last consideration of PE1837: Provide clear direction and investment for autism support on 17th November 2021

The Convener: The next petition is PE1837, on which colleagues might remember that we took evidence at our previous meeting. The petition was lodged by Stephen Leighton and 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 to allocate investment for autism support teams in every local authority or health and social care partnership in Scotland.

We last considered the petition on 6 October, when we took evidence from Kevin Stewart, the Minister for Mental Wellbeing and Social Care, and two Scottish Government officials: Hugh McAloon, deputy director for children and young people’s mental health; and Jacqueline Campbell, unit head, children and young people’s community mental health. The evidence-taking session highlighted a number of key themes, including learning disability and autism in legislation, access to support services, user-centred services and good practice; and funding.

At that session, the minister stated that the Scottish Government was committed to publishing a learning disability, autism and neurodiversity bill and to creating a commissioner to uphold and protect the rights of autistic people and others with neurodevelopmental difference.

The committee also heard that the support that is available to people with autism varies significantly across Scotland—that was quite marked—and could be particularly scarce for those who do not also have a learning disability or mental disorder, which is at the heart of the petitioner’s concern. That increased the risk that people could be turned away from services, leaving them with no alternative route for support.

The minister recognised the need “to ascertain what is going on out there that is right and what is not going ... so well” and emphasised the importance for people with autism to influence decision making. The minister also highlighted a number of recent funding announcements that are relevant to the petition, and it was a very informative evidence session.

Bill Kidd (Glasgow Anniesland) (SNP): I am aware that the petition is about people, particularly those with autism, who do not have a learning disability. The Scottish Government has already stated that it will publish a learning disability, autism and neurodiversity bill in order to create a commissioner role that will look into the range of autistic circumstances, and I think that that pretty well covers the matters that the petition relates to.

Paul Sweeney: Although it is encouraging that the Government's response has indicated the forthcoming legislation, it is important to give the petitioner some degree of assurance that the specifics of the legislation will address the concerns that are outlined in the petition and also perhaps offer a degree of assurance about more immediate measures that could be put in place. In order to satisfy the petitioner's concerns, a more specific response from the minister would be helpful.

The Convener: Yes—that is a fair request.

Alexander Stewart: I agree with Paul Sweeney's comments. A response from the minister about what might be in the legislation would give us more information for when we are scrutinising the bill. We found that there was a postcode lottery in the situation across councils and areas of Scotland, and there will be repercussions across many of those areas as to what can be achieved in the short and medium term, so that information would be very useful.

The Convener: David Torrance, do you agree as well?

David Torrance: I absolutely agree, convener.

The Convener: I was not sure whether you were going to make the same point or a different one.

We will write to the Minister for Mental Wellbeing and Social Care to ask how the Scottish Government will address the specific concerns that were raised in the petitioner's request, both in the short term and in the context of that forthcoming legislation. We will also write to the Minister to ask how he intends to collect and disseminate examples of good practice of services that are available.

Annexe C

Minister for Mental Wellbeing and Social Care submission of 16 December 2021

PE1837/BB - Provide clear direction and investment for autism support

Thank you for the recent opportunity to meet with the Committee. May I assure the Committee that we remain committed to improving the lives of autistic people who do not have a learning disability and/or mental disorder through our Towards Transformation Autism and Learning Disability Plan.

As you have requested, I now respond to *provide further details of how we will ensure people with autism who do not have a learning disability and/or mental disorder can access appropriate local support a) in the short-term and b) in the context of the new Bill and how we will ensure this support is available on an equitable basis across Scotland.*

We understand that many autistic people and their families have faced added pressures during the pandemic and we, therefore, provided additional support to address those pressures. We established a £500,000 fund to ensure local carer organisations could continue to provide advice and emotional support during an incredibly difficult time. Additionally, £170,000 funding was provided to national autism charities to help them deliver vital front line support to people struggling as a result of Coronavirus (COVID-19) and help reduce social isolation.

We continue to work collaboratively with the national autism charities and autistic led organisations to deliver a national autism post diagnostic support service which we launched in December 2020. This support aims to enable individuals to understand, embrace and develop their identity as an autistic person. It also aims to ensure that parents and carers will have access to information, support and advice to enable them to support their child's development and personal growth. We also

want to make sure that those with a late diagnosis can access support and connect with peers, should they choose to.

The charities involved reported good uptake of the post diagnostic support services and the sessions they ran. We will be publishing an independent evaluation of this work, with its recommendations, in January 2022.

We will be conducting further scoping work on post diagnostic support and have already engaged with Health and Social Care Partnerships (HSCPs) about the local support they provide. HSCPs need to ensure that appropriate support is in place locally. We have also continued our support through the pilot programme as we conduct further work. This is currently extended to the end of March 2022 and we are in further discussion with those charities.

This complements our new pilot work on adult neurodevelopmental diagnostic pathways. Working with the National Autism Implementation Team (NAIT), we will be conducting trials in four HSCP areas of new ways of achieving diagnosis in adults without a complete reliance on mental health services. This will draw in, for example, the role of Allied Health Professionals and Primary Care.

Each pilot area will have a local neurodevelopmental strategy or planning group with representation across relevant stakeholders and knowledge of the current local Autism, ADHD and Intellectual Disability provision and needs, together with local primary mental health care developments. Consideration will be given to third sector involvement, employment support provision and inclusion of people with lived experience in local decision making. Experiences of pilot sites will contribute to learning for all HSCPs and inform their future planning. The pilots will take place over 12 months, starting soon.

With regard to the proposed Learning Disability, Autism and Neurodiversity Bill, our work to develop the new Bill will need to include detailed consideration of the powers and duties of a Commission or Commissioner. The extent to which that body will be able to ensure the equitable provision of services will depend upon its legislative powers. Clearly, this is likely to be the subject of some debate and differing views that we will seek to reconcile. However, the establishment of this body will be a significant step forward in ensuring transparency around the

funding and provision of services and accountability where there are gaps. We would welcome the Committee's views on the issue of powers and duties, and how this may compare to the powers available to other Commissioners.

I note the Committee is also interested to know *how we intend to collect and disseminate examples of good practice in relation to services available to people with autism, but without a learning disability and/or a mental disorder, so that these can be replicated on a Scotland-wide basis.*

As part of the diagnostic pathways and post diagnostic support work, we intend to collate and analyse good practice. In addition, NAIT is establishing a network amongst HSCPs to support the pathways work which will allow early dissemination of good practice and sharing among all HSCP areas.

I would be happy to provide the Committee with a further update in due course.

Petitioner submission of 2 March 2022

PE1837/CC - Provide clear direction and investment for autism support

This submission is in response to the Minister for Mental Wellbeing and Social Care's submission on the 16th of December 2021.

The Minister's response did not explain specifically where autistic people, particularly those who do not have a learning disability or mental health issue, can access support. The Minister's response was vague and highlighted pilot projects which are obviously time limited and only available in some areas across Scotland. The pilot is now finished, therefore meaning this support is no longer available.

The autism post diagnostic pilot review was published in February 2022. The report did not highlight what supports are available for people that need ongoing and lifelong support after initial diagnosis. The conclusion was there needs to be further discussion as to what could be made available longer term after people receive a diagnosis.

The Scottish Government have still to address petition point 1; to clarify who supports solely autistic needs?

There is legislation in Scotland saying autism is a mental disorder, and clinicians and NAIT saying autism isn't a mental disorder.

The petition highlights the context as to why there is much confusion around who supports autistic needs in Scotland. Currently autism is defined as a mental health disorder under the Mental Health Care Treatment (Scotland) Act 2003, even though autism is not mentioned or referenced in the Act. Yet mental health clinicians and NAIT (National Autism Implementation Team for the Scottish Government) say autism is not a mental disorder.

This confusion is resulting in autistic people being signposted between services (mental health such as CAMHS, LD and social work services), often without support being provided, resulting in some autistic people being denied basic statutory supports such as s.12 of the Social Work Scotland Act 1968 (for adults), and s.23 & 24 of the Children's Act (Scotland) 1995 (for children & families).

This is why there needs to be clarification from the Scottish Government on who provides autism support ... is it social work or mental health?

A summary of the petition is being discussed at the next Chief Social Work Officer Committee in May 2022. I would recommend the Citizen Participation & Public Petitions Committee wait for the outcome of that meeting before deciding what further actions may be needed.