

Citizen Participation and Public Petitions Committee

15th Meeting, 2022 (Session 6), Wednesday
9 November 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 [4 May 2022](#). 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 4th May 2022

The Convener: Our next continued petition is PE1837, on providing clear direction and investment for autism support. The petition 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—that is the key idea—can access support and to allocate investment for autism support teams in every local authority or health and social care partnership in Scotland.

When the committee wrote to the Minister for Mental Wellbeing and Social Care on 17 November, we were particularly interested to find out whether the proposed learning disability, autism and neurodiversity bill would address the petitioner's concerns, and to know, in the interim, what support measures will be put in place for individuals who have autism but do not have a learning disability or mental illness. We also wanted to know how the minister intended to collect and disseminate examples of good practice.

The minister provided examples of current work and recent pilots, all of which are set out in full in members' papers. The minister indicated that, should a new commission or commissioner be created via the proposed legislation, detailed consideration would be required on what their powers and duties should be. In the meantime, the Scottish Government plans to collate and analyse good practice from health and social care partnerships.

The petitioner has responded, stating that the minister's submission, once again, did not explain specifically where autistic people who do not have a learning disability or mental health issue can access support. He notes that the pilot projects that were mentioned are time limited and area specific; that post-diagnostic support is required on a lifelong basis and not only at the point of diagnosis; and that the petition is due to be discussed at the next meeting of the chief social work officer committee, later this month.

Do members have any proposals? I suggest that we go back to the minister with the points that have been made. The minister told us that the powers and duties of a commission or commissioner would be reviewed. That might suggest that responsibility for the petitioner's particular objective might be allocated within that framework, but it has not actually been said. I would be happy to go back to the minister and ask again, very specifically, about the petitioner's concern about what is proposed for people who do not have a learning disability or mental health issue.

Are members content with that?

Members *indicated agreement.*

Annexe C

Minister for Mental Wellbeing and Social Care submission of 17 June 2022

PE1837/DD: Provide clear direction and investment for autism support

Thank you for your letter of 16th May requesting greater clarity on the following matters:

- what specific support is currently available for those individuals who have autism but do not have a learning disability or a mental disorder?
- how and when the Scottish Government will clarify with service providers which services are designed to support those individuals? and
- of the recent pilots, how many are expected to be fully rolled-out across Scotland, and what the timescale and potential phasing for this is?

Please assure the Committee that the Scottish Government continues to be committed to improving the lives of autistic people in Scotland. We are driving forward a range of work to support this aim and, to this end, I will address each of these issues in turn below.

- what specific support is currently available for those individuals who have autism but do not have a learning disability or a mental disorder?

As the Committee is aware, there is statutory support available through local Social Care provision. Autistic people who meet eligibility criteria and do not have a learning disability or mental health condition will have access to this support. While the Scottish Government has overall responsibility for Health and Social Care policy in Scotland, it is Local Health Boards and Health and Social Care Partnerships (HSCPs) which have the responsibility for providing and commissioning appropriate services to meet their population's needs. This will include support through autism specific providers.

Although some people's needs will be met through these statutory services, we acknowledge other support is often required for autistic adults and that this currently varies considerably across Scotland. The Scottish Government has recognised the need for greater consistency in the provision of non-statutory support for autistic people. This includes autistic people without a learning disability or a mental health condition.

To address this, we are conducting an adult neurodevelopmental pathway pilot as outlined in my previous letter of December 2021 and we have also invested in post diagnostic support. The post diagnostic support has now been extended until March 2023 and we intend to embed this more widely across Scotland going forward, alongside a new national digital resource hub which we have begun to develop. In tandem, we will be considering the longer term options that could build on the pathway pilot work. As part of this work we will engage further with HSCPs around their current activities.

In my last letter I described our post diagnostic support pilots which have been operating since December 2020. Although the seven organisations involved are working mainly with those diagnosed in the last few years, they are providing direct support to autistic people of all ages and their support is open to all autistic people seeking advice and support. They are not limited to those who may also have a learning disability or mental health issue. All but two of these organisations provide national support ranging from an advice line, chat facilities on websites, information hubs, 1 to 1 support sessions, peer support and a series of group sessions. This support is available now. The two local provisions provide autistic-led support in the Highlands and Central Belt specifically.

Since my last letter, the evaluation of the first six months of these pilots has been published. This tells us that autistic people and parents of autistic children did feel the support received was helpful. It assisted them when dealing with services; they knew where to get help and that help was accessible to them; they felt more connected to the autistic community and less isolated; they had greater confidence and were better informed; they understood themselves better and felt their mental health had improved.

As I've indicated, funding for this post-diagnostic support work has been extended until at least March 2023 in recognition of its continuing value and the high demand for support. This marks over £1m of funding in this area since 2020.

On your next point:

- how and when the Scottish Government will clarify with service providers which services are designed to support those individuals?

I am disappointed to hear that autistic people are being passed from service to service without receiving the help they need. Local services have a duty to assess support needs in their areas and are required to provide appropriate support. This will include those who are autistic and do not have a learning disability or a mental health condition. I am happy to write to HSCPs to remind them of their obligations and urge them to put in place services that will address the needs of autistic people. There is a need to ensure each service takes responsibility at the point the autistic individual reaches out; rather than to suggest that only one service is relevant to their needs.

There is good practice to draw from. We are aware of providers who support autistic people well locally, including statutory and third sector support services which are designed specifically for autistic people and recognise the ongoing need for support, whenever autistic people need it throughout their life.

As part of the post diagnostic support work, we are currently developing a national web Hub. This is intended to provide everyone - professionals, the public and autistic people alike - with a single source of information on autism support services. It will signpost a range of resources and services which practitioners can point to to assist individuals to embrace their identity as an autistic person and seek the level of help they need, at whatever point they feel they need it. The Hub is supported by an advice line with an additional on-line chat function which will offer advice and direction. We aim for this Hub to be active in the next few months and we will urge service providers to share it with those coming to them for assistance.

On your final point:

- of the recent pilots, how many are expected to be fully rolled-out across Scotland, and what the timescale and potential phasing for this is?

Our work on adult neurodevelopmental diagnostic pathways, in conjunction with the National Autism Implementation Team (NAIT), is in

its early stages and progress will continue throughout this year. The pilot work started in January 2022 and will be completed in December 2022. NAIT will provide a report on learning from pilot sites and recommended next steps in March 2023.

This work is key to our consideration of longer term options so we will be very focused on its outcomes. Plans for wider roll out of this work will follow after consideration of the evaluation report.

However, this does not prevent us from taking action now in the form of the national Hub and the nationally supported post diagnostic support work set out above. I am determined to enhance the support available.

I hope this provides the Committee with further reassurance that efforts are underway to address the issues raised in this petition and I am happy to offer additional information and support as required.

Petitioner submission of 13 September 2022

PE1837/EE – Provide clear direction and investment for autism support

I would like to inform the committee that I am satisfied with the outcome of the letter sent by the minister. The letter is a safety net that ensures all autistic people in Scotland have the legal right to at least an assessment of their needs, and therefore I would like to ask the committee to close the petition.

I would like to thank the committee, the clerks and parliamentary staff for their continued hard work.

The ethos of a unicameral approach towards committees within the Scottish Parliament, particularly the Citizen Participation and Public Petitions Committee, is a success. It allows the opportunity for the general public to help shape a better Scotland. During the lifespan of this petition, there was times members wanted to close, but other members wanted to continue to explore, and as a result there has been a very positive outcome, not only for autistic people, but also for this committee as it reflects the good work the committee is capable of. Therefore, I

encourage all committee members to continue to be patient and explore all aspects of petitions before deciding to close.