

Citizen Participation and Public Petitions Committee

7th Meeting, 2021 (Session 6), Wednesday
17 November 2021

PE1837: Provide clear direction and
investment for autism support

Summary of evidence

PE1837: Lodged 4/11/20

Petitioner Stephen Leighton

**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.

Webpage <https://petitions.parliament.scot/petitions/PE1837>

Introduction

1. This is a continued petition, last considered by the CPPPC on [6 October 2021](#). At that meeting, the Committee took evidence from –

- Kevin Stewart, Minister for Mental Wellbeing and Social Care;
- 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; Scottish Government.

2. The evidence session highlighted a number of key themes including –

- Learning disability and autism in legislation
- Access to support services
- User-centred services and good practice

- Funding
3. The Committee agreed to consider the evidence it had heard at a future meeting.

Learning disability and autism in legislation

4. An [independent review](#) of learning disability and autism in the context of the Mental Health (Care and Treatment) (Scotland) Act 2003 was published in 2019 and made specific recommendations relevant to this petition. These included (but were not limited to) –
 - That learning disability and autism were removed from the definition of mental disorder in the Mental Health Act.
 - That changes in law and improvements in services were put in place before this happened.
 - That a new law be created to support access to positive rights, including the right to independent living.
 - A new model be introduced for professional roles involved in making decisions with and for autistic people and people with intellectual disability.
 - Duties to be introduced on public authorities to provide a range of services, environments and professionals to meet the needs of autistic people and people with intellectual disability.
 - That a human rights-based system for all decision making should be introduced, including human rights assessment as a key tool for ensuring human rights were promoted and protected.
5. In his opening remarks, the Minister stated that the Scottish Government is 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. Scoping work on the Bill will commence shortly.
6. Members asked the Minister what action could be taken before the Bill is introduced, noting the independent review's findings and emphasising that protecting the human rights of autistic people is also important in the time before the new legislation is created.
7. The Minister stated that a full response to the report would be co-ordinated and that work has already been carried out to progress its recommendations. This included the Scottish Government publishing new mental health standards and commissioning the Scottish Learning Disabilities Observatory to carry out a study on the use of psychotropic medication.
8. Addressing the commitment to create a commissioner, the Minister acknowledged that there were “polarised views” on this proposal and that the Scottish Government will “have to listen to all sides if we are to get that right”.

9. The Minister also highlighted the upcoming Scottish Mental Health Law Review which is due to report in September 2022. The report will “make recommendations to give effect to the rights, will and preferences of the individual by ensuring that mental health, incapacity and adult support and protection legislation reflects people’s social, economic and cultural rights, including the requirements of the United Nations Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights”. To ensure rights are imbedded in the learning disability, autism and neurodiversity Bill, the Minister expresses that the Scottish Government needs to listen to people.

Access to support services

10. A disparity in the support provided across Scotland was highlighted in the meeting, as well as in written submissions received by the Committee.
11. These detailed challenges faced by individuals in accessing autism support services where they did not have a learning disability or mental disorder, including accounts of people being incorrectly directed to mental health services and being turned away from autistic support services, leaving no alternative route for support. The Committee therefore raised questions about access to support locally for autistic people, and specifically those who do not have a mental disorder or learning disability.
12. In response, Jacqueline Campbell from the Scottish Government highlighted the development of a single adult neurodevelopmental pathway for diagnosis and support, describing this as “quite critical” in providing support in a more holistic way. The Scottish Government and three or four health and social care partnerships will be working to test out these approaches.
13. The Minister also noted that “although the services...are very good in some areas, I cannot claim the same for other parts of the country.” It was acknowledged that there is still work to do in order to ensure that certain geographical areas have the right provision of services and that “it is fair to say that some parts have very few services to meet the needs of autistic people”.
14. When asked whether councils had been identified that require more support, the Minister stated –

“I know of a number of health and social care partnerships and local authorities that are doing very well in this area, and I know of a number of others that are not doing as well as they should be to meet their people’s needs. I will continue having the very detailed conversations that need to be had, to do that stocktake and to ascertain what is going on out there that is right and what is not going quite so well.”

User-centred services and good practice

15. The Minister also emphasised the importance of people with autism influencing decision-making in respect of autism services and the need to “put the person at the very heart”.
16. He stated that where person-centred approaches are not taken forward, “it causes great difficulty for the individual, their family and often their community”.
17. The Minister emphasised that approaches have to be looked at in the early stages “instead of waiting for somebody’s life to reach crisis point before the services that are required are provided”.
18. The Committee noted that a recurring issue raised during the evidence session was “the power imbalance that service users often experience” and Members questioned whether there could be a mechanism for individuals to report examples of good practice.
19. The Minister suggested that “the assumptions that we all make, rightly or wrongly, about what we think needs to be improved first and what our priorities should be are not necessarily shared by folks with lived experience” and that a more inclusive approach is “something we need to push further”.
20. The Minister highlighted specific areas of good practice such as South Lanarkshire, which operates an autism resources co-ordination hub, Edinburgh, which has a Lothian one-stop shop and Perth and Kinross which also has a one-stop shop.

Funding

21. In his evidence to the Committee, the Minister highlighted a number of recent funding announcements made to support people with autism –
 - £650,000 this financial year for tests of change [testing out areas for improvement with those most closely affected] for adult neurodevelopmental pathways for diagnosis and support;
 - £425,000 to trial the Scottish Government’s new learning disability and autism leadership and engagement work;
 - £400,000 for the Understanding Autism Project funding for a second year; and
 - £5.25 million for NHS boards to build professional capacity to support children and young people with neurodevelopmental support needs.

Action

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

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting -

- [PE1837/AA: Petitioner submission of 7 October 2021](#)

The Scottish Parliament launched a new website at the end of Session 5.

All written submissions received on the petition before May 2021 can be viewed on the petition on the [archive webpage](#). Written submissions received on the petition after May 2021 can be viewed on its [new webpage](#).