

PE1837/H

Professor Jean MacLellan OBE submission of 13 January 2021

As a former civil servant involved in national autism policy and a former Director of Autism Network Scotland, I am writing in support of this Petition.

I have listened carefully to the deliberations of the Committee and would like to make some broader contextual observations prior to commenting on the two specific asks.

In the early 2000s Scotland was regarded as a world leader in creating an autism needs assessment targeted at improving the commissioning of services. This was thought to be a global first and was focused on research and training as well as endeavouring to improve practice. The national Scottish Strategy for Autism followed in 2011 which many have invested in and which has created change to some degree but, as it draws to a close, there is a sense of disappointment.

The ten year programme is ending eight months early. A Covid related Transition and Recovery Group that considers the needs of those with autism and learning disability has seemingly widened its remit to consider how best to taper current activity and to consider the possibility of a new Strategy. It is unfortunate that a Group created for one purpose has had its remit extended in this way without broader consultation with autistic individuals and families.

There is considerable uncertainty about the future support that may be available. Autistic individuals and families are exhausted by simply surviving day to day. This can mean that those who would like to participate in policy development are too tired so imaginative person centred outreach is what is needed to assist in articulating what the needs are. There is good practice out there which is not always costly.

Moving to the two specific asks in the Petition, Recommendation 11 of the Scottish Strategy states that it should 'consider the specific supports needed for more able individuals with ASD.' The main way in which this was addressed was the creation of six one stop shops across Scotland where individuals could drop in and be supported. This lessened social isolation for many as well as managing anxiety and depression whilst also providing information, advice and support in terms of issues like employment. The Scottish Government funded this provision on a pilot basis but the lack of funding to sustain them when finances were withdrawn meant that some survived and others did not. The one stop shops were highly valued by many autistic individuals and families. In some areas, alternative models have emerged which are very effective, most notably in South Lanarkshire.

What is at the heart of this Petition is the lack of consistent support. What happens is that those with autism and no learning disability will not necessarily meet stringent eligibility criteria because they fall below thresholds and so are reliant on broader based support in the community (if it exists and if they can access it). When such support is given, lives can be transformed and individuals are able to live those lives as equal citizens.

If the Committee is so minded, I would respectfully suggest that it seeks views beyond those of Scottish Autism and the National Autistic Society. Whilst these organisations are integral to service provision, there are others that would widen the range of perspectives. The National Autistic People's organisations, the local autism societies, and HSCPs will all offer further depth of understanding the complexities here. Additionally, I would suggest contacting No. 6 which is an Edinburgh based service run by Autism Initiatives which runs support groups for those with autism alone.

To conclude, I would reiterate the point that MSP Burnett makes about diagnosis. We know how to do this now but systems need to match that understanding to reach people who can wait for years. Without diagnosis, post diagnosis support has little relevance.

We need a clear Vision for the future and a pathway to get there.

I support the Petition and would be happy to provide further information if that would be helpful.