

PE1837/G

Deborah McKenna submission of 5 January 2021

I write to you in support of petition PE01837: Provide clear direction and investment for autism support.

I support this petition for several reasons. I have worked with autistic people for ten years, specialising exclusively in the field of autism for the past four years, and have recently achieved my M.Ed Autism with the University of Strathclyde. However, most importantly, I have personal family experience of autism and have witnessed first-hand the difficulties that a lack of support can create for individuals and their families. The issues raised in this petition rightly describe many of the challenges that autistic people and their families face. There is currently a distinct lack of appropriate provision for autistic people across Scotland, despite the Scottish Strategy for Autism coming to an end.

At this moment in time there is an opportunity for meaningful support to be developed which could improve the lives of autistic people. The findings of the 2018 Microsegmentation Report (commissioned by Scottish Government) recommend that investing in specialist services for autistic people can result in the tangible improvement of outcomes and reduction in overall economic cost. For many of the people that I work with, there are clear points at which appropriate support would have made a difference – difficulties at work, a relationship change, a transition from education. Unfortunately, there is simply no relevant support on offer and often the situation that these people are in deteriorates and results in the support needed being far more substantial.

This has been the case time and time again across my professional experience. In many instances there are individuals who are in contact with Community Mental Health Teams (CMHTs), who have poor mental health due to the lack of appropriate support and therefore opportunity. These people are ultimately discharged, often as it has been determined that their difficulties are associated to the core characteristics of autism – differences and difficulties in communication and interaction, with flexibility of thought and repetitive and restricted behaviours or interests, and sensory processing – and as such are not “treatable” under mental health teams. This is not only a huge waste of money and time for both parties, but often results in further deterioration in mental health. The support detailed within the petition could end this cycle and produce real results for autistic people. In instances where an intervention is applicable, for example such as the delivery of psychological support for anxiety or depression, once the intervention is completed the clinician discharging will recognise that continuous social support is needed, however this is not available. The development of autism support teams could give these clinicians a referral route and ensure that people are not simply left with nothing.

Waiting times for diagnostic assessment can be difficult, however I feel that the real difficulty lies after a diagnosis has been given. Many of the people that I have worked with have described their diagnosis as “pointless”, as there is no tangible support available for autistic people. For some people who receive a diagnosis, such as those who were accessing mental health services, this means that this support is no longer appropriate (as you cannot “treat” the characteristics of autism) and they are discharged. Those who have tried to approach social work to have their needs

assessed are often referred to community mental health teams. Those who do have their needs assessed are often still left in the same situation as there are no suitable or appropriate services to spend their budget on. Reducing diagnosis waiting times will not make this situation better. Many people are slipping through the cracks whilst their difficulties are growing greater and greater. Autism support teams could fill this gap and could work in partnership across services to deliver the holistic approach that is required to adequately address the needs of people with autism.

Although the development of a post-diagnostic support pathway would be a big improvement on the 'leaflets in an envelope' support offered to my family at time of diagnosis, there is still no support for the day-to-day difficulties that many autistic people can experience. There is no quick-fix which will make it easier, there needs to be a whole-system change in the approach that is taken to autism support. I believe that the creation of autism support teams could not only prevent many of the difficult situations that have been created by the current system but could make a tangible and practical difference in the lives of autistic people and their families.