

PE1837/N

Jean McNally submission of 26 January 2021

I am in support of the petition reference number PE01837.

I have experience of caring for a 20 year old that has Asperger's but not a learning disability or mental disorder. As a result, we have not been able to access support in the areas of occupational therapy as occupational therapy in Glasgow is based in either the learning disability or mental health teams which the person does not meet the criteria for. We have been unable to access sleep support because sleep support like Sleep Scotland only goes up to 18 and there are not similar services for adults. Sleep disorders are very common among people with an autism spectrum disorder (ASD). As much as 80% of them suffer from one or more sleep disorders.

When the person was at college we tried to get support from the National Autistic Society (NAS) and South Ayrshire Autistic Society (SAAS) would have paid for this service but NAS could not provide a worker and they were left with no support for one year. Services like the Autism Resource Centre (ARC) have had services cut and were unable to offer any support. In Glasgow the ARC no longer provides the service it was set up for and no longer meets the needs of people in Glasgow who have ASD. We have been left with no services or support because they do not have a learning disability or mental disorder. They have received no support from health or social work as an adult.

My uncle also had a diagnosis of Asperger's. He was diagnosed with Asperger's at twenty-eight. My gran got dementia and could no longer care for him and he went into residential care. He was sectioned shortly after around twenty-five years ago. He stayed in residential hospital institutions until he died a few months ago. For the last nine years he stayed in a small community hospital. He continued to live there because there was nowhere in Scotland which could meet his needs. They have talked about closing this hospital in line with government guidelines for the past three years but they are unable to because there is nowhere which can meet their needs. Care in the community has not worked for this group and the majority of people in this hospital will never be able to return to the community.

He is not the only person with ASD who died well before he should have. Autistic people have been found to have an overall risk of early mortality more than double that of the general population. Schendel, D.E. et al. (2016). Autistic people die on average 16 years earlier than the general population. For those with autism and learning disabilities, the outlook is even more appalling, with this group dying more than 30 years before their time. Hirvikoski, T. et al. (2015).

People with autism are at increased risk for experiencing mental health problems, particularly anxiety and depression. People with ASD are more likely to experience mental health problems than the general population. This can be because there are fewer resources and support to help develop coping skills. Also, they can experience more negative life events, and face stigma and discrimination from people and services.

The support provided in psychiatric hospitals is not geared towards people with ASD, the staff do not have enough ASD training or understanding. People with ASD need

the right support at the right time. There needs to be specialised services for those with ASD which does not depend on having a learning disability or mental health problem to access the service.