

PE1837/P

DIFFERabled Scotland submission of 26 January 2021

We are a Charity set up, (by parents/carers of children on the Autism Spectrum & co-existing diagnosis') specifically to support, highlight and unite the needs of (fellow) families with children/young people and adults on the Autism Spectrum – to share information, signpost, create awareness & understanding within our own families & our communities. To create meaningful, vital support & services for the benefit & value of our individuals on the Autism Spectrum. In addition to supporting our families & community members; we are also an Autistic led organisation. We provide real-time-1:1 peer support, online sessions for families to come together, Autism & Neuro-Diversity Sensory training workshops; for parents/carers & family members, who would like to create awareness & understanding. Creating further support for their individuals on the Autism Spectrum.

DIFFERabled Scotland are placing our submission in full support of this Petition.

There is an immense feeling of disappointment shared within our 'neuro-diverse families,' and our community, particularly around the complexity of 'Autism/ASD.'

There appears to be confounded interpretations of the legal and clinical approval of Autism Spectrum Disorder.

As families, many of our individuals do not have a Learning Disability – 67% **do not.**

We would like to highlight issues that present themselves to DIFFERabled on a weekly, if not daily basis. Many of which create further barriers and impacts for our ASD individuals, as well as their families:

- 1) Many of the children/young people can be on 'The diagnosis process,' for up to 3.6yrs. NICE(2017) recommends that an ASD diagnostic assessment begin within 3mths of first referral – for both children and adults.
- 2) Receiving diagnosis, they are then given handouts and sent on their way (lack of post-diagnosis support/lack of emotional support throughout the process).
- 3) CAMHS support? Difficult to receive support due to complex nature of the ASD diagnosis – Mental Health – postcode lottery on who receives and who does not! (ICD-11/DSM-5 (328.0 Meaning of 'mental Disorder.' In this Act 'Mental Disorder,' is as:
 - a) Mental illness
 - b) personality disorder
 - c) learning disability

Autism on its own, is not covered within this Act. Therefore, this 'lack of Autism direction within any manual specifically defining what Autism is or is not, prevents accessing support. Attempting to create support for their child/young person within CAMHS, is very often met with, "We are not an Autism service. Autism is not a Mental health issue. Anxiety experienced with your child is based on specific Autism associated behaviours. The inability to understand or make sense of the environment is not a mental health issue, but a behavioural issue"

- 4) Lack of support around Asperger's (pre-post) Diagnosis
- 5) Lack of understanding/support within Education
- 6) Lack of Carers support
- 7) Lack of appropriate housing support/accommodation toward ASD individuals
- 8) Lack of appropriate understanding/awareness/training Employment support toward ASD individuals (& potential employees)
- 9) Alarming rates of individuals on the Autism Spectrum being sectioned (specifically young people). Once sectioned many of our young people/adults are very often placed in residential settings/units far from their own homes and communities. There is no specific ASD supported/setting or unit for young people In Scotland.
- 10) Lack of services to support transitions/funding - E.g., Social work/Children with disability assessment. Without Social work assessment, the application for SDS cannot be submitted. Access to Adults services become increasingly difficult without one service supporting/communicating with the other. Breakdowns in these vital links or 'collaborating/multi service support, results in further impacts & barriers to our individuals' journey.

There is a persistent financial failure toward the Social Care Support for our individuals with ASD. Third sector organisations are stepping in to provide this shortage of inconsistent provision. Autistic individuals and their families are unfortunately becoming the resource! Becoming ever more exhausted/depleted, by an unmet provision toward their individuals. Resulting in services needed for the entire family. Furthermore, services that require acknowledging and supporting autistic individuals with co-existing conditions; NICE(2017) estimates that on average 70% of ASD individuals present with these 'additional conditions,' such as, ADD, ADHD, Sleep Disorders, Tourette's, Anxiety based Disorders, Gender identity Issues, Ritualistic & Repetitive behaviours; and/or OCD etc. All of these can/may also be present with or without an intellectual Disability.

- We require positive outcomes, provision and services for the ASD individual and their families and interventions that will lead to and sustain positive impacts for our ASD individuals.
- We require clarity on how autistic people, who do not have a learning disability and/or mental disorder, where/can access support.