

PE1837/S

Deborah Best submission of 2 February 2021

I strongly agree with petition PE01837 .

I was diagnosed autistic myself in February 2020. I sought this diagnosis to bring closure and fully identify with my Neurodiversity. In the weeks, months that followed, I wanted the diagnosis retracted. I didn't feel different, but many in the world who had accepted me as I was, changed their behaviour towards me. Many speak of the euphoria of diagnosis, the closure, but for me all the 'stuff' which was brought up was left unsupported. My clinician suggested I was referred for counselling but I had to follow through this option on my own. I was on a waiting list at the adult autism team for a post diagnostic group support group, but early into lockdown, I received a letter to say it had been cancelled and signposted me once again, but to nowhere really.

I've tried to access some services but 'I don't quite fit'. I've been described 'as being a pendulum which swings between the neurotypical and neurodiverse worlds'. I would like to fit somewhere, but since my diagnosis I don't. It has been damaging to my mental health with no suitable post diagnostic support. I can't imagine what service could be offered to me where I could feel supported ' invisibly'. I don't want to stand on a rooftop celebrating my diagnosis. I want support to reconnect with that 'lost little girl' and help me understand my life's difficulties and my vulnerabilities. I try to navigate the invisible daily difficulties I experience, which will continue to challenge me without any suitable support. My anxiety is debilitating.

I care for a 20 year old autistic person whom I've had to fight for since early years. No appropriate support at nursery or school, no childcare which would 'tolerate ' their autistic behaviours, no social activities which would include them. They were even asked to leave an arts project aimed at young people on the spectrum because they 'wern't autistic enough'. They had SDS and a personal assistant for 6 years but wasn't disabled enough for SDS as an adult. They fell off the 'cliff edge' on leaving School with their mental health irreversibly damaged, attempting to fit into a system which didn't understand them nor even want to. Exclusion, isolation and inequality are what being autistic means to them. A damaged child reaching an adult world where even less people care about their rights and needs.

We are NOT 'disabled enough' .