

PE1837/M

Wendy Ferguson submission of 22 January 2021

I feel strongly about the content of the above petition which is why I have decided to write this document, despite the significant difficulty this involves for me.

Imagine having various tests done at hospital, over several years and then the health practitioner confirming that you need surgery but there are no services available to deliver this. And any that do exist you don't qualify for since you are not ill enough. Imagine the absurdity of this just for a moment.

Because this is what happens to an autistic adult at diagnosis. It happened to me. After years of waiting lists and appointments, all the while suffering for reasons I did not understand. I expected that receiving diagnosis would open the door to the support I so desperately needed. But it didn't. Because there wasn't any.

Since we live with a medical model where we seek medical assistance and it is there, unconditionally. Why should this be different with autism? Despite it being something I find difficult and overwhelming, I have tried to engage with some of the large autistic societies in Scotland – National Autistic Society and Scottish Autism. At various times in the last few years, I have asked for help to access any available local support through charities etc. I was surprised to find that neither of these societies provide direct support to people like me. In my last contact with Scottish Autism the person who promised to email me with information didn't. I had wasted the energy on the call, for nothing.

In November 2019 I engaged with an organisation called RAMH. It had taken me months to make the initial call to try to arrange an appointment to get help. I attended an in depth session which was exhausting due to the content. I wanted to try to deal with my lifelong anxiety and the detrimental impact it was having on my daily life. The person I saw knew nothing about autism. This meant I had to explain a lot of things in depth, adding to the exhaustion. I attended session one of the Anxiety Management course suggested and was so significantly anxious because of the facilitator style that I did not go back. I was supposed to receive an invite for another course with a different facilitator, this didn't happen.

By February 2021 I was experiencing such significant daily challenges that I saw my GP. I had come to a point where significant self-management was not working. I was mentally unwell. I believe this happened as a result of years of no support following my autism diagnosis in 2017. Referrals were to be made to social work, mental health services. I had no one to advocate for me and found myself having to call social work and mental health services while I was mentally unwell to try to establish support. Sadly what was evident was that I didn't fit in, anywhere. Social work seemed surprised that I was referred to them as I didn't "qualify". The mental health professionals typically do not understand autism and therefore do not understand me, my life, perspectives and ultimately what will help me most. I have received no support at all to help me with autism and the effect it has on my daily life. I have been unable to work for almost a year. I had to stop because it was making me increasingly unwell.

What I have learned about autism has all been through my own investigation, personal reflection and expense. Until very recently, I qualified for no financial support to assist me. It has been an exhausting journey. Not at all what I was expecting when I decided to seek a diagnosis. I have grown up with the medical model where you consult the health professional and they give you the help you need. Except, it seems, when you are an autistic adult and do not have a learning disability.

Imagine that scenario again of being ill and in need of life changing surgery. And the health professional saying they couldn't help, almost turning their back on you. Your GP offering a "sticking plaster" to see if it made any difference. And you then watching a Youtube video or two and doing a DIY job for yourself. I wonder how the end result would compare to that of a suitably qualified surgeon with all the necessary resources at their fingertips?

As an autistic adult, I need easy access to well informed, empathetic people with premises, resources and solutions to help me in daily life. I did not choose this diagnosis, I was born with it and lived into my forties managing it (or not) by myself. I just thought there was something wrong with me. Now I know different.

As I see support readily available, it seems to focus on children. It's as if the world has forgotten that autistic children grow into autistic adults. The daily challenges never go away, they are inherent, intrinsic to who we are and need specialised support which can easily be accessed, without a fight about whether we qualify or not, are unwell/disabled enough or not.