

PE1837/F

Thom Kirkwood submission of 5 January 2021

Neurodiversity, a topic difficult to cover, as many people do not understand it and many feel uncomfortable with it. Many don't understand the world of mental health and like those within that world need a label to give them a peg. That peg can be round or square. Square pegs do not always fit into round holes and vice versa. Pegs or labels can be right wrong or completely misleading. With society's obsession with labelling in a modern complex world, and, the [United Nations 2030 Agenda for Autism, Inclusion and Neurodiversity](#), which most, if not all countries have signed up to. It's time we had a meaningful grown up societal discussion on what this means. Associated to a component contributions to 2030 Agenda for Sustainable Development, which includes [17 Sustainable Development Goals \(SDGs\)](#) and 169 targets that promise to "leave no one behind." In 2016 the World Autism Awareness Day focused on Inclusion and Neurodiversity.

A discussion, not just about those with minimal support needs, but those with high levels of support. Does neurodiversity directly correlate in the modern world to a neurodevelopment condition? Does diagnostic context genuinely mirror societal context?

In a societal context does neurodiversity matter? In my mind it does. Big caveat, as a society we must not use 'umbrella labelling' for the sake of short-termism in either policy or political sense, nor for the sake of the variances within neurodevelopment conditions, that require both diagnostic and supportive specialisms and associated knowledge and understanding.

Neurodevelopmental conditions, for example Autism, ADHD, Learning Disability, are not in a societal context a mental health disorder, yet currently in diagnostic and clinical terms they are out of kilter. This was highlighted in the recent Independent Review of Mental Health (Care and Treatment) Scotland Act 2003, Autism, Learning Disabilities.

Until recently, I worked as the Engagement and Participation Officer at Autism Network Scotland covering Scotland. I saw some wonderful practice and partnership working in action.

Unfortunately I also saw disenfranchisement from inclusion at various levels. With sadly too much assumption that big two speak for all. How can one have active citizenship, choice and control, when their voices are not heard? This could be argued and equally applicable to the Cross Party Group and the Evaluation of the Scottish Strategy for Autism.

Lots of smaller organisations at local levels some constituted some not, some attached to schools and other larger charities as family support groups, the majority of whom feel left out ignored. The majority, if not all, deliver valuable service often at very little costs to society. Meaningful provision that have direct impact on people's lives.

There are also local authority operations that are central to service integration and delivery of post diagnostic support at the right time, by the right person in the right

place, yet I know have little direct input on the wider arena when it comes to positive practice.

Both of those have significant potential in addressing some of the components of the Scottish Government's Microsegmentation Report, Mar 2018. A report that seemed never ending in arriving, yet when it did, with some perceiving it was predominantly geared to organisational sustainability of the few, not the many. Perhaps this is reflective in both the discussions associated to what next and to who is spoken to in the evaluation of the Scottish Strategy for Autism. Centralist predetermined outcomes.

I like many of my associates and colleagues across Scotland, when ANS were achieving improvement at local level via key officer collaboratives and my 'keeping it real' input from a balanced objective advocacy and parental perspective, encompassing the sharing of positive practice, incorporating reflective learning, this work stopped. Why? It never stated that it had to stop when we had our monitoring meetings. This was a regular decision, taken by I presume by government as it was seen as no longer a priority, it was like, - 'making a difference, lets stop it', with focus moving to aspects of issues whilst important, but often further away than the reality of the time dictated – tactical avoidance perhaps?

We must all recognise the lack of accountability is not directly a result of the Scottish Strategy for Autism nor will an Autism Commissioner reasonable address those matters. The accountability or lack of, which is not universal across Scotland neither for families, or by authority area. This unaccountability exists, because of centralist control, not clear if this is political or their civil servant driven, seeking to control a greater percentage of the decisions at all levels.

Such approach does not bode well with families, practitioners, or local councillors. Indeed it is repressive and suppressive, stifling imaginative innovation, inclusion and regressive ignoring the fantastic opportunity for grounded theory learning, refer back to my point re the cohesive work of ANS. This is an essential component to strive re our contributions to the aforementioned UN Agenda.

May I remind the committee, if I recall correctly, a cabinet minister for finance said in the chamber this government would fund public services so as not to leave provision behind or word to that effect.