

AUTISM AND MENTAL HEALTH: POSITIVE BEHAVIOUR SUPPORT, RESTRICTIVE INTERVENTIONS AND SAFETY IN RESIDENTIAL CARE

I have been diagnosed with High Functioning Autism, I have a sibling with a diagnosed mental illness and I work with Adults who have severe Autism in Supported Accommodation. I want to see more being done in terms of accommodation, research, training, support for carers and the development of a National Disability Insurance Scheme.

Since the introduction of the *Disability Act 2006* I have noticed many improvements in how many people with disabilities are supported in the system, however it appears that the needs of people on the Autism Spectrum are not adequately met in this legislation.

I am all for empowerment, advocacy and community inclusion, however I am sick and tired of seeing people wait forever to get their family members into care, only to see them and their staff get belted up by clients because people are too scared to advocate for safe boundaries. Why? for fear of the paperwork jungle of red tape required by the Office of the Senior Practitioner due to the perception of all boundaries as being "restrictive interventions".

So what happens? - many workers are receiving permanent injuries and suffering nervous breakdowns despite following approved procedures, which could have been avoided with a few simple boundaries in place. Unfortunately one has to receive an injury first in order to be able to prove that the need for the intervention is justified- then it usually is not approved. I believe that restrictive interventions and positive behaviour support principles are not mutually exclusive and the safety of all is of paramount importance. After all, that is often the reason many of these people were given up by their families and carers in the first place; it is certainly the reason my brother left the family home at the age of ten.

I understand that de-institutionalisation of attitudes is just as important as closing down the institutions themselves. However the pendulum appears to have swung too far the other way. Our obsession with freedom at all costs is coming at a high price. Don't get me wrong, I am not denying people's right to inclusion in society (after all I am Autistic myself) but it must be done SAFELY or not at all. This might

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mean a few more locked doors, higher staff to client ratios and more resources (such as more vehicles per house) and so on, but isn't that better than the current disaster zone we now have in place? Aren't these issues more important than endless paperwork devoted to proving how many outings people have been on- and debates over semantics regarding terminology such as person-first language...?

More research should be done into these issues and more training should be made available for staff who work in this field. It is obvious that many staff are still stuck in the "normalization" mode of endless outings, enforced group activities and insensitivity to sensory requirements; all of which need to be managed carefully when supporting people on the Spectrum. There is no way I would want to live like this- but oh, but we're supposed to promote communal eating at the table in the name of "inclusion"? (Well, I usually eat alone at home and I like it that way!) Then when people get hurt, some staff give up and become complacent- and the motivated ones move on to easier houses where there are people with fewer behaviours of concern.

In the meanwhile, those with severe Autism live in a constantly changing world of high staff turnover rates and unpredictability in routines- which is the last thing they need. Their gifts and skills become hidden in a minefield of staffing issues, chaos and managerial-butt-covering-red tape. This raises the anxiety levels of clients and staff alike, leading to mental health issues for both!

So what will happen to us if my brother or I should ever need to go into care? What will happen when our parents pass on? Our relatives are overseas and nobody knows what the future holds. The pathetic state of the mental health system is well known so I won't bore you with the details here- and I believe the disability system has a long way to go before it meets the needs of people on the Spectrum. I strongly believe we need a **National Disability Insurance Scheme** to assist with meeting the needs outlined above so we don't end up on the streets one day.

Thank you