

SUBMISSION FROM JANE KEOGH

1. During the last years of attempting to gain services for my children, I have been sadly disappointed by the struggle to not only gain a diagnosis, but also to receive any form of treatment or therapy after that. Luckily, my children are mid level on the spectrum, but at the same time the lack of severity does not mean they do not deserve the appropriate attention and support. The most success has been gained from voluntary organisations, other parents, and from myself. Without a voice and brain of my own, I doubt we would be where we are today, which after long periods of meetings, which seem to be dealt with politically correctly - but not practically or honestly. Generally what suits the educational bodies seems to be what happens, with as little input as possible been put in. Minimal addressing of possible mental health issues, which for me are priority. Academic achievements and minimal disruption in class and home - all these issues start with the mental health of the child, how they are feeling about themselves (if they can actually do that) and how their parents are coping with the situation day to day.
2. The current situation of a lack of duty to care and provide for 5,000 people's future is tantamount to mass exclusion, and in no way should be accepted. I understand it is a huge task to address, and that given the variability of autistic spectrum disorders (ASD), there will be no clean cut guides or manuals to assist families and carers, but just because a task is difficult does not mean it should be ignored. The sad reality is that by avoiding these issues, more harm is done in the long term. Carers will struggle throughout school age times, and then when the child grows into adulthood, times become even harder. Parents presently seem to lack any support when their child enters transition to adult services - I know of many families of adult ASD folk, and all their experience is one of them 'falling off the earth' when the child becomes 16 years old. Without the maximum input during school age years, then what hope is there for them when they leave school - when in fact if guidance was put in place, assisted work placements of some kind, of a consistent structure and type, some kind of security for the future of gaining life skills, and optimising the focussed skills that many Aspergers folk possess - duties and a meaning to the day could be found, instead of slow dive into isolation, depression and a waste of possible abilities. The rise in mental health issues is almost a certain future for those with ASD right now, the only question of the future is the degree of harm.
3. The knowledge of professionals throughout services of the nature of how ASD can affect people is disturbingly minimal - teachers, learning support, before we even begin on the general public's lack of knowledge is frightening, bearing in mind the amount of information available free on line, the courses provided by the National Autistic Society (NAS), and the awareness raising of these last few years. Yes, it requires a lot of learning, but once learned - life becomes considerably more understandable and

many issues can be worked with, understood, and possibly even successfully addressed. It's all very well have a 'toolbox' but having people who know how to use these tools is more important, and not the case currently.

4. I have been relatively lucky with my children and their school places, both are becoming teenagers soon, and it concerns me how things will develop, especially as this is a difficult time for most children, never mind with additional needs, and I am unsure as to where I can get support and how practical it can be. My mind dreads the thought of them leaving school and how much worse the situation will be by then, seen as so much cost cutting to be happen.
5. All parts of the Autism (Scotland) Bill are entirely relevant and required - standards and procedures need addressing, and clear guide lines of training levels are required for those professionals who are likely to come into contact and engage with those on the spectrum. It should not be a postcode provision, dependant on parents will to fight, their knowledge and abilities, and how able they are to battle on for such long periods of time to gain support, diagnosis and then provision of expected and needed treatment.
6. By ignoring the needs of families of ASD, an immense loading of mental welfare services is being set up for the future, with parents who are already struggling to function, getting to a point where coping is no longer an option.

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