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Support across the lifespan in the UK

So where have we got to in the UK? Although services have improved greatly, with early identification, better support and inclusive practices in schools and more access to training for teaching staff and professionals in education, health and social care. Across the UK, services remain inconsistent and patchy at best. The SEN CoP (2014) and Autism Act (2009) highlight how there is still a long way to go in reaching a consistent pathway of support across the lifespan. Children with autism are usually supported within mainstream classes in primary however transition to secondary school and post 16 is often difficult. Adult diagnostic services need further development, as do treatments and support for mental health and well-being. The so called ‘epidemic’ of children are already reaching adult services, and although much time has rightly been invested on early identification and intervention, it has been at the expense of developing support post secondary school. Beyond secondary, adequate autism provision and support in further education, training and employment is limited, and reportedly only 15% of autistic adults in the UK are currently in full-time paid employment (cited on www.autism.org.uk).

The concept of neurodiversity rose to prominence in the 1990s in the U.S.; it can be defined as naturally occurring cognitive variations with

distinctive strengths, which appear as a result of normal variations in the human genome. The autism neurodiversity movement in the UK is growing in strength, to promote the voice of individuals with autism by individuals with autism.. Autism understanding across the general public is changing, it appears to have moved away from the ‘rain man’ representation to a variety of representations reaching mainstream literature, theatre and screens (e.g. *The Reason I Jump*, *The Curious Incident of the Dog in the Night-time*, Temple Grandin’s biopic, Sheldon in ‘*The Big Bang Theory*’, etc.). Support or inclusion in the wider community is emerging by providing ‘autism friendly screenings’ in cinemas and theatre and Manchester airport has produced an autism specific booklet to download from their website. No doubt this is a result of parental organisations, self advocacy groups and charitable organisations raising awareness. However, for the general public ‘autism’ remains a mysterious condition, which many have heard of, however understanding does not usually extend beyond some vague notion of unusual social behaviours.

Into the future

The question that keeps most parents I work with up at night, and many siblings too, is ‘what will happen when [parents] are no longer around?’ I am not the first to highlight that the billions of funds that goes to research in causes

and even more concerning, to medical interventions, needs to be redirected to provide ongoing, improved and new social, psycho educational interventions and support services, that will make a real difference to the day to day lives of individuals with autism, and their families. Although it is now largely accepted among parents and many professionals (i.e. teachers, psychologists, speech therapists) working closely with individuals with autism, that the most effective approach is to build on the strengths and interests; there seems to be a lack of flexibility in processes and systems to fully enable this. When such provisions do exist, it is often only accessible to a limited few, available for a short period of time or under-resourced. There is an on-going need for training of educational staff (in early years, primary, secondary, college and university) and flexibility within educational systems to provide adequate and evidence based practices that are based on the individual needs of each child or young person with autism.

Awareness also needs to continue to be raised beyond educational provision to the wider community (police, hospitals, supermarkets, transport staff, service industry staff, criminal justice system, etc.) and employment market. If autism is less mysterious, there will be less fear of difference, less exclusion and more understanding and inclusion. Society needs to change to make the every day life of individuals with autism less disabling, allowing for strengths and talents to develop, only then will we have a truly neurodiverse community.

Finally and most importantly, to properly plan for the future of autism we need to ask people with autism what they need, and we need to listen.

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Jennifer worked as a behaviour analyst, early years educator and assistant psychologist with children and families whom have diagnosis of autism in Ireland, prior to commencing a Doctorate in Educational & Child Psychology in London, in 2007. Jennifer completed her doctoral thesis on ‘Support groups for Siblings of Children with Autism’. Jennifer has published a peer reviewed article and book chapter, and presented at the BPS: DECP Conference (2012), HCPC Primary Care Conference (2012), and XI Autism-Europe International Congress (2016).

Research areas: autism, early years transitions, autism interventions & models of support

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