

Our Son was diagnosed with autistic disorder (DSMIV) in 2003. At the time the incidence of autism was around 1/300 Australian children and diagnosis required a triad of impairment in social interaction, communication, and restricted, repetitive, and stereotyped patterns of behaviour, interests and activities, with onset before the age of 3.

His journey included mainstream preschool program with challenges, participation for 1 year in a pilot specialised program with substantial gains, mainstream primary school with challenges despite a supportive school population, specialised high school with a very positive and happy experience (IQ estimated at 44), development of mental health issues on leaving school culminating in a diagnosis of Bipolar Disorder eventually responding to ECT (substantial challenges with mental health pathways), adult onset absence seizures, and now aged 24, living in SIL and functioning above his IQ due to the strengths of his autistic traits.

20 years later the incidence of autism in Australian boys is approaching 1/10 and the nature of diagnosis and breadth of spectrum has dramatically changed, with an increasing number of adults being diagnosed with autism for the first time.

Sarovic's unifying theory of autism proposes a deconstruction of autism into 3 contributing features (an autistic personality dimension, cognitive compensation, and neuropathological risk factors). The autistic personality represents a common core condition, which induces a set of behavioural challenges when pronounced. Risk factors, both endogenous and exogenous, impact neurodevelopment affecting cognitive compensation, impacting ability.

Importantly this theory argues for a common autism personality that like all personalities carries a set of traits (equivalent to neurodiversity) but is not a disorder or a disability.

It is critical that in the setting of markedly increased diagnosis of autism that the specific needs and lived experience of a person with a disability (as per DSM IV diagnosis in 2003) is represented. People such as our son do not have the intellectual ability or communication skills to express their experiences or needs. Their shared journey is with those who care for them. It is critical that their voice (through their carers) is included in decision making bodies and specific consideration is given to the needs of people with autism and intellectual impairment as a group when developing policy impacting their lives (early childhood education and what works, school, post school programs and services, housing, and health) so that they can enjoy their best lives.

Our experiences as a family highlight the importance of specialised early intervention, the important role of special schools, and the need for Intellectual Impairment and Autism specialised units for supporting health care and mental health service delivery.

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