

From: Inquiry into Abuse in Disability Services POV eSubmission Form
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Subject: New Submission to Inquiry into Services for People with Autism Spectrum Disorder

Inquiry Name: Inquiry into Services for People with Autism Spectrum Disorder

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SUBMISSION CONTENT:

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21st March 2016

RE: VICTORIAN PARLIMENTARY ENQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

Prevalence of ASD in Victoria

Internationally there is some disagreement regarding the prevalence of Autism Spectrum Disorders (ASD). This in part relates to differences in diagnostic criteria used (eg DSM-IV, DSM-V, ICD-10 and a range of screening – assessment tools such as the Childhood Autism Rating Scale, the ADI/ADOS), representativeness or otherwise of population surveyed, (Clinical vs Community samples, selective groups such as children with developmental delay/intellectual disability, administrative groups such as those in receipt of special services), and socio-cultural factors, such as the availability of specially funded services for children with an ASD. The type of prevalence is not always specified or might differ between studies, for example point versus period prevalence. Taking these factors into account, published studies of prevalence indicate an increase in prevalence of ASD in preschool children. There have been several relatively recent studies relevant to Victoria which indicate that using the more inclusive DSM-IV criteria and diagnostic/screening tools associated with these criteria that the prevalence is around 1 per 100-130 preschool children if not somewhat greater^{1,2}. The field work trials on the application of the new DSM-5 criteria for ASD have indicated that these criteria are less inclusive than the DSM-IV criteria if they are strictly and systematically applied, which should mean that prevalence rates will be less. However it appears evident from the increasing rate of registration of young children in Victoria to receive the Commonwealth Helping Children with Autism funding and the unexpectedly high number of children being registered with an ASD in the Barwon NDIS pilot project that the administrative prevalence appears to be even higher perhaps at around 1 in 60 children. Therefore a possible contributing factor to this increase in children receiving an ASD diagnosis might be the availability of funds for early intervention which otherwise might not be available to such an extent for children who have developmental delay and a range of neurodevelopmental problems which are not due to or associated with an ASD. What is not in doubt is that

all the children in Victoria currently receiving funded early intervention services or funded early intervention services specifically for an ASD have neurodevelopmental problems and benefit from these services and extra support.

The Availability and Adequacy of Services

Over the last few years, Commonwealth, State and Local Government early intervention services for young children with an ASD have significantly improved. This, in part, is due to the increased funding available under the Helping Children with Autism initiative and the introduction of some special Medicare Items for psychology/allied health assessment and early intervention services. Improved training of Medical (Paediatric/Psychiatry), Psychology and allied health professionals in childhood neurodevelopmental disorders and in particular ASD have also contributed to improvement in services. In the primary school years, increased training and support for teachers and Medicare Item support for psychologists and allied health professionals have improved services for children with an ASD attending primary and secondary schools. Increased training and expertise in special school teachers and support staff have also improved services. Some dedicated special schools for children with an ASD have developed and there is no doubt that this is helpful in promoting the educational and social development with some children with an ASD but there is no evidence that this exclusive approach always improves the outcome of children with an ASD or is necessarily of added benefit to the receipt of a more broad-based properly supported programme in mainstream or general special schools. The availability of education aide support and a planned individual learning programme for children with an ASD in school is a critical element. Unfortunately the existing criteria for supported school programmes for children with an ASD in Victoria has narrow and exclusive criteria requiring the presence of an intellectual disability and/or significant speech and language delay. This excludes many children with an ASD who nevertheless experience significant handicap due to their symptoms of autism and frequently also have serious emotional and behavioural problems^{3,4} which create significant school management difficulties which often lead to suspension or ultimately exclusion from school. Children with an ASD also frequently suffer severe anxiety at school associated with social stress, learning problems, bullying, and sensory sensitivities, for example to sound. This overwhelming anxiety leads to school refusal and adds further burden on stressed families. Therefore in Victoria there are a problematic number of children with an ASD who are not attending school and face serious limitations on their future development and ultimate participation in the community.

The biggest gaps in services for individuals with an ASD are for adults and the elderly. There is a lack of clear and effective pathways for young people with an ASD into post school options. Paradoxically services are better if the young person also has an intellectual disability because of the range of generic services available for people with a disability. However adult disability services may lack special skills and training necessary to respond to the specific needs, symptoms and emotional and behavioural problems presented by people with an ASD. There is some Victorian evidence that at least 30% of young adults with an ASD who do not have an intellectual disability have no employment or support and are essentially at home going nowhere⁵. Employment services are usually not able to provide mentoring and on the job support to enable a person with an ASD to manage the complex transition into a workplace even if they have the necessary skills to undertake that work. There is a lack of expertise in public mental health services to assess and identify the complicating presence of an ASD in adults with mental illness or alternatively assess the presence of mental illness in adults with an ASD. Adults with an ASD are at higher risk of suffering comorbid mental illness and emotional and behavioural disorders which, depending on the study, co occurs in around 20-40% of adults with an ASD⁶. The compartmentalisation of government services into health, disability, employment and housing often means that services are fragmented or unavailable to adults with an ASD who have complex mental health, disability, employment and housing needs. Community inclusion is also often denied given a lack of understanding about their social, communication and behavioural difficulties and their need for supported inclusion into community activities. Times of transition are critical for individuals with an ASD and their families and carers. In Victoria, the Education Department has developed innovative transition planning protocols and programmes for children moving from preschool to primary school and to a lesser extent from primary school to secondary school⁵. There is evidence that support and planning through these transition phases leads to positive outcomes which can be of enduring benefit. There is a need for transition support from school to post school options and in to employment opportunity.

The National Disability Insurance Scheme

It is difficult to provide an informed and evidenced based comment on the impact that the NDIS may have on services for people with and ASD. Anecdotal information regarding the Barwon pilot programme indicates that a number of families with children with an ASD are pleased with their capacity to develop an individual plan and influence the services that the child requires. It appears that the pilot project has demonstrated that there might be a lack of appropriate services, even when the individual service needs have been specified. Families report that NDIS services will be available to individuals with an ASD who meet a DSM-5 Severity Level 2 or 3 requirements. This raises a number of concerns. Firstly, older children and adults with autism do not have a DSM-5 diagnosis and therefore will require reassessment. Extra costs will be incurred by the family and demands placed on the professionals whose availability are already seriously stretched to do these assessments. Further, the DSM-5 clearly specifies that the determination of level of severity should not be used for the allocation of services and funds and at this time. There are no internationally agreed gold standard assessment tools which can reliably and validly assess the DSM-5 very general specifiers of level of severity. Therefore it is likely that levels of severity be arbitrarily assigned that will ensure the provision of funded support given the reality that everyone who genuinely has an ASD has a complex range of support needs related to their specific symptoms of autism and frequently associated mental health, emotional and behavioural, learning, neurodevelopmental and general health problems.

Economic cost

It is clear that neurodevelopmental disorders such as intellectual disability and ASD place considerable extra cost and burden on families, carers and the community. There is Australian evidence that the high risk of associated emotional, behavioural and mental health problems in children, adolescents and adults with an ASD, considerably add to these costs and burden^{7,8}, for example, in extra staff requirements in schools, need for respite care, and workers compensation claims. There is some Australian evidence which includes Victorian young people to indicate that only around 10% of young people with an intellectual disability including those with autism receive any specific or specialised services for their serious emotional, behavioural and mental health problems⁴. Therefore it is likely that this lack of mental health services will contribute to an inflation of the high costs and burden of care on families and the community. Conversely the provision of needs based services, support for families, focused transition point support, improved professional and service work force training and support, improved mental health service training and programmes, and targeted programmes for adults will require increased funding. However the consequent reduction of family burden, improved individual outcomes in mental health, and educational, community and workplace participation will create savings to offset innovative investment of government funds.

General comments

There is no doubt that individuals with an ASD have a range of special needs and may require special approaches that take their neurodevelopmental, symptom and mental health profile into account. However there are a range of other neurodevelopmental conditions such as Fragile X Syndrome, Prader Willi Syndrome, William Syndrome, Down Syndrome and Foetal Alcohol Syndrome which also require special approaches to their care and management because of their specific profile of neurodevelopmental, learning and emotional and behavioural symptoms and characteristics. However people with these specific conditions also share much in common with the support, care and community participation needs of all others with neurodevelopmental problems regardless of whether or not a specific diagnosis can be made. For example, there is evidence that the provision of an evidence-based parent education and skills training programme will promote continuing improvements in child adjustment and reduce parental stress for children with any form of developmental delay and neurodevelopmental disorder including an ASD^{9,10}. Therefore, although we fully support and endorse an enquiry into the special needs of people with an ASD and the need to develop informed targeted and evidence based programmes, it must be acknowledged that this should not be at the expense of and exclude all other members of our community who have neurodevelopmental disorders, disabilities and handicap. Equity needs to be a primary consideration in service delivery which should be needs based and which we understand is to be a central feature of the national disability insurance scheme.

References.

1. Williams, Katrina, et al. (2008). "The prevalence of autism in Australia. Can it be established from existing data? " *Journal of paediatrics and child health* 44.9: 504-510.
2. Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological medicine*, 45(03), 601-613.
3. Einfeld, S. L., Piccinin, A. M., Mackinnon, A., Hofer, S. M., Taffe, J., Gray, K. M., Bontempo, D. E., Hoffman, L. R., Parmenter, T., & Tonge, B. J. (2006). Psychopathology in young people with intellectual disability. *The Journal of the American Medical Association*, 296(16), 1981-1989.
4. Tonge, B. J., & Einfeld, S. L. (2003). Psychopathology and intellectual disability: The Australian child to adult longitudinal study. *International review of research in mental retardation*, 26, 61-91.
5. Tonge, B., Brereton, A. & Bull, K. (2008). *Life Transition Problems: Young People with Autism Spectrum Disorders*. Project Funded by Victorian Government Department of Human Services.
6. Mohr, C., Tonge, B. J., & Einfeld, S. L. (2005). The development of a new measure for the assessment of psychopathology in adults with intellectual disability. *Journal of Intellectual Disability Research*, 49(7), 469-480.
7. Doran, C.M., Einfeld, S.L., Madden, R.H., Otim, M., Horstead, S.K., Ellis, L.A., Emerson, E. (2012). How much does intellectual disability really cost? First Estimates for Australia. *Journal of Intellectual and Developmental Disability*, 37, 1-29.
8. Einfeld, S.L., Ellis, L.A., Doran, C.M., Emerson, E., Horstead, S.K., Madden, R., Tonge, B.J. (2010). Behaviour problems increase costs of care of children with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, 3, 202-209.
9. Tonge, B.J., Bull, K.J., Brereton, A.V., Wilson, R.P. (2014) Review of evidence-based early intervention for behavioural problems in children with autism spectrum disorder: the core components of effective programs, child-focused interventions and comprehensive treatment. *Current Opinion in Psychiatry [P]*, 27: 2, 158-165.
10. Tonge, B. J., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. J. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: A randomised controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*. 45(5), 561-569.

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File2:

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