

Victorian Parliamentary enquiry into Services for people with Autism Spectrum Disorder (ASD)

Getting an exact figure of the prevalence of autism is tricky, however it is clear that diagnoses of ASD are on the rise in Australia, including Victoria. In 2007 Autism Victoria found that the prevalence of ASD is 1 in 160 Children and that this figure has been rising since the early the early 1990's. In 2012 A4 estimated that 1 in 63 Australian School children reported as having ASD and in 2015 according to Australian Government carers allowance data the figure is 1 in 49 children have ASD.

The data above shows the significance of ASD in society. However, the intervention to date has focussed on children 7 and under, particularly those who have an IQ under 70.

For a child under 7 with a low IQ the following services are available through the Commonwealth, State and local Governments.

- \$12000 FACSIA funding
- Special schools
- Free therapy at the special schools
- If in mainstream schooling, subsidised or completely funded therapy;
- Access to integration aides
- Additional funding and support for a variety of aides and therapies including respite.

If, however the child with ASD has an IQ over 70, there is not the same degree of government support. A child with ASD over 7 with a 70+ IQ has very limited Government assistance including:

- 10 subsidised consultations with a psychologist through a Medicare mental health plan; and
- A combined total of 5 subsidised allied health consultations per annum.

This is grossly inadequate. While a person with an IQ of over 70 does not have the same intellectual learning problems than A sub 70 IQ if they have ASD, they still have the same therapy needs. Also children aged over seven still have ASD and still require therapy. Age and IQ should not be the sole determinants as to whether a child is entitled to government funded therapy and support.

As a result of the lack of support for children with ASD who are over 7 with an IQ above 70 we see the following:

- Falling behind at school and potentially having to drop out of mainstream schooling
- Not having appropriate skills to be able to engage in society
- Increased mental health issues
- Increased unemployment and requirements for care and support in adulthood.

As a result of the lack of Government support ASD for this group can be more "disabling" than it needs to be. With additional therapies, those with ASD over 7 with a 70 + IQ will reach their full potential at school and hold and maintain a job. This will also assist in being able to engage in society for example having meaningful relationships with others, raising a family etc. etc. Without this support, this group is left behind. They may become isolated from society, become unable to interact with others, may not be able to hold a job or even care for themselves properly.

Aside from the detriment this has to both the individual and to society, there is also the economic cost both to Government through increased welfare and care costs etc.; and society due to an increased number of people who are not able to contribute to the economy.

Availability of services

If diagnosed under age 7 there is good initial funding for therapy at least while the FaCSIA funding lasts. Note however while it is \$12,000 in reality this buys between \$8000- \$10,000 worth of therapy because of the additional administration fees that the service providers charge to use the FaCSIA funding. There is also a cap on how much of the funding money can be spent per financial year, and how much can be spent on therapy vs therapeutic aids. This funding is only available once you have the ASD diagnosis. To obtain a diagnosis privately it can cost up to and even exceed \$2,000 because it can take up to 12 months to get a diagnosis with many visits to psychologists/ occupation therapists and speech therapists, as well as the costs of the various assessments and reports needed.

Note to get a diagnosis through the public system can take up to 2 years before the initial appointment.

Education support.

The support available through the Education department is very limited. If an ASD student manages to qualify for an integration aide, that aide is often shared with other students. The criteria required to be met to be eligible for an aide mean that a large number of students with ASD miss out on the support they require in the classroom and the playground. Also, the eligible hours that a student is deemed to need if they do manage to qualify for an aide are often not enough to make a real difference. The lack of support and the unsuitable nature of the classroom sees many students with ASD forced out of the public education system and into either private, independent, alternative or home-school options, where there is generally more support available and the ability for the school to provide a more appropriate classroom environment.

The increased cost to the family of these alternative education options means in many cases families have to make substantial sacrifices, higher mortgages, or forgoing home ownership in order to pay for the ASD child's education and therapy. Due to the additional cost not all of these alternative education options are universally available and accessible.

Employment

The support available to adults with ASD is almost non-existent, therefore support with employment is also negligible. ASD does not disappear in adulthood. While there is reasonable adjustment available for people with disabilities, this is very difficult in an ASD context. What is required for adults with ASD to maintain employment is recognition that people with ASD process information differently, are more literal, may take more time to perform tasks etc. The solution is a balance between the employer recognising that the ASD person is different and will have different competencies; and the employee having appropriate qualifications/skills to perform jobs where the autistic traits are minimised and do not interfere with the job.

Participation within society

Having an ASD makes interacting within society a lot more difficult. The difficulties with social communication – including receptive and expressive language skills – as well as processing times, and other comorbid disabilities, all stand in the way of a person with ASD participating in society in the usual way.

Navigating team sports is a struggle, and there is limited support for those who do struggle but want to be involved. It relies upon finding a sympathetic coach who understands the limits of ASD and is willing to work around those to help the person succeed.

Public transport is a minefield with cancellations, delays and things such as break downs or track work requiring the change from train to bus. A typical problem for someone with ASD is the struggle with rigidity and change of routine - a train being cancelled has the ability to cause an anxiety attack. This then interferes with what the person can or cannot do for the day.

Common events such as visiting the show, attending a theatre performance, going to see Santa or even just heading out to the shops can cause meltdowns and anxiety for both children and adults, due to the extreme sensory input experienced at these events. While there are a growing number of "sensory friendly" events within Melbourne, the outer regions of Victoria do not experience the same number of these.

I am happy to discuss any of the above issues with the Committee.

Angus Mackellar