



21st April 2016

Gateways Support Services Submission to the Inquiry by the Victorian Family and Community Committee into Autism Services.

Gateways Background Information

Gateways Support Services provides a range of services for children and adults with autism in the Barwon area in the NDIS trial site, including autism assessment, early intervention, therapy, in home support and community participation (incorporating respite for families), social recreation groups for children with and without intellectual disabilities, and adults with autism and intellectual disabilities, support coordination, individualised day activities, shared supported accommodation, individualised accommodation, and out of home care for children with autism and complex needs.

Gateways' government funding for autism assessment has been significantly reduced with the transfer of Barwon disability funding to the NDIS, so Gateways current autism assessment service is run using a small amount of Victorian mental health funding, supplemented by community donations and philanthropic grants.

Gateways currently provides some autism assessment services for young children in the Western District, as well as facility-based respite, flexible packages, and one supported accommodation service for adults with autism and very complex support needs.

Gateways also provides a state-funded early intervention service for young children and their families in the Brimbank / Melton area.

Previous Statewide Autism Consultations

A major statewide consultation was completed prior to the development of the autism state plan in 2009. We believe that information from that extensive consultation will still be of relevance to the current inquiry.

Recent Publications

We also note the publication of the "Autism Spectrum disorder: evidence based/ evidence informed good practice supports provided to preschool children, their families and carers" by Jacqueline Roberts et al 2016.

This report recommends 20 hours per week of early intervention with a staffing ratio of 1:1 to 1:3.

It is not clear at this stage how this will be reflected in NDIS packages which generally do not currently fund such intensive interventions.

Prevalence

A recent Australian study has been published in 2016 on prevalence - "Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample" - Melinda Randall, Emma Sciberras, Amanda Brignell, Elfriede Ihsen, Daryl Efron, and Cheryl Dissanayake and Katrina Williams.

It found that the prevalence of autism spectrum disorder was 2.5% (95% confidence interval = [2.0, 3.0]) in the B cohort compared to 1.5% (95% confidence interval = [1.2, 2.0]) in the K cohort. In both cohorts, children with autism spectrum disorder had poorer mean quality of life, emotional-behavioural functioning and receptive vocabulary compared with non-autism spectrum disorder peers, and a higher proportion of children with autism spectrum disorder had problems in these areas. However, between 6% and 9% of children with moderate to severe autism spectrum disorder and 12–20% with mild autism spectrum disorder were not reported to have problems with social interaction.

Reliable Information

There is an enormous range of information now available on the internet, but there is a need for reliable sources of evidence based information which is also 'user friendly'.

Autism Assessment

Difficulties in obtaining an autism assessment continue with substantial waiting lists for public services and significant gap payments for private assessments. Because the NDIS relies on functional assessment rather than a diagnosis, it is still possible to access the scheme without a diagnosis, but the autism assessment process is very important in helping families to understand their child and recommending appropriate early intervention services.

An Autism Assessment completed by a team with input from a paediatrician, speech pathologist and psychologist is seen as a best practice model for such an important diagnosis.

Information gathered and reported in the assessment report is also often very valuable in informing the NDIS eligibility assessment process as well as the NDIS planning process. Even though the NDIS can fund supports to a child without an Autism Diagnosis, there have been examples where families have reported that they have been informed by the NDIS that they cannot be considered for eligibility for the scheme until they have an Autism Diagnosis. In

speaking with NDIA staff, it appears that this is more about the developmental information provided in the report which supports the allocation of funds, as opposed to the diagnosis itself.

Education Options

Kindergarten

In Victoria, Kindergarten Inclusion Support (KIS) packages can fund the following supports:

- An additional assistant who supports flexible inclusion into the entire group of children. (Group size could be 11, 22 or 33 depending on the capacity of the room.)
- A specialist consultant who can provide programming support, training recommendations and other supports directly to the teacher.
- Funding for staff to attend training that is specific to the developmental needs of the child.
- Minor building modifications.

Larger group sizes can present sensory overload for some children with autism and complex needs. The rotating group model can also cause issues for a child with autism who may cope best with a set structure and routine.

School Education

Gateways believes that all children with autism have the right to an education. Many people with autism have great potential to contribute to our society with the right supports around them. There does not appear to be a consistent policy around schooling for children with autism in Victoria at present.

Up until now, a significant number of children with high functioning autism have not received any additional funding to meet their specialist educational and social needs within mainstream school settings.

Gateways therefore welcomes the very recent announcement by the Victorian government that the Government has set a new agenda for inclusive education for all students with disabilities and additional needs, with additional funding that includes:

- \$17 million to better support students with learning difficulties including dyslexia and autism who are not eligible for the PSD program
- \$3 million to provide transitional support in 2017 and 2018 for those who received the PSD in primary school but are no longer eligible when transitioning to Year 7

Gateways recognises the importance of 'Autism Friendly' school environments including:

- a physical environment which minimises sensory overload
- a whole school culture which respects and values all students and deals effectively with bullying, and promotes team work with families and other relevant services
- structured learning opportunities and lunchtime recreation activities
- positive behaviour support approaches
- access to autism training and secondary consultancy for teachers

In Victoria we don't currently have options like autism units within mainstream schools which may suit some students with autism.

At present, it is difficult to access NDIS funded therapy in school environments because of the separation of what is NDIS funded and what are defined as state education responsibilities.

Special School Options.

There are a number of autism schools in Melbourne but none in regional Victoria. These schools attract higher funding levels than other special schools.

Restricted Attendance and Non-attendance.

Gateways knows of some children who have restricted access, or who are excluded from school, because of their behavioural needs, while other children refuse to go to school. Reliable state-wide data is needed to form a baseline to quantify the scope of this issue and to measure improvements in educational engagement, wellbeing and learning outcomes.

Training and Support Services

There is a need for affordable ongoing training for universal service staff, disability staff and community service staff in relation to autism.

There have been a number of time limited initiatives such as the **ASD case consultant program** within DHHS funded services, and **autism coaches** within Department of Education and Training (DET) Services. There is a continuing need for these types of training opportunities, but it is not clear how this would be funded in an ongoing way in the NDIS environment.

Gateways is currently providing an introductory '**Understanding Autism**' one day training program for DHHS staff in metro and regional Victoria, to provide this kind of basic training for all those who come in contact with people with autism. There is also an increasing range of 'on line' training programs being developed, but these are less interactive.

There is also a need for access to skilled specialist 'positive behaviour support' consultancy for families and service providers which is practical and timely. There are some services

available in the NDIS environment, but to date there have been delays in obtaining reports which outline recommendations.

Parent to Parent Support

The literature reports that families who have a child with autism often experience greater stress than other families with a child with a disability. Parent to parent networks are very valuable, and cost effective programs such as the Strengthening Parent Program (funded by DET) play a valuable role in this area, and we therefore request that it be expanded. Effective 'easily accessible' autism helpline services are also valuable.

Understanding Autism in the NDIS Environment.

In the Barwon area, people with autism have made up 22% of NDIS participants to date. The NDIS insurance approach favour supports which reduce over time, whereas some people with autism and complex needs and their families need ongoing support. We hope that there will be an ever increasing understanding of people with autism as the NDIS policy framework is further developed.

Therapy and Early Intervention Supports

Initially, the NDIS has provided increased therapy support for school aged children and waiting lists for early intervention were eliminated. However, now that we are close to bilateral targets being met for the NDIS, we have observed that there are currently waiting times for new participants to access NDIS funded services in the Barwon area.

Social Participation Opportunities.

In our experience, the NDIS has had a positive impact on encouraging and funding social activity and community participation options for people with autism.

Supported Accommodation for People with Autism and Complex Behavioural Needs.

Accommodation and support options for people with autism and complex needs is an area of high need. The NDIS has recently released a draft housing strategy which will hopefully stimulate significant growth in housing options.

The design of the environment and building fabric is important to promote safety, and to enable people to choose when to spend time on their own and when they want to engage with others.

Well trained and positive staff are also required as well as sound quality and safeguards systems.

Quality and Safeguards

In the NDIS trial period, unregistered providers do not have the same quality and reporting requirements as registered providers. NDIS full scheme design requires a robust quality and safeguards scheme to provide protections for all vulnerable consumers, and there needs to be recognition of the costs associated with quality service delivery.

Employment

Promoting access to employment is of great benefit to the person with autism and to the broader community. We hope that the NDIS will promote significant new opportunities in this area.

Signed

A solid black rectangular box used to redact the signature of Rosemary Malone.

Rosemary Malone

CEO

Gateways Support Services