

13 August 2020

Our ref: HD-VK/KS

***Confidential***

Committee Secretary  
Select Committee on Autism  
Department of the Senate  
PO Box 6100  
Parliament House  
Canberra ACT 2600

By email: [REDACTED]

Dear Committee Secretariat

**Inquiry into services, support and life outcomes for autistic people in Australia and need for a National Autism Strategy**

Thank you for the opportunity to provide feedback on the current approaches and barriers associated with services, support and life outcomes for autistic people, and the need for a National Autism Strategy (the **Inquiry**). The Queensland Law Society (**QLS**) appreciates being consulted on this important issue and the related legal, social, and health frameworks.

QLS is the peak professional body for the State's legal practitioners. We represent and promote over 13,000 legal professionals, increase community understanding of the law, help protect the rights of individuals and advise the community about the many benefits solicitors can provide. QLS also assists the public by advising government on improvements to laws affecting Queenslanders and working to improve their access to the law.

QLS is committed to promoting the principles and practices of diversity and inclusion in the Queensland Legal Profession and in the community more broadly. We support this important inquiry and particularly, the steps being taken towards understanding and working to improve early and ongoing access to support, funding for research and to reducing barriers for people with Autism.

This response has been compiled with the assistance of the QLS Health & Disability Law Committee, members of the QLS Diverse Abilities Network and with the assistance of our members who have lived experience in this area.

QLS has reviewed the terms of references and provides the following comments for the consideration of the Select Committee.

## **Inquiry into services, support and life outcomes for autistic people in Australia and need for a National Autism Strategy**

### **a. Current approaches to barriers to consistent, timely and best practice Autism diagnosis**

Our members report significant deficiencies in the areas of resourcing for support services and funding for research of Autism Spectrum Disorder (**ASD**). As a result, a research deficit in Australia requires clinicians, families and patients to rely on international studies to shape policies. Most studies on parental experiences of ASD diagnosis come from the United Kingdom, with some studies from the United States. Australia is vastly underrepresented in this field of research.

The release of guidelines by the Cooperative Research Centre of Living with Autism and the National Disability Insurance Agency provide guidance around shaping the process of diagnosing Autism in Australia<sup>1</sup> and are intended to bring uniformity and consistency to this process across the country.

The submission made to this inquiry by Reframing Autism strongly recommends that research is prioritised and funded to examine the requirements for positive, helpful and respectful diagnostic communication.<sup>2</sup>

In addition, the submission and recommendations made by the Autism Advisory and Support Service, include:

- Best practice should be a multi-disciplinary approach with a paediatrician, psychologist, and Occupational or Speech Therapist
- An assessment for any comorbid issues should occur at the same time to save time/money and prevent disjointed treatment of the child's needs
- Diagnostic funding should be available across the lifespan and not solely early intervention age groups.<sup>3</sup>

The recommendations from these key stakeholders supports the feedback from QLS members regarding the significant resourcing and research deficit, which negatively impacts access to healthcare, appropriate programs, equal education, employment, housing and social opportunities for people with ASD.

QLS strongly supports the implementation of these recommendations. Very importantly the implementation process must ensure that equal access to services is provided to persons and families who are located in regional and remote areas.

### **b. Prevalence of Autism in Australia**

QLS notes the submission of The Royal Australasian College of Physicians (**RACP**) refers to estimates of the prevalence of ASD in Australia stating that *'In 2018 Australia's largest ASD-specific service provider, Autism Spectrum Australia (Aspect) estimated that 1 in 70 people in Australia have ASD'*.<sup>4</sup>

QLS understands from other submitters to this inquiry that there is difficulty accessing reliable data as to the prevalence of ASD in Australia<sup>5</sup>. National databases, such as Centrelink and

<sup>1</sup> <https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline>

<sup>2</sup> [Reframing Autism](#)

<sup>3</sup> [Autism Advisory and Support Service](#)

<sup>4</sup> RACP Submission to the Senate Select Committee on Autism, May 2020 at page 5.

<sup>5</sup> AMA Submission to Select Committee on Autism, 7 July 2020, page 1.



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NDIS should be improved to enable the collation of statistics – in consultation with key consumer and healthcare stakeholders and with appropriate privacy protections built in.

Where there are difficulties determining prevalence due to constraints related to access to clinicians and diagnostic assessment<sup>6</sup>, it is critical that adequate funding is provided to enable diagnostic processes to be increased, and in doing so establish equitable access and support for children and adults with ASD.

Privacy issues do not warrant any constraints on the funded research for which QLS advocates. Researchers in the disability and health sectors have access to well-documented protocols for pseudonymisation and anonymisation of individuals' sensitive information for privacy protection.

### **c. Misdiagnosis and under representation of females in Autism data, and gender bias in Autism assessment and support services**

Significant research is urgently required to improve clinical knowledge of the presentation of ASD in females.

This must lead to the development of both a set of comprehensive and consistent guidelines for diagnosis of girls, and specialised training for professionals in differentiating ASD presentation between the sexes.

QLS is concerned that current clinical knowledge and under-diagnosis has culminated in significant discrimination of non-male persons with ASD. Diagnosis on the basis of perceived gender prevalence has led to delayed access to treatment and exclusion from early intervention programs.

The NDIA report provided to the COAG Disability Reform Council in March 2020 (the **NDIA report**) lists the percentage of male participants with plans based around autism to be 23% and females at 7%.

Further, leading autism expert and clinical psychologist Professor Tony Attwood states:

*"Recently, a fascinating research study conducted in Scotland (Rutherford et al, 2016) showed prevalence rates across the genders at 5.5 boys for every 1 girl for very young children, 3.5:1 for children and adolescents overall, 2.3:1 for adolescents only, and 1.8:1 in adulthood. These findings indicate not only that the true prevalence of ASD in women is far higher than once thought, but also underlines that females are being diagnosed much later."*<sup>7</sup>

QLS supports recommendations from other submitters that differentiation in criteria from the male experience at every life stage is required to build a comprehensive understanding of ASD prevalence in the community. We also support recommendations to ensure that gender discrimination does not impact upon a person's possible diagnosis and access to treatment.

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<sup>6</sup> See for example recommendation 1 of the Australian Medical Association, AMA Submission to Select Committee on Autism, 7 July 2020.

<sup>7</sup> <https://attwoodandgarnettevents.com/>



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### **d. International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity**

More effective integration and recognition of international research and practical experience of service providers would assist clinicians and families in Australia. QLS recommends that government consult with key stakeholders to assist in establishing these connections and fostering current Australian research. Alongside this, QLS recommends providing funding which will allow Australian service providers to build international best practices in training, diagnosis, education and support services available in Australia.

We note for example the work being undertaken in Australia by Associate Professor Amanda Webster whose research "is focused on creating inclusive learning communities to support the achievement and self-determination of individuals on the autism spectrum".<sup>8</sup>

This transfer of information and integration must include mechanisms to provide Australian families with accurate information about the evidence-base for – and against – analysis and intervention models, such as Applied Behaviour Analysis (**ABA**) and Early Intensive Behavioural Interventions (**EIBIs**). Information provided must be accessible and appropriately detailed to enable Australians with ASD and their families to make informed decisions about their healthcare choices, in keeping with common law principals of autonomy and self-determination. In relation to ABI and EIBIs, this should include any reasonable knowledge related to long term psychological harms or other adverse impacts which are associated with these treatments.

QLS is advised that international models which provide a comprehensive healthcare framework for diagnosis, support services and education may provide improved outcomes for individuals with a diagnosis of autism. This approach may include:

- training community nurses to identify Autism traits in males and females, so that they may flag any concerns;
- diagnosis by a multidisciplinary team consisting of paediatrician and/or psychologist and allied health professionals; and
- Diagnosis of ASD to be free, with consideration to be given to the provision of free testing to be expanded to include screening for common ASD comorbidities across the lifetime of the participant to capture any ongoing concerns that may arise.

### **e. The demand for and adequacy of Commonwealth, State and local government services to meet the needs of autistic people at all life stages**

Significant increases in funding, training and resources is required to improve outcomes of people with ASD in relation to health, education, employment, justice and housing. QLS recommends that a program of consultation with key stakeholders is undertaken for each of these sectors, to ensure that resources provided to improve each of these outcomes is appropriately targeted and funded.

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<sup>8</sup> [https://scholars.uow.edu.au/display/amanda\\_webster](https://scholars.uow.edu.au/display/amanda_webster)



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A national strategy with intersecting funding to State and local government services must be developed to ensure that these services are accessible and, where necessary, tailored to meet the needs of particular communities, including Aboriginal and Torres Strait Islander peoples, persons with disability, and persons located in regional or remote locations.

Consideration should also be given to ensuring that evidence-based tests such as the Wechsler Preschool and Primary Scale of Intelligence, ("**WPPSI test**") is able to be accessed (where needed) by children. This should include those with a confirmed diagnosis of ASD and those children not yet diagnosed but who demonstrate behaviours which may be suggestive of ASD. This will ensure that families and schools are equipped with the comprehensive information they need to ensure that individual children's abilities and additional support needs are well understood. This will require all schools to receive adequate funding required to facilitate comprehensive cognitive testing (such as the WPPSI test) of individual students, allowing the student, parents/caregivers and the school to form an understanding of a child's baseline cognitive functioning and facilitate teaching strategies to deliver optimal learning outcomes for these students.

Section 36 of the Queensland *Human Rights Act 2019* provides that:

- (1) Every child has the right to have access to primary and secondary education appropriate to the child's needs.*
- (2) Every person has the right to have access, based on the person's abilities, to further vocational education and training that is equally accessible to all.*

Consideration should also be given to the particular barriers experienced by children and adults with ASD in regional and remote areas and how diagnostic tests and supports can best be delivered where practitioner resourcing 'on the ground' may be more limited.

f. The interaction between services provided by the Commonwealth, state and local governments including:

- i) health and mental health;
- ii) education
- iii) employment
- iv) justice; and
- v) housing

We refer to our response to item (e) above, and reiterate that services provided in relation to the identified sectors must be adequately resourced. However, it is important to recognise that issues impacting persons with ASD will rarely fall into just one of the categories set out above – in most circumstances, a shortfall in services in one sector will have a negative impact for a person in relation to another sector. For example, a person with ASD who regularly experiences discrimination in the recruitment process and is therefore unable to find stable employment may also struggle to obtain affordable housing. A person who is homeless is more likely to come into contact with the justice system – and so on. Accordingly, effective provision of services, with positive outcomes for people with ASD, depends on a strategic interaction between all levels of government.

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It is therefore critical that Commonwealth, state and local government services intersect, and that there is a shared approach to and responsibility for overall outcomes and objectives to be adopted.

Significant improvements in education services and training are needed to positively impact on the overall health, social and economic prospects for children with ASD.

This includes:

- improved strategies for schools and parents to accommodate students with diverse needs;
- increased training and resourcing of special needs teachers – including availability and quality of tertiary courses;
- resources and funding to integrate children with ASD into schools, whilst ensuring that mainstream teachers and all students are properly supported in classes to achieve optimal learning outcomes. This should include increases to the numbers of special education, academic support, counselling and guidance staff for each school;
- assisting schools to develop policies of inclusion and diversity, including neurodiversity
- promotion and incentivising roles of Heads of Special Education Services and staff within schools and the community;
- implement a program teaching social skills within the national curriculum;
- removal of all restrictive practices and replace with evidence-based behaviour management strategies, behaviour-support plans, functional behaviour assessments and safeguards; and
- implement strategies to improve the relationship between the NDIS and the State school system. We note that parents sometimes are forced to apply for funding through the NDIS to fill gaps in education services. Professor Helen Dickinson has noted an increase in this practice to support remote learning for children with a disability during COVID-19 home-schooling periods.<sup>9</sup>

Improvements in relation to the other sectors outlined above would be supported by:

- Increases to advocacy services, including a robust complaints system to allow for timely investigations in relation to treatment of and impacts to persons with ASD;
- Development of a national autism agency/body that will manage and care for all issues related to having a diagnosis of ASD
- Increases at national, state and local levels, of support coordination for impacted families

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<sup>9</sup> <https://theconversation.com/only-one-fifth-of-school-students-with-disability-had-enough-support-during-the-remote-learning-period-143195>



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- Extension of the Helping Children With Autism program so that it may be an option to anyone with an autism diagnosis whilst waiting for NDIS support.
- Education and training for service providers who support adults with ASD
- Government funded campaigns for inclusion and community understanding should be developed in consultation with advocacy groups, including a program promoting the skills that individuals with ASD have to offer to business and the broader community.

### **g. The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people**

Data identified by the Australian Bureau of Statistics and referred to in the submission made to the Committee by Reframing Autism, states only 40.8% of persons identifying with ASD are employed. This is lower than persons with disability, and significantly lower than persons without disability. The data shows that over 31% of persons with autism are unemployed. This amounts to a substantial social and economic burden for these persons, and for the broader population.

Significant funding and expansion of services relating to equal education access for children with autism, as well as improved recruiting services and work training programs would improve employment figures for people with autism, and would result in improved social and economic outcomes.

More needs to be done generally to increase employment of people with ASD. We suggest that consideration may be needed into how artificial intelligence systems affects recruitment practices. For example, there is existing research into how conversational agents<sup>10</sup> may need to be adapted to effectively communicate with neurologically diverse applicants.<sup>11</sup> There are also questions around how *'emotion processing algorithms may misinterpret the facial expressions of someone with autism'*<sup>12</sup>

A fundamental tenet of privacy law is that a person's personal information should only be used in an open and transparent way. The use of a person's personal information in a context involving unfair algorithmic biases is contrary to this privacy principle and State and Federal anti-discrimination laws.

Employers should be provided with better skills and training to support their employees – including whole of staff worker diversity and training. Avenues of workplace complaint should be expanded to better manage relationships and treatment of employed persons with ASD. Whilst there are avenues for complaint under anti-discrimination laws, often by the time a complaint is made the working relationship has broken down to an irretrievable state. An early intervention workplace advocacy scheme, intended to address unfavourable treatment, including bullying and harassment, before the denigration of a relationship to a point at which

<sup>10</sup> "Conversational agents provide conversational experiences to end users for various practical applications, including customer service [69], education [13], and health support [22]": <http://www.sigaccess.org/newsletter/2019-10/quo.html>.

<sup>11</sup> Special Interest Group on Accessible Computing, October 2019 Newsletter, 'Toward Fairness in AI for People with Disabilities: A Research Roadmap', <http://www.sigaccess.org/newsletter/2019-10/quo.html>.

<sup>12</sup> <http://www.sigaccess.org/newsletter/2019-10/quo.html> at para 2.1.1.

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it cannot be salvaged would assist in better economic and social outcomes overall. Government guidelines and/or oversight may be useful to communicate the standard expected.

Additional consultation is urgently required to address shortfalls in obtaining housing for persons with ASD. As mentioned, this challenge is apparent for individuals who may encounter difficulty obtaining a job and subsequently also, affordable rental accommodation.

Housing is also a significant challenge for elderly persons with ASD, who may be seeking affordable independent living options in retirement villages, navigating the complex retirement villages system of entry, and finding a village with services and options to support the needs of a resident with autism.

### **k. Social inclusion and participation of autistic people with the economy and community**

It is apparent that significant improvement in understanding, education, and working practices is required to progress social inclusion and participation of people with ASD in community and business settings.

Government funded campaigns to promote social inclusion and participation must be underpinned by an understanding of the anxiety that is often a constant part of the lives of individuals with ASD<sup>13</sup>. Whilst there is a need to understand and respond to the breadth of barriers and issues experienced by people with ASD (which must be informed by people with lived experiences); governments can also assist in promoting acceptance of ASD by: adequately funding and publishing research to prevent misinformation in the community and providing families and persons with ASD with holistic approaches to support to facilitate equitable access to education, the workforce and community life.

If you have any queries regarding the contents of this letter, please do not hesitate to contact Senior Policy Solicitor Vanessa Krulin at [REDACTED] or Policy Solicitor Kerryn Sampson at [REDACTED], or by phone on [REDACTED]

Yours faithfully

[REDACTED]  
Luke Murphy  
**President**

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<sup>13</sup> QLS member feedback based on lived experience.