

**Feedback from the Australian Advisory Board for Autism Spectrum Disorders
and Autism Queensland on:**

**Australian Law Reform Commission
Equality, Capacity and Disability in Commonwealth Laws Issues
Paper: November 2013**

The National Disability Insurance Scheme 2013 Act

The National Disability Insurance Scheme 2013 Act under Section 34 Reasonable and Necessary Supports currently states:

The support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;

This statement has important implications as regards the issues identified on Page 50 of the Australian Law Reform Commission (ALRC) Issues paper, particularly in relation to:

- service provider regulation and registration processes;
- the need for appropriate safeguards and monitoring;

Feedback from the Australian Advisory Board for Autism Spectrum Disorders

- The NDIS rules provide very minimal standards in relation to service provider regulation and registration processes, and the need for appropriate safeguards and monitoring. At forums on the NDIS, the NDIS staff have said that the NDIA will not be concerned with the evidence-base of services that they fund, as *'families should be allowed to make their own mistakes'*. This is far from an "insurance approach" which is based on making informed assessment of the cost-benefit of any intervention in order to reduce the trajectory of disability, and its associated cost, to the Scheme over time (as envisaged by the Productivity Commission Report)
- One of the major barriers to a sustainable "insurance approach" is the expectation on planners to be knowledgeable of the evidence-base for early intervention in regard to **all** disability populations. In relation to this, an insurance approach is not simply about choice, it is about choice within the evidence that a particular intervention will work to reduce the trajectory of disability. From a planning perspective, early intervention and other services are quite different in scope. Early intervention aims to change the trajectory of disability (and associated long term cost) while other services aim to maximise the person's participation within the framework of their disability. Consequently, the skills and knowledge required of planners to plan early intervention, as opposed to other support services, are quite different especially taking into account that families of newly diagnosed

children are not themselves aware of the evidence-base for intervention approaches. Planners, therefore, need to be aware of what interventions work to reduce the trajectory of disability and what does not. There is a design flaw in the way planners are being used (i.e., lack of framework to operate within an insurance based approach). In other words, there is no differentiation in the operational requirements for planners of early intervention (including knowledge) compared with other support services. Unless this design flaw is remedied, it will potentially have a significant impact on the trajectory of disability for children with Autism Spectrum Disorder. In addition, it will fail to provide an insurance approach and, as such, the cost to the scheme long term will be significant.

- The NDIS needs to be aware of the very real risks involved in funding services that are unsupported by evidence. For example, in the case of children with Autism Spectrum Disorder (ASD), many services are marketed to families as offering to 'cure' autism. These services are often more attractive to vulnerable and desperate families than conventional early intervention programs that do not promise a cure. They are usually provided by private companies, who operate on a for-profit basis and in some cases charge exorbitant rates. Although their interventions may be supported by little or no evidence, they often entice families with 'pseudo-scientific' explanations of their capacity to treat the underlying 'cause' of autism, and an impressive collection of testimonials from satisfied customers. Examples of some that are potentially harmful include 'chelation' which is an intervention that involves using one or more chemicals or other substances to correct the chemical balance in the bodies of individuals with autism by removing toxic materials. There are cases of children with ASD who have died as a direct result of this intervention. Other interventions include a wide range of dietary supplements, dolphin therapy, camel's milk, prism lenses, and hyperbaric oxygen chambers. Given that one of the guiding principles of the NDIS is to ensure that people with disability are not subjected to abuse and exploitation, it is incumbent upon the agency to ensure that families of children with disabilities are not being encouraged to spend their limited NDIS funds on interventions that are known to be ineffective and therefore are a waste of taxpayers' money, especially where they are potentially harmful.
- In the 5 years that the *Helping Children with Autism Program* has been operating, the Australian Department of Social Services (formerly FaHCSIA) became aware that they were often funding interventions that are known to be ineffective. They responded by funding a review of the research to identify the most effective models of practice in early intervention for children with autism spectrum disorders (Prior, Roberts, Rodger & Williams, 2011) that included a list of interventions that are eligible and ineligible for funding. The NDIS should learn from the *Helping Children with Autism Program* experience, by continuing to use these guidelines developed by FaHCSIA, and developing similar guidelines in regard to interventions for children with other disabilities. The NDIS also needs to play a role in disseminating high quality evidence-informed information to families, so that they are in a better position to make informed choice.
- In relation to '*service provider regulation and registration processes*', there also needs to be some minimum standards in relation to appropriate mentoring and supervision of clinicians providing services to children and adults with disabilities, and access to professional development for clinicians. Without this, services that

do provide appropriate mentoring and supervision and professional development of clinicians will be disadvantaged in an open-market place system as they will not be able to compete with services that do not provide this support to their clinicians. Ultimately this will lead to reduced quality services for people with disabilities, particularly in highly specialised areas such as such services for people with ASD.

The Disability Discrimination Act 1992 –

Section 22 in relation to Education of the Disability Discrimination Act states that

(2) It is unlawful for an [educational authority](#) to [discriminate](#) against a student on the ground of the student's [disability](#):

(a) by denying the student access, or limiting the student's access, to any benefit provided by the [educational authority](#); or

(b) by expelling the student; or

(c) by subjecting the student to any other detriment.

Feedback from the Australian Advisory Board for Autism Spectrum Disorders

Students with ASD often present with challenging behaviours which are directly related to their condition (e.g., difficulty with behavioural flexibility and difficulty with socially appropriate behaviours). Schools frequently respond by:

- (a) Repeatedly suspending students with ASD (They have been found to be 20 times more likely to be suspended or excluded than typical adolescents) (Barnard et al., 2000)
- (b) Frequently calling parents to ask them to take the student home
- (c) Restricting the student's time at school (e.g., 1-2 hours/day or 1-2 days/week).

'Expelling the student' (Section 22 Disability Discrimination Act) could therefore be expanded to include *'substantially restricting the student's school attendance because of issues related to their disability'*.

Specific Legislative Areas: Employment Issues Paper (Page 53 of the ALRC)

In relation to affirmative action point as outlined on Page 53: *'whether positive duties with respect to the employment of people with disability, should be imposed, for example, through quotas or targets.'*

Feedback from the Australian Advisory Board for Autism Spectrum Disorders

- According to the Australian Bureau of Statistics (2009), the labour force participation rate for people with autism was 34%, as compared to 54% labour force participation rate for people with disabilities and 83% for people without disabilities. Recent Australian studies found that the level of unemployment among people with ASD who do not have an intellectual impairment (around 60% of those with ASD) have to be around 45-50% (Autism Spectrum Australia, 2012; Neary, 2012). As people with ASD are physically able and often intellectually able, it is reasonable to expect that they should be able to access employment, but they are often challenged by the social and communication requirements of employment, particularly during the interview process. As they sometimes require substantial support to find employment, employment agencies often don't prioritise clients with ASD. It has been demonstrated that consistent and stable ongoing on the job support greatly increases the participation rate of people with ASD, and thus employment providers need to be resourced accordingly.
- Because of the high levels of unemployment among people with ASD, the Australian Advisory Board for Autism Spectrum Disorders supports legislated affirmative action for people with disabilities through quotas or targets. As recommended by Disability Employment Australia, Report: *'Improving the employment participation of people with disability in Australia'* (February, 2013), the Australian Advisory Board for Autism Spectrum Disorders supports adoption of a long-term target for employment of people with disabilities in Australia, and mandatory reporting of the number of employees with a disability by employers. However, the unintended consequence of this strategy could be that employers recruit more able people and thus reducing further the incentive for employers to recruit people with complex barriers,

especially job seekers with ASD. Incentives and programs that would greatly enhance the prospects for job seekers with ASD could include:

- Additional incentives such as a loading for ASD similar to the Commonwealth Government “Moderate Intellectual Disability” loading;
 - Supporting and promoting specialist Autism employment providers;
 - Funding for specialist school to work transition programs, the success of which has been supported by international research;
 - Targeted funding packages to pilot different and innovative approaches to assisting jobseekers with ASD; and
 - Increasing the wage subsidy incentives for jobseekers with ASD.
- ASD needs to be recognised as a distinct disability type and not included in the broad category of “Neurological Disorders”. The prevalence of ASD has grown significantly over the last two decades with a significant impact on education and disability budgets. However, due to the lack of a distinct category for ASD in disability census-type instruments, there is very fragmented data available on which to project future needs and costs. John Walsh (NDIS Board Member and key author to the Productivity Commission Report into Disability Care and Support) has noted the lack of information available on individuals with ASD over the age of 22 years.

Jobseekers with ASD make excellent employees and the participation rate of people with ASD in the workforce, both nationally and internationally could be much greater than it is now with the right mix of knowledge, resourcing and support.

References:

- Autism Spectrum Australia (2012). *We belong: Investigating the experiences and needs of adults with Asperger's Disorder and high functioning autism*. Sydney, Australia, Author. Retrieved from http://autismspectrum.org.au/images/We_Belong_Report_amended_May_2012.pdf
- Barnard, J., Prior, A., & Potter, D. (2000). *Inclusion and autism: Is it working?* London: The National Autistic Society.
- Disability Employment Australia Report, February 2013: '*Improving the employment participation of people with disability in Australia*' Retrieved from <http://disabilityemployment.org.au/file/494af7ce8d9ced3f55a68416be25be5c43a25e6b/improving-the-employment-participation-of-people-with-disability-in-australia.pdf>
- Neary, P. (2012) *Parents'/ Carers' Perceptions of Post-School Circumstances and Service Requirements of Teenagers and Adults with High-Functioning Autism or Asperger's Syndrome*. Unpublished masters dissertation, Queensland University of Technology, Brisbane, Australia.
- Prior, M., Roberts, J. M. A., Rodger, S., Williams, K., & Sutherland, R. (2011). *A review of the research to identify the most effective models of practice in early intervention of children with Autism Spectrum Disorders*. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia.