National Organisation for Fetal Alcohol Syndrome and Related Disorders
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Submission to the Government regarding the National Disability Insurance Scheme

NOFASARD is Australia's peak body representing people living with Fetal Alcohol Spectrum Disorder (FASD), the caregivers and families who support them and other concerned individuals.

NOFASARD is fully supportive of a National Disability Insurance Scheme for Australians however we respectfully request that the following issues are taken into consideration when this scheme is finally established.

Further information about FASD can be found in the attached document.

Submission:

Page 2 of the Overview……"Around 360 000 people would receive scheme funding"……….

The prevalence of FASD internationally is estimated as one per cent of the population[1]. Australia's current population is 2.2 million and we might deduce an estimated 220,000 Australians whose lives are affected by fetal alcohol exposure with an additional 2,500 new affected individuals born each year.

FASD is non-discriminating however, individuals affected by FASD will be over-represented in the most marginalised, excluded, mis-understood and higher need population groups in our community. This group will experience a disproportionate level of poverty, involvement with the criminal justice system, homelessness, mental health (including risk of suicide and alcohol and other drugs dependency) when compared to the general population. Australia currently lacks its own prevalence data. FASD remains largely invisible and as a result, strategies to address FASD are limited in both public policy and practice.

Few people affected by fetal alcohol exposure have been correctly diagnosed and we submit that the current absence of diagnostic services does not negate the incidence of FASDs in Australia. Currently a team led by Professors Carol Bower and Elizabeth Elliott from the Telethon Institute of Child Health Welfare in Perth is developing the first Australian FASD Diagnostic and Screening Protocol, the consequences of which will result in an increase in identified individuals.

We submit our commentary and inquiries for your consideration:

- It is the experience of families supporting affected children, adolescents and adults that they are not approved for services essential to their needs because FASD is not a recognised disability even though the needs of people with FASD and their families are just as great as children diagnosed with Autism or Asperger's. Will this scheme address this discrepancy or will individuals diagnosed with an FASD remain excluded?

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[1] SOURCE – Phil May et al 2010

- If FASD is not to be included in the NDIS because it is not on the Australian Government list of Recognised Disabilities or because it has not been factored in, how will affected individuals be supported?

If FASD is to be included in the NDIS, it should be noted that the recorded cases of FASD in Australia are very low although it is generally acknowledged that under-ascertainment is likely, given poor data quality and the difficulties associated with determining an accurate diagnosis of the full spectrum.[i2] With the development of Australia's Diagnostic and Screening Protocol for FASD, the number of people to be supported by this scheme is likely to be much higher than previously calculated – will this scheme be expanded if necessary to include this group?

That the entry requirements into services available for people with disability are not based solely on IQ……….

For some individuals with FASD, relatively high IQ scores preclude funding and/or servicing opportunities. In addition, the inherent limitations of traditional IQ tests restrict their usefulness in directing effective strategies. In a study on the relationship between FASD and IQ undertaken by the University of Alaska in Anchorage, it was found that fewer than 35% of individuals (with FASD) would have qualified for special education given the criterion of an IQ under 71[3].

For people with FASD an IQ assessment will not identify the true nature and seriousness of the disability. Assessing executive or adaptive functioning by a neuro-psychologist who has undertaken comprehensive studies into FASD will reveal the true nature of disability in an individual with FASD.

Individuals with FASD have brain damage that has a profound a profound effect on their behaviour. Service providers who have not had training in FASD often assume that affected persons are choosing to misbehave or are not trying hard enough and their neurological dysfunction goes unrecognised and inappropriately supported. [4]

Many parents and carers who contact NOFASARD for support and information on this condition have identified the inclusion of IQ as a measurement as causing great distress and hardship. Organisations which provide services for people with disability for which eligibility is based on IQ, are not taking the multifaceted and complex nature of this disability into consideration.

That the experience and suggestions from parents of children, adolescents and adults with FASD are accepted and that input from parents and carers is required when developing service plans……….

The parents and carers of people with disability in general and people with FASD in particular understand inherently what works and what doesn't for their child. While there are a collection of signs and symptoms which combine to identify FASD, there are also idiosyncrasies which are only obvious when one is living with the affected person. In Canada and the United States, parental input is welcomed from the diagnostic process to the preparation of an individualised management plan[5].[6]
People with FASDs can have very good verbal and expressive language skills. It is these skills which confound service providers and others who have relatively short term intervention with the affected individual. It is these perceived skills which can belie the brain injury and make it difficult for people to believe there is a problem.

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[2] Elliott EJ, Payne JM, Morris A, Haan E, Bower CA. Fetal alcohol syndrome: A prospective national surveillance study. *Arch Dis Child* 2007

[3] FAS Evaluation *Relationship of IQ to Fetal Alcohol Spectrum Disorder (FAS Report Technical Report No. 23 YEAR)*

[4] ***FASD and the Brain*** 2000-2010 Teresa Kellerman www.fasstar.com accesed online 28/4/11 http://www.come-over.to/FAS/brochures/FASbrainBrochure.pdf

[5] *Creating a Foundation for FASD Diagnostic Capacity* Ontario May 2006 accessed online 28/11/11 http://www.fasd.ie/documents/fasd_stake_holders.pdf

[6] Elliott EJ, Payne JM, Morris A, Haan E, Bower CA. Fetal alcohol syndrome: A prospective national surveillance study. *Arch Dis Child* 2007 [Epub ahead of print].

[6] FAS Diagnostic & Prevention Network *FASD Diagnostic Training for Interdisciplinary Clinical Teams* accessed online 28/11/11 http://depts.washington.edu/fasdpn/htmls/team-train.htm

This is why it is necessary for parents and carers to be involved in their service plan.

The practice of allowing people with disability to take responsibility for their decisions……..

This principle cannot be so easily translated for individuals affected by FASDs. The presentation of apparent strengths in expressive language and the ability to be positive, agreeable and apparently capable can contribute to the misunderstanding by support services that taking responsibility would be the next step in empowering the individual towards independence. The invisibility of the brain injury that is FASD creates this dichotomy between actual and apparent ability. It renders affected individuals neurologically incapable of taking responsibility for their actions, or learning from 'tough love' or 'natural justice'.

Allowing someone affected by an FASD to make life decisions is likely to result in consequences that the individual, parents and service providers who support them are unable to meet. It assumes that the child, adolescent or adult has the ability to make wise choices if the consequences are severe enough. The person with FASD has impaired judgment and makes the same mistakes over and over, even when strict consequences are consistently applied. The child's ability to make a wise choice depends on how well his/her brain is functioning[7].

Convention on the Rights of People with Disability……..

Failure to address FASD contravenes the Convention on Rights of Persons with Disabilities Article 25 (b) that affirms that States Parties shall: "Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons"

Conclusion

For those people prenatally exposed to alcohol and their families, life is as difficult if not more so as those people with disabilities for which recognition is automatic and disability specific services readily available.

While supportive in general to the National Disability Insurance Scheme, NOFASARD's Executive Committee believes that by including FASD affected individuals and their families fully in the NDIS, a social injustice that has existed for decades would be partially restored.

Signed by

Anne Russell
Executive Officer for the
The Executive Committee of the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)

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[7] Adapted from Teresa Kellerman the 15 BEAMS Rules for FASD Behaviour Management (YEAR)