



roundsquared submission to

***Inquiry into Effective approaches to
prevention, diagnosis and support for
Fetal Alcohol Spectrum Disorder (FASD)***

***Noela McKinnon
Policy Consultant
roundsquared
PO Box 460
Moruya NSW 2537***

roundsquared.net.au

ABN. 75 100 256 264

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INTRODUCTION

roundsquared is an independent peer organisation providing a range of support services as well as support coordination and plan management to people with disabilities and their families/carers receiving support through the National Disability Insurance Scheme [NDIS] in locations across rural and regional NSW including the Illawarra, Shoalhaven, Eurobodalla, Bega and southern highlands, as well as in the northern rivers district and parts of Sydney (for more information see www.roundsquared.net.au)

roundsquared provides the following submission with particular reference to Term of Reference:

(k) access, availability and adequacy of FASD support available through the National Disability Insurance Scheme, including access to effective and early intervention services for individuals diagnosed with FASD.

WHAT IS FASD?

Fetal Alcohol Spectrum Disorder [FASD] is an ‘umbrella’ term used to encompass the diagnostic categories of Fetal Alcohol Syndrome [FAS], partial Fetal Alcohol Syndrome [PFAS], Alcohol-Related Neurodevelopmental Disorder [ARND] and Alcohol-Related Birth Defects [ARBD]([cited in Bower 2016](#)). Evidence of maternal use of alcohol during pregnancy is critical to a diagnosis as alcohol crossing the placenta can result in severe impairment in three or more of the 10 domains of neurodevelopment. The following domains are known to be affected by pre-natal alcohol exposure (PNE):

1. Brain Structure/Neurology
2. Motor skills
3. Cognition
4. Language
5. Academic Achievement
6. Memory
7. Attention
8. Executive Function, including impulse control and hyperactivity
9. Affect Regulation
10. Adaptive behaviour, Social Skills or Social Communication ([Bower et al 2016:5](#))

In addition to prenatal alcohol exposure and neurodevelopment impairment, facial and other physical features must also be present for a diagnosis of FASD. These facial features include short palpebral fissures, thin vermilion border and smooth philtrum with the diagnosis falling into of 2 sub-categories:

- i. FASD with three sentinel facial features
- ii. FASD with less than three sentinel facial features

FASD with three sentinel facial features replaces the diagnosis of Fetal Alcohol Syndrome [FAS], but without a requirement for growth impairment. FASD with less than three sentinel facial features encompasses the previous categories of Partial Fetal Alcohol Syndrome [PFAS] and Neurodevelopmental Disorder-Alcohol Exposed [NDAE]). (Bower 2016:4)

Despite the development of these diagnostic guidelines in 2016 through funding from Department of Health, there is inconsistent use of diagnostic criteria, diagnostic terminology, methods of documenting prenatal alcohol exposure and cut-off points to determine impairment in growth and neurodevelopment. In the *Foreword* to the **Australian Guide to the Diagnosis of FASD[2016]**, the difficulties of diagnosis are acknowledged:

In Australia FASD is under-recognised and often goes undiagnosed, such that it is described as a 'hidden harm.' Health professionals are often unaware of the diagnostic criteria, of how to diagnose FASD and where to refer for diagnosis or treatment. Many have not read the NHMRC national guidelines to reduce health risks from drinking alcohol and few routinely ask pregnant women about alcohol use in pregnancy. Some are concerned about stigmatising families through making a FASD diagnosis. Limited training opportunities for health professionals, the lack of a nationally adopted diagnostic instrument, confusion about diagnostic criteria and perceived lack of evidence-based treatments are persisting barriers to early diagnosis and appropriate management and prevention of FASD. [Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)].

GETTING A FASD DIAGNOSIS

FASD is under-recognised/under-diagnosed by medical professionals in Australia. According to an ABC report FASD is thought to affect up to 5% of the population. The **National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018 – 2028** estimates of prevalence based on State and Territory data to be in the vicinity of 0.01 to 0.68 per 1,000 births, but acknowledges that this is likely to be a significant underestimate 'and that as many as 2% of Australian babies may be born with some form of FASD' ([national-fasd-strategic-action-plan-2018-2028:10](#)). This Strategic action Plan also cited a report from WA that found that 'within the juvenile justice system that 36% of 10 -18 year olds in Banksia Hill Detention centre (WA) were diagnosed with FASD ([national-fasd-strategic-action-plan-2018-2028:10](#)). Whatever the incidence of FASD, many children and adults are missing out on NDIS funding because there are 'so few specialists who can diagnose and assess the impact of the disorder' with only 265 people with a primary disability of FASD having approved NDIS plans to June 2018. (<http://www.abc.net.au/news/2018-09-13/fetal-alcohol-spectrum-disorder-obstacles-to-ndis-funding/10218842>). This is despite the development of the **Australian Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Instrument** in the **Australian Guide to the Diagnosis of FASD**.

The process of obtaining a FASD diagnosis is lengthy and complicated requiring access to a specialist paediatrician and a skilled team of occupational therapists, psychologists and speech therapists to carry out in-depth assessments. (<http://www.abc.net.au/news/2018-09-13/fetal-alcohol-spectrum-disorder-obstacles-to-ndis-funding/10218842>). A small number of specialist FASD clinics is in operation in Australia that include a paediatrician, psychologist, speech and language pathologist and an occupational therapist. These clinics are few in number and for families in rural and regional areas access to such specialised services can be very difficult

with the current waiting periods in NSW being in excess of 8 months (interview with Jessica Hannan 14/11/2019). This is doubly difficult for families on low incomes and with limited education. What also needs to be considered is that the 'assessment process may be confronting for the individual, their caregiver and family' and that appropriate practical and psychological support needs to be in place to support the family. [[Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder \(FASD\)"\]\].](#)

The importance of early diagnosis and interventions to improved health and social outcomes for the child cannot be over-emphasised. Ensuring such early diagnosis requires comprehensive training of GPs and other health professionals as well as coordinated support through health, early childhood services, education and community services.

roundsquared strongly supports the following comments made in the **National FASD Strategic Action Plan 2018-2028**.

Access to screening and diagnostic services in rural and remote locations is often limited. This is a crucial issue as these geographical locations are frequently high-risk areas, and where it can be difficult to engage women in relation to health, particularly those in Indigenous communities.

- *Given workforce and service limitations, primary health care providers in remote locations can play a key role in the coordination of screening services.*
- *A key objective under the Plan is to consider how access to appropriate and evidence-based diagnosis and support services can be improved. Existing programs and screening tools (including those being used internationally) should be examined and combined with strategies to ensure appropriate communication and training is delivered to professionals engaged in these programs.*

RECOMMENDATION 1

roundsquared therefore strongly endorses the Objectives and Activities outlined under **SCREENING AND DIAGNOSIS** in the **National FASD Strategic Action Plan 2018-2028**.

Objective: Increase screening, diagnostic skills and knowledge in frontline professionals

Objective: Improve capacity for screening, diagnosis and surveillance.

To ensure rural and regional areas have better access to screening and diagnosis, **roundsquared** strongly supports the following activities:

- *Examine opportunities to improve access to appropriate and evidence-based diagnosis and support services through existing programs (such as the Medicare Benefits Schedule), and to ensure appropriate communication and training to professionals engaged in these programs.*
- *Work with primary health networks and other health service providers to enable practitioners to encourage discussion of alcohol consumption with all women of childbearing age, and build the capacity of practitioners to appropriately respond to women who identify alcohol use during pregnancy.*
- *Support the dissemination and use of tools and training for assessing child development in a range of health care settings to assist in identifying all forms of neuro-developmental impairment, and as an alert for potential further assessment to determine if FASD is present. Training must stress that one cause of neurodevelopmental impairment which needs to be considered is alcohol exposure during pregnancy.*

STIGMA & UNDER-DIAGNOSIS

The stigma associated with an admission of drinking alcohol during pregnancy can also contribute to an under-reporting by mothers of their drinking behaviour, complicating diagnosis. Assessment of prenatal alcohol exposure 'requires a non-judgemental approach'[*Bower C, Elliott EJ 2016:10*] using language that does not blame or stigmatise the mother. Alcohol consumption is broadly accepted as part of the social and cultural fabric in Australia with beer and other alcoholic drinks being major sponsors for sporting (football, horse racing) and other social events. The ***National FASD Strategic Action Plan*** refers to research that sees the following factors associated with drinking during pregnancy - drinking patterns prior to pregnancy; lack of awareness of alcohol consumption on fetal development; unplanned pregnancy; partner's drinking patterns; and exposure to domestic violence, substance use and high life stressors such as poverty and unemployment.

The National Organisation on Fetal Alcohol Syndrome (NOFAS) ran a campaign to **STAMP OUT STIGMA [2013]** associated with FASD through the use of non-stigmatising language to enhance opportunities for babies and children to be diagnosed and receive early intervention treatment services. Central to the campaign was the revision of 10 widely used FASD prevention messages that focussed blame on mothers eg '*FASDs are caused by a woman drinking alcohol during pregnancy*'. The alternative wording said: '*FASDs can occur in an individual who was exposed to alcohol before birth*'. (<http://www.nofas.org/stigma>)

roundsquared strongly supports the following comments made in the ***National FASD Strategic Action Plan 2018-2028***.

Community and public education should embed the message that everyone has responsibility for prevention of alcohol-exposed pregnancies, not just women themselves. All approaches to dealing with alcohol consumption during pregnancy must consider the range of socio-economic needs and pressures which affect women's behaviours. In particular, services for pregnant women who are alcohol dependent or have problematic alcohol use must be provided by trained specialists in a compassionate and sensitive manner. [National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018 – 2028]

RECOMMENDATION 2

roundsquared strongly supports the Objectives and Activities outlined under **PREVENTION - PRIORITY OBJECTIVES** in the ***National FASD Strategic Action Plan 2018-2028***.

Objective: Reduce access and consumption of alcohol in the Australian community

Objective: Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy

RECOMMENDATION 3

roundsquared supports the use of non-stigmatising language as suggested in the **NOFAS STAMP OUT STIGMA** campaign.

FASD – ACROSS THE LIFESPAN

The difficulty of diagnosis increases with age, as the facial anomalies become less distinctive with puberty, although behavioural and cognitive impairments may become more pronounced, with misdiagnosis of autism, ADHD or oppositional defiance disorder ‘without appreciation that brain damage is the underlying cause of these disorders’ (http://en.wikipedia.org/wiki/Fetal_alcohol_spectrum_disorder#Fetal_alcohol_syndrome).

Children with FASD experience neurological abnormalities ‘including a decrease in the overall brain volume with reduction in gray matter as well as disorganisation of the central nervous system’ (Mattson 2019:1050); poor coordination and deficits with fine motor skills; intellectual disability, speech and learning difficulties; and a range of challenging behaviours including impulsiveness, hyperactivity, attention deficits, anxiety and depression and difficulties with social relationships.

Adults with FASD are likely to ‘experience severe mental health issues at some point in their lives’ (MHCN 2017) with poor education and employment outcomes, low self-esteem, feelings of isolation, drug and alcohol issues, homelessness and incarceration as well as being at greater risk of sexual, physical, financial, social and emotional abuse (NOFASD 2013). According to Mental Health Carers NSW, ‘access to support under the NDIS would provide people with FASD the greater access to treatments and support, referral to both new and existing specialised services, more support groups and respite services for their families and carers’ (MCHN 2016).

Adolescents with undiagnosed FASD often have mental health and alcohol and substance use issues often resulting in difficulties with the law. The **FASD Strategic Action Plan 2018- 2028** notes that ‘the range of impairments associated with FASD can lead to significant secondary disabilities, including substance abuse and mental health problems, as well as reduced ability to live independently, difficulty obtaining a job and increased contact with the criminal justice system’ but that ‘there are a range of social, behavioural and pharmacological interventions which have been shown to benefit the lives of individuals with FASD and their families through helping to manage the secondary conditions those with FASD experience’ ([national-fasd-strategic-action-plan -2018-2028 :26](#)).

The FASD Strategic Action Plan emphasises the need for improved screening tools for high risk groups such as young people in detention and for the consideration of FASD in the diagnosis and management of people with mental health and developmental disorders. It also recommends better integration of supports across the lifespan from individualised education plans at school with input from multidisciplinary teams including speech therapists, OTs and psychologists.

RECOMMENDATION 4.

roundsquared strongly supports the Objectives and Activities outlined under **SUPPORT AND MANAGEMENT - PRIORITY OBJECTIVES** in the **National FASD Strategic Action Plan 2018-2028**.

Objective: Implement and evaluate better models of management, support and care

Objective: Support for parents, carers and families and in education and employment settings.

FASD AND THE NDIS

Access to the NDIS is dependent on the person meeting a range of requirements including age (must be under 65 years); residency requirements (an Australian citizen or permanent resident); and particular disability requirements as outlined in Section 24 of the NDIS Act 2013. These include:

- (a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and*
- (b) the impairment or impairments are, or are likely to be, permanent; and*
- (c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:
 - (i) communication;*
 - (ii) social interaction;*
 - (iii) learning;*
 - (iv) mobility;*
 - (v) self-care;*
 - (vi) self-management; and**
- (d) the impairment or impairments affect the person's capacity for social and economic participation; and*
- (e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime. [NDIS ACT 2013]*

Fetal Alcohol Syndrome (FAS) is recognised as a permanent and significant disability by the NDIS under **List D – Permanent Impairment/Early intervention under 7 years – no further assessment required**. FAS is at the more severe end of the FASD spectrum. It requires the presence of facial anomalies in addition to evidence of growth deficiency [height and weight], abnormal brain growth [small head circumference] and neuro-behavioural impairments [cognitive and behavioural] (Mattson 2019). Where facial anomalies are not present, and where there is no confirmation of pre-natal maternal alcohol use, a diagnosis of FASD can be extremely difficult.

Without a FASD diagnosis, evidence of permanent and significant disability or developmental delay resulting in functional impairment can be difficult to provide, resulting in FASD not being recorded as the primary disability with the NDIS. For children under 7 years without a FASD diagnosis, the NDIS may record the disability either as developmental delay, intellectual disability, or 'congenital conditions – causes where malformation cannot be corrected by surgery or other treatment and result in permanent impairment' (<http://www.ndcowa.net.au/fetal-alcohol-syndrome-and-the-ndis-2>). What needs to be remembered is that 'FASDs last a lifetime. There is no cure for FASDs, but research shows that early intervention treatment services can improve a child's development'. Diagnosis before the age of 6 year; a loving, nurturing, and stable home environment during the school years; the absence of violence and involvement in special education and social service can help reduce the effects of FASDs and help people with these conditions reach their full potential ([fasd_english-508](#)).

Under **SUPPORT AND MANAGEMENT Objective: Implement and evaluate better models of management, support and care** in the *National FASD Strategic Action Plan 2018-2028*, one of the *activities* listed was ‘examine applicability of existing programs (including the National Disability Insurance Scheme) for providing families and individuals with greater access to support services’. In our recent submission to ‘Improving the NDIS Experience’, *roundsquared* highlighted a number of issues impacting negatively on the NDIS experience – many of which are very pertinent to a person with FASD gaining access to the NDIS and to the development of a plan with funding sufficient to address the complexity of their needs. These include:

- The need for the development of an integrated service model to underpin the NDIS to ensure that Government Departments at both the Federal and State/Territory levels work collaboratively to break down the silos of responsibility that currently undermine service provision to optimise the participant’s opportunities to enhance their functional capacity
- The need for the recruitment and training of planners and local area coordinators with specific experience dealing with people with mental illness and psychosocial disability
- The need for greater recognition of the difficulties and additional costs faced by people in rural and regional areas in accessing services and supports
- The need for consistent information to be provided by NDIA planners and LACs to participants and their families as well as greater transparency around the decision making process
- The need for greater recognition of the caring role of families so that it aligns with the ‘recognise and respect’ terminology of the *Carers Recognition Act 2010*.

The NDIS pathway, from meeting access to the development a plan with funded supports, is often not smooth for participants and their families. The Early Childhood Early Intervention (ECEI) is based on the impact of a disability or developmental delay on the child’s ability to participate in activities or perform tasks or activities for their age. Evidence of the disability or developmental delay is required to determine eligibility with children being transitioned from the *Better Start Initiative* to the NDIS by 30 June 2020. Children aged over 7 years must have a permanent and significant disability to access support through the NDIS. Developmental delay is not considered to fit these criteria of permanent and significant.

Accessing supports though the NDIS may well be based on evidence of functional impairment, not simply the diagnosis of disability or disabling health condition. Where a child has been diagnosed with a developmental delay to access the NDIS through the ECEI provisions, a diagnosis of disability is required to continue getting support through the Scheme once they turn 7. For children under 7 with undiagnosed FASD, a determination of developmental delay or even intellectual disability may have provided early interventions including access to speech therapy, occupational therapy, physiotherapy and psychology, but may not have covered the scope and specificity of need for the child. The FASD Strategic Action Plan emphasises the imperative of an early diagnosis to ensuring appropriate early interventions. This is why it is important to have the FASD diagnosis as their primary disability with the NDIS to ensure supports and therapies are put in place to address the complexity of lifelong physical, intellectual, behavioural and emotional issues impacting on the young person. To ensure children with FASD do not fall through the gaps it is therefore vital that the capacity for screening and diagnosis be improved with the development of a FASD pre-screening tool

for use in a broad range of health services, including GPs, child and maternal welfare services and adolescent health services ([national-fasd-strategic-action-plan-2018-2028:23](#)). This is even more important once the child gets to the age of 7 and is at school where integrated services and supports need to be in place to ensure optimum learning outcomes for the child. In addition to better training of health professionals, NDIS planners and LACs also need to be provided with information and training about FASD to ensure that their approach to the participant and their family is non-judgemental and the complexity of the Spectrum is understood.

In *roundsquared's* recent submission on *Improving the NDIS Experience*, we drew attention to the comments made by planners about core supports no longer being provided for children under 15 years. Using a de-identified case study *roundsquared* reported that a mother of a young boy with complex physical, intellectual and psychological issues had been told at the beginning of the plan review that he would not be receiving core funds as supports previously provided through core supports were considered to be the parent's responsibility and not the government's. Shortly after receiving her son's new plan, the mother contacted the planner's supervisor about the comments and was told: 'You have become dependent on this funding. You had the child and he is your responsibility'. Such stigmatising comments could have very adverse consequences if said to the mother of a child with FASD.

FAS is recognised as a disability for adults under **the NDIS List B – Permanent conditions for which functional capacity are variable and further assessment of functional capacity is generally required**, under sub-section '*Congenital conditions – cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment but with variable severity*' ([ndis.gov.au](#)). FASD, however, is not specifically recognised with both the Australian Medical Association and Mental Health Carers NSW calling for its recognition to ensure that those requiring lifelong support receive it in the form of integrated multi-disciplinary support rather than piecemeal interventions based on particular aspects of the disorder such as depression, mood and anxiety disorders, ADHD and conduct disorders ([MHCN 2016:3](#)).

Meeting the access requirements for the NDIS based on a person's psychosocial disability is not a straight forward process. In *roundsquared's* recent submission to *Improving the NDIS Experience*, we argued that the episodic nature of mental health conditions and the concept of recovery were not only poorly understood by planners, but also that participant's experience of the current pathway was often a 'negative one, resulting in further trauma and distress' ([MHA 2018:8](#)). The Mental Health Association (MHA) goes on to explain that 'People with psychosocial disability often experience the inherent vulnerabilities which result from a personal history of mental health hospital admissions and potentially involuntary treatment, including seclusion and restraint. This can make it difficult to navigate an often fragmented mental health sector ... [where] ...mental health services are generally poorly resourced, operating in an environment where there are major gaps in service provision across the country and ongoing uncertainty about the provision of support both within and outside the NDIS.' ([MHA 2018:4](#)) The stress of the application process, stigma, high levels of anxiety and possible experiences with the justice and prison systems may well be some of the reasons why so few people with FASD have NDIS Plans. Reform of the NDIS psychosocial pathway would have implications for improved NDIS access for people with FASD.

roundsquared made the following recommendation on psychosocial disability in their *Improving the NDIS Experience* submission:

That Mental Health Australia's call to improve the access process for people with psychosocial disability by building specific competencies in mental health and psychosocial disability for planners and LACs; ensuring there is expert oversight of plans for people with psychosocial disability; and 'providing a greater level of information and support (including peer support) for people with psychosocial disability at the pre-planning stage' (MHA 2018:22) be supported.

roundsquared welcomes the announcement by the Council of Australian Governments (COAG) Disability Reform Council in their *Communique* 9 October 2019 that stated:

- The Council agreed to an approach to improve the access and experience for participants with psychosocial disability in the NDIS and to address interface issues between the NDIS and mainstream mental health systems. The Council's discussions underscored the importance of improving access to the NDIS for people with psychosocial disability through a range of strategies, and **the need for effective interaction between the NDIS and the clinical mental health system through a coordinated approach to care, information sharing and concurrent supports**, which are critical to optimising outcomes for people requiring both mental health treatment and psychosocial disability support. The Council welcomed **the establishment of a Psychosocial Disability Recovery Framework**, with a strong focus on recovery and supporting episodic needs, noting that this would be developed in consultation with states and territories.
- The Council agreed the National Disability Insurance Agency (NDIA) will introduce **Justice Liaison Officers (JLOs)** in each state and territory to work across their justice systems. The JLOs will provide a single point of contact for workers within each state and territory justice system, providing a coordinated approach to supporting NDIS participants in youth and adult justice systems. The Council also agreed that targeted resources and training will be developed and implemented to improve the coordination of supports for NDIS participants interacting with the justice system
- Council also agreed that targeted resources and training will be developed and implemented to improve the coordination of supports for NDIS participants interacting with the justice system. (https://dss.gov.au/documents/communique-drc-9-october_2019)

This was followed by the announcement on 10 October 2019, Minister for Families and Social Services, Paul Fletcher, and Assistant Minister for Disability Services, Sarah Henderson, jointly announced a new psychosocial disability stream. They stated that 'the new stream will be implemented progressively and includes:

- the employment of specialised planners and Local Area Coordinators;
- better linkages between mental health services and National Disability Insurance Agency (NDIA) staff, partners
- a focus on recovery-based planning and episodic needs
- better communication on the psychosocial pathway NDIS scheme
- face to face sessions.'

When implemented these changes should improve access for people with FASD experiencing mental health issues and those who have experienced an interface with the justice system. What needs to be ensured is that these reforms are fully and promptly rolled out.

RECOMMENDATION 5

That the new psychosocial disability stream be fast tracked to address the current inadequacies of the NDIS access and pathway processes to ensure that people with psychosocial disability, whether this is a stand-alone disability or part of a broader spectrum condition such as FASD, have access to support services and therapies to facilitate greater social and community inclusion and functional capacity consistent with their mental health recovery.

CONCLUSION

roundsquared has more than 250 members with a range of intellectual, physical, sensory and psychosocial disabilities, some with multiple conditions that limit their capacity across a range of areas including personal and domestic care, social support, employment, learning, communication and mobility. Although we have a number of members with a diagnosis of FASD *roundsquared* believes there are others who have not been diagnosed due to either the stigmatised attitudes to such disclosure in a small regional community; or the impediments to diagnosis and treatment. It is with this in mind that this submission has been made and in particular reference to some of the issues that *roundsquared* members have experienced in relation to gaining access to the NDIS and to securing the level support needed for them to achieve their goals and maximise their functional capacity.

roundsquared acknowledges that the issue of provisions of services and supports through the NDIS for individuals with FASD needs to be part of a much broader response that includes community education highlight the risks of alcohol consumption in during pregnancy and the need for better access to early diagnosis and interventions. *roundsquared* strongly supports the need for better community education about the risks associated with drinking alcohol during pregnancy and particularly in those early weeks before pregnancy is confirmed. Such education needs to be well targeted and culturally appropriate for different groups in the Australian community including Aboriginal and Torres Strait Islander communities; culturally and linguistically diverse groups and communities where social disadvantage (poverty, DV, unemployment, substance use) is endemic and access to health and other services is limited. Stigmatising the mother for drinking, when our society uses alcohol as the social lubricant for sport, entertainment and celebrations, is inappropriate and short sighted, and fails to recognise that it take 2 to make a baby and that the nurturing in utero is not only the responsibility of the mother and father but also the community.

roundsquared also supports the funding for improved access to diagnostic teams and for the development of a FASD pre-screening tool for use in a broad range of health services, including GPs, child and maternal welfare services and adolescent health services. With no cure for FASD, early diagnosis [before the age of 6] and intervention treatment services can help reduce the effects of FASDs and help people with these conditions reach their full potential. Particular attention needs to be paid to ensuring access to these diagnostic and early intervention services for individuals and families in rural and regional communities.

THE NDIS is ideally place to provide early interventions and on-going lifelong support to individuals with FASD. Improved access requirements, better integration of services and supports for individuals with FASD particularly in rural and regional areas and better training of NDIA planners and LACs to improve their understanding of the scope of impairment resulting from FASD would enhance the opportunities for individuals with FASD to reach their potential, reducing their interface with the criminal justice system and reducing their social isolation and stigmatisation.

REFERENCES

*Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: **Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)***

Corrigan P, B Shah, J Lara, K, Mitchell, P Combs-Way, D Simmes [2019] *Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder* **Addiction Research & Theory** 27:2 (<https://tandfonline.com/doi/abs/10.1080/16066359.1478413>)

Mattson S, G Bernes, L Doyle [June 2019] *Fetal Alcohol Spectrum Disorders: A Review of the Neurobehavioural Deficits Associated with Prenatal Alcohol Exposure* **Alcoholism: Clinical and Experimental Research** 41, 6

National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018-2028

MHCN [2016] Recognising Fetal Alcohol Spectrum Disorders as a Disability in Australia for Access to Support under the NDIS – Position Statement by Mental Health Carers NSW [MHCN] February 2017

https://en.wikipedia.org/wik/Fetal_alcohol_spectrum_disorder#Fetal_alcohol_syndrome

<https://www.nofas.org/stigma/>

<http://www.abc.net.au/news/2018-09-13/fetal-alcohol-spectrum-disorder-obstacles-to-ndis-funding/10218842>

<https://raisingchildren.net.au/guides/a-z-health-reference/fasd>

https://dss.gov.au>documents>communique-drc-9-october_2019

<http://www.ndcowa.net.au/fetal-alcohol-syndrome-and-the-ndis-2>