



Delivered by the
National Disability
Insurance Agency

National Disability Insurance Agency Submission Community Affairs References Committee

***Effective approaches to prevention, diagnosis and
support for Fetal Alcohol Spectrum Disorder***



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1. Summary

The National Disability Insurance Agency (NDIA) recognises Fetal Alcohol Spectrum Disorder (FASD) as a condition resulting in permanent impairment which may meet the Early Intervention or disability access requirements of the National Disability Insurance Scheme (NDIS).

FASD is multifaceted and requires a whole of government response to prevent critical gaps in service delivery. Since 2014, the Australian Government has invested over \$27m towards FASD prevention and awareness programs and diagnostic services.¹

Health, justice and law enforcement systems are responsible for identifying national priorities relating to alcohol and committing to harm minimisation strategies. The Commonwealth Department of Health's aim is to reduce the prevalence of FASD and the impact it has on individuals, families, carers and communities. The Department of Health's priorities for FASD focus on prevention through awareness activities, FASD screening and diagnosis (including to communities of high need), provision of supports, and services to high-risk women.

NDIA's aim is to provide much-needed supports to children and adults with FASD where the adult's functional impairment or child's functional impairment or developmental delay impacts on their daily functioning. These include supports to assist with their communication, mobility, self-care or self-management.

In order for people with FASD to receive streamlined supports, Commonwealth and jurisdiction services need to work collaboratively. The NDIA recognises the need to use linkages and opportunities to cooperate and partner responsibly with mainstream service systems, which brings clinical and non-clinical providers together. NDIA is working with the Department of Health to help realise several of its Strategic Action Plan objectives including 'implementing and evaluating better models of management, support and care'.

Due to associated learning and behavioural challenges, people with FASD will likely require supports and services from a variety of mainstream service systems outside of the NDIS, which may include:

- Health: clinical diagnosis, ongoing medical care.
- Education: specialist childcare supports in school, reasonable adjustments for learning and educational progression.
- Justice: For older children, supports to assist with impulsivity and behavioural challenges and court diversion programs for people with disability through justice system.
- Child Protection: children with FASD may come from complex backgrounds or family situations resulting in the need for out of home care arrangements.
 - In 2012, after a government *Inquiry into the prevention, diagnosis and management of FASD*, a report titled 'FASD: The Hidden Harm' was published by the Australian House of Representatives Standing Committee. The report supports the strong causal connection between FASD diagnosis and entering care arrangements.

The NDIS provides funding for long-term, individualised care and support that is reasonable and necessary to meet the needs of people with permanent disability, where a person's disability significantly affects their communication, mobility, self-care or self-management. The NDIS operates alongside other mainstream service systems such as health and education, to improve the lives of people with disability in line with the National Disability Strategy.

¹ Australian Government Department of Health (2019) Submission to the Senate Community Affairs References Committee: Inquiry into the effective approaches to prevention, diagnosis and support for FASD. Available at: www.apf.gov.au



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Consistent with many study findings internationally and in Australia, the NDIA recognises the NDIS must operate in an environment that has aspects and policy on the prevention and management of alcohol-related conditions spread through many layers of Government and portfolios.

The NDIA acknowledges the significant step forward in the development of National FASD Strategic Action Plan 2018 – 2028. However, the NDIA also recognises that there is no clear focus on coordinated, multi-sectoral efforts for a more comprehensive approach to the prevention and management of FASD.

Most studies into FASD have recognised the need for specific requirements on broad-based preventative awareness programs, training and support for parents and caregivers, inclusive education in mainstream schools and training of relevant professionals.

The NDIS is not the lead agency on FASD. The Agency is not designed to replace or mitigate existing mainstream service systems responsible for providing supports to people with FASD. This means where a FASD support is most appropriately funded by another system, the NDIS should not fund that support.

The NDIS also has a broader mandate to continue to support people with FASD who may not become an individually funded participant by providing community linking, information and capacity building support. The NDIA, Local Area Coordinators (LAC) and Early Childhood Early Intervention (ECEI) partners will continue to build relationships with mainstream service providers and the local community to improve their understanding about how they can assist people with FASD.

Summary of data

As at 31 May 2020, there are 907 participants in the NDIS who list FASD as their primary disability, and a further 453 who list FASD as a secondary disability. The data (see summary tables at **Attachment A**) provides a breakdown of these participants by age group and state/territory.

2. Access

Access to the NDIS is not dependent on diagnosis, rather a person must demonstrate that they have a permanent disability due to an intellectual, cognitive, neurological, sensory or physical impairment or psychiatric condition.

A prospective participant will meet the disability requirement if they meet each of the requirements set out in section 24 of the *National Disability Insurance Act 2013* (NDIS Act). For people with a FASD diagnosis:

- Section 24(1)(a) of the NDIS Act will likely be met. A person with FASD will likely have 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.
- There is no cure for FASD and its effects last a lifetime so section 24(1)(b) of the NDIS Act will always be met.
- Whether a prospective participant meets the section 24(1)(c) access criteria is likely to be dependent on whether or not the impairment arising from FASD results in substantially reduced functional capacity in communication, social interaction, learning, self-care and self-management. Mobility is less likely to be a factor for people with FASD.
- Capacity for social and economic participation may be impaired (Section 24(1)(d)).
- Due to the nature of the impairment they may require supports for life by the NDIS (section 24(1)(e)).



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FASD and Early Intervention Access

In order to meet Early Intervention criteria, a person must demonstrate they meet all of the following:

- The person has a disability that is likely to be lifelong or is a child with a developmental delay; and
- Early Intervention is likely to benefit the person by:
 - Reducing the need for disability support in the future; and
 - Building, or maintaining, their functional capacity in one of six life skill areas (i.e. communication, social interaction, learning, mobility, self-care or self-management); or
 - Strengthening the sustainability of their informal supports (including building carer capacity).

Currently, FASD is included in the access (for early intervention) under 'congenital conditions'. The reason for this relates to the significant difference FASD can have on an individual's functional capacity. While a child/adult with FASD may meet NDIS access requirements due to the functional impact of the condition, there will continue to be some people with FASD who do not meet the disability or early intervention access requirements.

- Congenital conditions – cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment but with variable severity.

The pattern and severity of outcomes for an individual with FASD are dependent on the timing, frequency and quantity of alcohol exposure in utero. Consequently, the range and severity of FASD-related symptoms and the functional impact of the condition will vary from person to person, meaning access would need to be considered on an individual case by case basis. Currently evidence can be in the form of psychologist reports, educational reports, speech therapist reports, Occupational Therapist (OT) reports etc.

Strengthening access guidance for Access Assessors, to ensure a strong focus on obtaining the right evidence in a far more flexible way has commenced for Early Intervention.

The NDIA recognises that Access to appropriate supports remains a significant challenge for people with the condition of FASD. The NDIS can focus on this issue with more consideration now that the considerable challenges of the NDIS transition are almost completed.

Of significant note to the NDIA in the current data is the indication the NDIS is not engaging with or supporting many very young children with a likelihood of FASD at an early enough stage.

The NDIA acknowledges the NDIS must better engage with all aspects of FASD as a condition so that children and young people with FASD can more flexibly meet the early intervention access criteria to obtain the support services they need promptly.

The NDIA will review the early intervention evidence requirements in acknowledgment that many people with FASD will not have the means or diagnostic/assessment services available to meet the current stated requirements. This will include collaboration between NDIS and Health services to identify possible solutions to this identified barrier.

The NDIA ECEI Approach is the NDIS age appropriate intervention designed to respond to young children and their families. A key focus of the Approach is early engagement with families of very young children with developmental delay or disability. The NDIA recognises the sensitivities and stigma often attached for very young families with a child that may have FASD.



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The NDIA through ECEI partners will adopt a more assertive approach to early engagement and will work through community organisations and leaders to develop sensible and culturally appropriate strategies of engagement.

3. NDIS Planning and funded Supports

What NDIS supports are likely to be required by a participant with FASD?

Participants with FASD will likely experience significant learning and behavioural challenges including:

- learning difficulties;
- memory problems;
- impulsiveness;
- limited attention span, ease of distraction or hyperactivity;
- difficulty relating actions to consequences;
- difficulty following instructions (but able to repeat them verbally);
- difficulty with abstract thinking – such as about mathematics, money or time;
- slow cognitive processing (thinking); and
- difficulty with social relationships².

Given the likely impairments in executive function, memory, language, learning and attention, NDIS supports may be required for:

- personal care for daily living;
- capacity building for activities of daily living and skills building / social skills;
- behavioural support;
- supports to find and keep employment ;
- Allied Health e.g. OT, psychology, speech therapy;
- accommodation supports e.g. Supported Independent Living, Respite, Medium Term Accommodation, Short Term Accommodation and Specialist Disability Accommodation; and
- transport / supports to access community, personal safety.

Respite

Respite aims to support carers or those providing informal support with short-term breaks from their caring responsibilities.

Funding for respite, including for participants with FASD, has always been available for participants and will continue to be so, however the NDIA recognises this may not always have been clear.

The Minister of the National Disability Insurance Scheme and NDIA Board Chairman introduced a specific respite line item for short-term accommodation in the NDIS support catalogue. The NDIA implemented this in December 2019.

One of the outcomes that a participant and their family may seek is respite, in which case they can choose a combination of supports such as:

- short-term accommodation for the participant;
- temporary periods of extra personal supports, enabling the participant to remain at home when families are not available; and
- support to participate in community activities, resulting in a break for carers.

² Better Health Channel, Fetal Alcohol Spectrum Disorder, 2019,
<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/fetal-alcohol-spectrum-disorder-fasd>



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Adequacy of NDIS supports

Ensuring NDIS FASD participants and their family have the individualised reasonable and necessary supports they require is a priority for the NDIA. Generally, NDIS funds FASD related supports that focus on capacity building and early intervention and aim to improve or reduce the deterioration of a participant's functional capacity. Funding is also targeted at helping their family and carers support them.

Reasonable and necessary supports enable FASD participants to pursue their goals and support their social and economic participation. To deem supports as reasonable and necessary, NDIS planners consider a range of factors including barriers to the participant accessing economic and social participation, any informal supports already available to the individual and any other supports provided by mainstream systems, such as health and education systems. Informal arrangements concern those that are part of family life or other connections with friends and community services.

A number of projects are underway to provide a consistent approach to assess Scheme eligibility and determine equitable plan budgets that help support a participant's goals. A key element to inform decision-making is consistent and equitable functional and needs assessments.

The Productivity Commission's Disability and Care Report 2011 and the Review of the NDIS Act Report 2020 recommended that the NDIA engage independent health professionals to undertake assessments for prospective participants seeking to receive support under the NDIS. It is the NDIA's intention to build on an initial pilot and commence a voluntary independent assessment process in the third quarter of 2020. Improving the assessment process will help make the Scheme more reliable, consistent and equitable for everyone, ensuring it provides appropriate support for people with disability and their family.

Other current projects are focusing on supporting plan flexibility and introduce a goal attainment framework to improve the monitoring of progress against plan goals and measurement of plan effectiveness.

There is broad agreement that multidisciplinary models of care are optimal for the management, support and care of individuals with FASD. The nature and type of disability experienced by the individual varies, requiring a personalised program of care.

The NDIA notes that the current approach to FASD lacks a comprehensive multidisciplinary approach that reflects the needs of the individual, bringing clinical and non-clinical providers together (such as health, education, child protection, employment, housing and justice) to determine the most appropriate supports.

The NDIA acknowledges the varying level of understanding by partners and planners of FASD in the processes of developing NDIS individual plans. In addition, the NDIA has identified the need to establish strong connections between Health, Education, the NDIS and related agencies/providers to co-ordinate the planning for and care plans for people with FASD. The use of local service networks of clinical, disability services, with capable navigational supports are vital to ensuring people, and families do not get lost.

The NDIA will work with LAC and ECEI Partners, Health and the disability sector with the aim of promoting holistic needs assessment and plan development through multiple agency input.



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Supply of specialist and Early Childhood Intervention Services

Developmental screening in infancy and preschool by health professionals can identify concerns and provide the basis for referral for more detailed screening and, if indicated, diagnosis of FASD. While screening may identify a child at risk of FASD, it is not always possible to make a diagnosis at that point in time, and many children at risk of FASD need paediatric follow-up and assessment where appropriate.

In terms of diagnosis, people seeking a FASD diagnosis face several key constraints: few specialists, long waiting lists, travel costs and the stigma attached to a diagnosis. The NDIA recognises the lack of specialised service providers in many parts of Australia. This means many young people are on wait lists spanning many months and in the worst cases not receiving services at all. While the NDIS can provide funding for disability services through NDIS plans the issue of supply of these services and supports remains a significant challenge.

4. Planning Considerations for Children

The impact of FASD on a child's development varies considerably. Children may have delays across several developmental domains including but not limited to cognition, self-care skills, communication and emotional development³.

For very young children (0-6 years), the NDIA has developed the ECEI approach in recognition of the need to be proactive, to engage early and assist easy access to early intervention supports through NDIS. Through the Early Childhood Partner, supports will be provided for families by discussing the child's development, any identified needs for their children, the current supports, both formal and informal, in the child's life and potential next steps. Many children with a diagnosis of FASD may require longer term ECEI particularly where there is low level informal supports or the home environment is not fully functioning/or is a complex situation and will be supported to access the NDIS by the ECEI partner.

Early intervention is particularly important for children with FASD to provide timely support, improve their functional outcomes and build their family's understanding and confidence to address developmental delay or disability. For early intervention to have the most beneficial effect for children, their family/carer must be actively involved with the planning and delivery of these supports to ensure all new skills and knowledge are translated for the child into everyday life. This poses some challenges for all services that support families of children with FASD to work holistically with NDIS early intervention supports to maximise the results.

FASD and ECI Best Practice Principles

The National Organisation for Foetal Alcohol Spectrum Disorder Australia (2018) has acknowledged that children with FASD benefit from early intervention and positive outcomes can be achieved when families are appropriately supported to understand their child's developmental needs.

Early Childhood Intervention practitioners use best practice principles when working with children and families. Best practice principles cover family centred and culturally responsive practice, inclusion, teamwork and evidence based approaches focusing on outcomes⁴.

³ National Organisation of Fetal Alcohol Spectrum Disorder Australia, 2018.

⁴ Early Childhood Intervention Australia (2016). National Guidelines. Best Practice in Early Childhood Intervention. Sydney, Australia: Early Childhood Intervention Australia. Retrieved from <https://www.ecia.org.au/Portals/4/Resources/Other%20Resources/ECIA-National-Best-Practice-Guidelines.pdf?ver=2018-06-05-172656-123>



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It is essential that Early Childhood Practitioners engage with families in a collaborative manner that is respectful, non-judgemental and minimises the stigma that is sometimes associated when a child receives a FASD diagnosis. Early Childhood Practitioners have the knowledge to work cross-culturally, inclusively and engage effectively with local communities.

The NDIA's ECEI Partners play a very important role in supporting children to receive the right level of supports for the right amount of time. Authentic participation within a child's natural environments such as the home, education and community settings is promoted by ECEI Partners who additionally support families to collaborate with key stakeholders such as health sector, early childhood sector and child protection to achieve positive outcomes for their child.

For some children with FASD, it will be immediately clear that they will require access to the Scheme for longer term supports. For others, the ECEI Partners will ensure that they and their families have early access to supports, connections to the community and to specialist and mainstream services. This will also provide the time to determine if the child will require longer term early childhood intervention and for the family to have access to information which will assist them to make the right decisions for their child.

ECEI national performance and improvement

The NDIA is establishing its capacity to collect more data on children who meet the partner network (including how long children/families wait for an initial response).

Just over a third of participants given access to the NDIS in the December 2019 quarter were aged 0-6 years old. Since 1 July 2019, 19,636 participants aged 0-6 years have gained access to the Scheme. This is driven by our clear commitment to early intervention for all children 0-6 as quickly as possible.

Barriers to Early Childhood Access - Difficulties with diagnosis

Children with FASD can present with a wide range of complexities including Global Developmental Delay, Cerebral Palsy, Intellectual Disability, cognitive disabilities, physiological disabilities and chronic ill health.

Evidence suggests that FASD is often underdiagnosed for numerous reasons including limited understanding of diagnosis within the health community, confusion about diagnostic criteria and concerns around the stigma associated with a child receiving a FASD diagnosis⁵.

FASD may not be diagnosed at birth unless specific facial features and growth factors are evident. It can be hard to diagnose FASD early on as diagnostic assessment for FASD can be difficult and limited in scope when assessing children. Frequently children do not receive a FASD diagnosis until they have entered school as this is when behavioural concerns and learning difficulties tend to become more apparent.⁶

The Australian Psychological Society note that: "Individuals along the FASD spectrum will each experience a specific set of symptoms and a specific set of secondary conditions according to the environment they grow up in. It is important to remember that not all people with FASD will have visible facial characteristics, low IQ, mental illness, violent behaviour or substance addiction.

⁵ Bower, C., & Elliott, E.J. on behalf of the Steering Group (2016), *Report to the Australian Government Department of Health: Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*, retrieved from: https://www.fasdhub.org.au/contentassets/32961d4a5cf94de48ebcf985c34d5456/australian-guide-to-the-diagnosis-of-fasd_all-appendices_feb2020.docx.pdf

⁶ National Organisation of Fetal Alcohol Spectrum Disorder Australia. (2018), *The Effects of FASD*, retrieved from <https://www.nofasd.org.au/parents-carers-and-families/the-effects-of-fasd/>



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The unique pattern of individual differences in the expression of FASD symptoms makes the assessment of FASD particularly difficult. As a result, FASD appears to be under-recognised and under-treated, particularly in vulnerable populations, such as those living in psychiatric settings, the child welfare system, and juvenile detention and correctional facilities”⁷.

As previously stated the NDIA will work with the Commonwealth Department of Health to establish a criterion for children who are identified as ‘at risk’ of FAS and FASD and exhibit deficits in functioning across multiple domains as a means to test potential access to the scheme under developmental delay. An Early Childhood Partner can assist families in these instances to gather evidence necessary to meet the access requirements and complete the access request process.

5. Aboriginal and Torres Strait Islander Communities

The NDIA recognises that more work needs to be done to assist Aboriginal and Torres Strait Islander peoples, particularly those living remotely to understand and access the NDIS or appropriate health service.

The NDIA is committed to working closely with its Commonwealth partners, jurisdictions and Indigenous stakeholders and communities to increase the Government’s knowledge about populations vulnerable to FASD and what NDIS supports are available to them.

The NDIA recognises that whilst FASD is more prevalent in some communities and warrants tailored engagement, it is important to consider FASD in the context of a broader societal problem, and not one that only affects particular parts of the community. At a broader level, the social and economic effects of FASD are increasingly evident across Australia, notably in the health, education, child protection and justice systems.

The Department of Health, as the lead agency for FASD, has initiated several FASD initiatives specific to Aboriginal and Torres Strait Islander peoples, notably the National Aboriginal and Torres Strait Islander Health Plan 2013-23 and National FASD Strategic Action Plan 2018-28.

Although not solely an Aboriginal and Torres Strait Islander issue, the prevalence of FASD in this cohort is high. Among Aboriginal and Torres Strait Islander peoples estimates indicate that the incidence of FASD may range from 1.87 to 4.7 per 1,000 births.⁸ The Australia Medical Association estimates prevalence in some Indigenous communities may be as high as 12 per cent.⁹ Rates of FASD nationally are estimated to be 0.68 per 1000 live births.¹⁰

In 2017, the Australian Psychological Society reported that Aboriginal and Torres Strait Islander women are more likely to self-medicate with alcohol due to their experience of trauma, grief and

⁷ Ralph, S, ‘Fetal alcohol spectrum disorder in Indigenous adults and the role of psychology’, Australian Psychological Society (2017), InPsych, vol. 39, issue. 2, retrieved from <https://www.psychology.org.au/inpsych/2017/april/ralph/>

⁸ House Standing Committee on Social Policy and Legal Affairs (2012) FASD: The Hidden Harm. Available at: https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_representatives_Committees?url=spla/fasd/report.htm

⁹ Fitzpatrick JP, Elliott EJ, Latimer J, et al. (2015). Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lillilwan Project. Journal of J Paediatric Child Health. 2015 Apr;51(4):450-7. doi: 10.1111/jpc.12814. Epub 2015 Jan 15. PMID: 2559424

¹⁰ House Standing Committee on Social Policy and Legal Affairs (2012) FASD: The Hidden Harm. Available at: https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_representatives_Committees?url=spla/fasd/report.htm



loss, family violence and chronic socioeconomic disadvantage.¹¹ Anecdotal evidence shows that women across Australia remain unaware that the timing and intensity of alcohol exposure can contribute to foetal harm with facial anomalies resulting from first trimester exposure, when a woman may be unaware she is pregnant.

Of the 825 NDIS participants with FASD listed as their primary disability, 421 participants (51 per cent) identify as Aboriginal or Torres Strait Islander and 126 chose not to disclose. This means that 3.62 per cent of the 22,749 participants in the scheme who identify as Aboriginal or Torres Strait Islander have FASD.

The Commonwealth recognises the importance of early intervention. It is a critical factor in ameliorating both the primary and secondary symptoms of FASD. But many people with FASD are not identified until relatively late in life, or not at all.¹² In particular, adolescents with FASD are often undiagnosed.¹³ To address this, from 2013-14 and 2016-17 the Government undertook specific activities to enhance the capacity of maternal and child health services in Indigenous communities to prevent and manage FASD included:

- The development and implementation of FASD Prevention and Health Promotion resources (FPHPR), by Menzies School of Health Research, in partnership with NACCHO and the Telethon Kids Institute. This project is now complete and a web accessible version of the resources is available on the FASD Hub.
- The development of FASD awareness messages, translated into six languages and broadcast through the National Indigenous Radio Service for three months during the AFL season.
- FASD specific grant rounds through the National Health and Medical Research Council's Partnership Projects program. These grants were aimed to support collaboration between policy makers, program managers, service providers and researchers with experience or interest in Aboriginal and Torres Strait Islander Health.

More recently, under the National FASD Strategic Action Plan Program Funding – \$7.2m over four years (2018-19 to 2021-22), the Department of Health, has initiated several FASD initiatives specific to Aboriginal and Torres Strait Islander peoples, notably the National Aboriginal and Torres Strait Islander Health Plan 2013-23 and National FASD Strategic Action Plan 2018-28.

In terms of diagnosis, Aboriginal and Torres Strait Islander peoples are subject to the same constraints facing the wider Australian community: few specialists, long waiting lists and the stigma attached to a diagnosis. Regional and remote Aboriginal and Torres Strait Islander peoples also face the high costs in travelling to specialist clinics. Without a diagnosis and a subsequent full assessment from an allied health team, an Indigenous potential participant cannot complete the NDIS documentation required to be considered for the Scheme.

NDIA recognises the need to intersect thoughtfully with state and territory provided health services. In terms of FASD and Aboriginal and Torres Strait Islander peoples, jurisdictions are providing key services, such as the:

- provision of Aboriginal maternal and infant health services by Aboriginal Community Controlled Health Services and local health districts; and
- delivery of Aboriginal and Torres Strait Islander-specific alcohol and pregnancy initiatives focused on information and raising awareness.

¹¹ Ralph, S, 'Fetal alcohol spectrum disorder in Indigenous adults and the role of psychology', Australian Psychological Society (2017), InPsych, vol. 39, issue. 2, retrieved from <https://www.psychology.org.au/inpsych/2017/april/ralph/>

¹² Spohr, H-L et al. (2007) Fetal Alcohol Spectrum Disorders in Young Adulthood. The Journal of Pediatrics. Volume 150, Issue 2, 175-179.e1

¹³ National Organisation for Fetal Alcohol Spectrum Disorders (2013). What is FASD? Available at: <https://www.nofasd.org.au/alcohol-and-pregnancy/what-is-fasd/>



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The NDIA is also complementing the Department of Health's focus by driving forward with several initiatives that aim to help Aboriginal and Torres Strait Islander people with disability, including FASD, to better understand and access the Scheme.

The NDIA's Aboriginal and Torres Strait Islander Strategy provides high level commitment and guidance for the Agency on strengthening its engagement and work with Aboriginal and Torres Strait Islander communities to enhance participants, families, their carers and communities understanding of, and access to, the Scheme. Its priority to date has been on developing local solutions, cultural leadership and cultural competency. The Agency is in the process of revising this Strategy to recognise achievements over the last two years and to mitigate identified gaps, including coordinating more closely with health and education systems. In line with the Tune Review findings, this will include biannual jurisdictional and national consultative roundtables to improve our understanding of Aboriginal and Torres Strait Islander peoples' experience with the NDIS and enable us to advance culturally appropriate mitigating measures. This overarching commitment has guided the development of specific NDIA initiatives designed to improve Aboriginal and Torres Strait Islander peoples' access to the Scheme.

The NDIA has worked with Institute of Urban Indigenous Health (IUIH) program to support Aboriginal and Torres Strait Islander people in South-East Queensland to access the NDIS and receive support for their first plan process. Working with a trusted, culturally appropriate organisation to facilitate access and participation will provide insights into how the Agency can improve the experience of Aboriginal and Torres Strait Islander peoples engaging with the NDIS.

Jurisdictional Work

In October 2019, Commonwealth, state and territory Disability Ministers endorsed the Disability Reform Council program of works. This program of work includes:

- Mental Health: Improve access and plan utilisation rates for people with psychosocial disability and coordination of NDIA supports, mental health and other relevant service systems.
- Health: To monitor the impacts of Council's agreement in June 2019, to the approach for disability related health supports.
- Information Linkages and Capacity (ILC) building: ensure ILC, including the functions of Local Area Coordinators, improves participants' connections with mainstream services and community programs to create connections between all people with disability and the communities in which they live.
- Market Effectiveness: monitor the growth of the market and respond to challenges with market development including market failure.

Some of the expected deliverables from this work include the development of information sharing protocols between the NDIA and clinical mental health systems; the introduction of National Psychosocial Recovery Framework; interim evaluation of ILC Investment Strategy and forward targeting; implementing a think markets strategy and monitoring the number of Aboriginal and Torres Strait Islander NDIS providers.

FASD and remote locations

Recognising the link between remote locations, Aboriginal and Torres Strait Islander communities and disability, the NDIA has focused on improving its assistance and service delivery to remote communities. In the third quarter of this year, the number of Scheme participants in remote and very remote areas this quarter increased to 1.9 per cent of new entrants, compared with 1.4 per cent in previous quarters combined.



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The NDIA's Remote Community Connectors (RCC) program targets these remote communities to engage, inform and assist Aboriginal and Torres Strait Islander participants. RCCs are local, community-based people, employed by Aboriginal Community Controlled Organisations to promote understanding and awareness of the NDIS. In 2019, the Minister for the National Disability Insurance Scheme announced a \$20 million expansion to create a National Community Connector Program (NCCP) building on the RCC program to support targeted communities that find it harder to understand and navigate the NDIA. NCCP Community Connectors will assist Aboriginal and Torres Strait Islander peoples with disability, including psychosocial disability, in remote, rural and urban communities within all states and territories of Australia.

Evidence shows that early identification and tailored intervention improves life outcomes for individuals affected by FASD.¹⁴ The Australian Government has allocated funding to contribute to the development of a FASD identification guide for use in the early childhood setting. It is intended that this guide will provide information for people working in early childhood education settings to identify children who potentially meet the assessment criteria for FASD, and how to facilitate discussions with parents/carers on undertaking a formal FASD diagnostic assessment.¹⁵

The NDIA's Early Childhood Supports (ECS) Program has committed to investing \$20 million for Aboriginal Medical Services (AMS) and Aboriginal Community Controlled Organisations (ACCO). Operating in the Kimberley, Pilbara and Goldfields region, this program employs regional allied therapy teams to support children under seven years of age with developmental delay to receive early supports and services. The NDIA is carefully monitoring this investment to determine its applicability at a national level.

FASD and the justice system

A recent study in Banksia Hill Detention Centre (Western Australia) on the prevalence of FASD within the juvenile justice system found that in the 99 young people studied (74 per cent of whom were Aboriginal) 36 per cent were diagnosed with FASD.¹⁶ NDIS potential and existing Aboriginal and Torres Strait Islander participants involved in the Justice System face unique challenges that make it difficult for them to access the broader services they need. Aboriginal and Torres Strait Islander peoples are significantly over represented in both disability populations and justice settings.

The intellectual, behavioural and social challenges associated with FASD may result in an increased risk of contact with the criminal justice system. When people with FASD do come in contact with the criminal justice system, these challenges mean they will have an impaired ability to navigate the system effectively. The states and territories, through the Justice System, other mainstream systems and the Commonwealth, including through the NDIS, all have a role in providing responsive and well integrated services to ensure the best outcomes for Aboriginal and Torres Strait Islander peoples with disability.

In December 2019, Commonwealth, state and territory Disability Ministers agreed that NDIA and states and territories would strengthen relationships with Aboriginal and Torres Strait Islander justice settings. In response, the NDIA has developed a number of specific Indigenous Justice

¹⁴ National Organisation for Fetal Alcohol Spectrum Disorders (2013). What is FASD? Available at: <https://www.nofasd.org.au/alcohol-and-pregnancy/what-is-fasd/>

¹⁵ Department of Health (2018) National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018-23. Available at: <https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>

¹⁶ Bower C, Watkins R, Mutch R, et al. (2018) Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia BMJ Open 2018; 8:e019605. doi: 10.1136/bmjopen-2017-019605



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deliverables which we are working with states and territories to advance in order to help Aboriginal and Torres Strait Islander participants who are in contact with the justice system access reasonable and necessary supports. These deliverables include Justice Liaison Officers working closely with their Aboriginal counterparts and NDIA Community Connectors to support potential and existing Aboriginal and Torres Strait Islander NDIS participants to successfully transition from a justice setting, through timely pre-release planning, the provision of NDIS supports, post-release support and access to diversionary programs, as appropriate.

To assist in this work, the Department of Social Services (DSS) has commissioned a consultancy that examines the current practices of identifying and assessing disability and/or impairment in Aboriginal and Torres Strait Islander prisoners and ex-prisoners. This includes all Australian jurisdictions and the current practices of supporting the needs of Aboriginal and Torres Strait Islander prisoners and ex-prisoners with disability and/or impairment while transitioning back into the community.

These culturally appropriate, tailored deliverables complement wider mainstream justice initiatives being implemented by the Agency, including Justice Liaison Officers. The NDIA is implementing practices to improve understanding of operational roles and responsibilities between jurisdictions and the NDIA as well as developing information and data sharing mechanisms. Under the Department of Health's FASD Strategy, the Australian Government has allocated funds for Justice and policing resources. Its intent is to review and adapt existing resources for the recruitment and employment personnel, to guide them in understanding FASD and assist people with FASD to obtain and retain employment, and for people working in the criminal justice system, to assist them in recognising people affected by FASD and improve their understanding of the implications of the disorder within the criminal justice system.

To increase NDIA's cultural responsiveness and awareness amongst its staff, it has developed cultural capability training services for its staff, and enhanced training for those front-line members who have direct contact with Aboriginal and Torres Strait Islander participants, their families, and communities. In collaboration with the Centre for Cultural Competence Australia (CCCA), the NDIA has developed a cultural awareness package which provides foundational knowledge of Aboriginal and Torres Strait Islander peoples' cultures. Over 64 per cent of staff have completed this training which was introduced in late 2019.



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Attachment A

Primary Disability of FASD – 31 May 2020

Number of active participants with an approved plan with FASD as a primary disability

| Age Group | State & Territory | | | | | | | | | Total |
|--------------|-------------------|-----------|------------|------------|-----------|-----------|----------|-----------|----------|------------|
| | NSW | VIC | QLD | WA | SA | TAS | ACT | NT | OT | |
| 0 to 6 | 23 | 12 | 29 | 11 | 1 | 0 | 0 | 7 | 0 | 83 |
| 7 to 14 | 146 | 38 | 152 | 54 | 23 | 16 | 4 | 33 | 1 | 467 |
| 15 to 18 | 40 | 11 | 39 | 32 | 7 | 5 | 0 | 21 | 0 | 155 |
| 19 to 24 | 32 | 4 | 27 | 22 | 7 | 7 | 2 | 9 | 0 | 110 |
| 25 to 34 | 19 | 8 | 18 | 1 | 6 | 2 | 0 | 4 | 0 | 58 |
| 35 to 44 | 8 | 4 | 5 | 0 | 4 | 0 | 0 | 0 | 0 | 21 |
| 45 to 54 | 5 | 2 | 3 | 0 | 0 | 0 | 1 | 0 | 0 | 11 |
| 55 to 64 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 |
| 65+ | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Total | 273 | 80 | 274 | 120 | 48 | 30 | 7 | 74 | 1 | 907 |

Secondary Disability of FASD – 31 May 2020

Number of active participants with an approved plan with FASD as secondary disability

| Age Group | State & Territory | | | | | | | | | Total |
|--------------|-------------------|-----------|------------|-----------|-----------|-----------|----------|-----------|----------|------------|
| | NSW | VIC | QLD | WA | SA | TAS | ACT | NT | OT | |
| 0 to 6 | 8 | 4 | 12 | 9 | 3 | 1 | 0 | 4 | 0 | 41 |
| 7 to 14 | 55 | 29 | 48 | 22 | 6 | 4 | 1 | 10 | 0 | 175 |
| 15 to 18 | 33 | 8 | 41 | 10 | 3 | 3 | 2 | 4 | 0 | 104 |
| 19 to 24 | 17 | 3 | 13 | 10 | 4 | 2 | 0 | 4 | 0 | 53 |
| 25 to 34 | 10 | 2 | 19 | 5 | 4 | 0 | 2 | 2 | 0 | 44 |
| 35 to 44 | 5 | 3 | 5 | 1 | 2 | 0 | 1 | 1 | 0 | 18 |
| 45 to 54 | 3 | 1 | 7 | 0 | 1 | 0 | 0 | 0 | 0 | 12 |
| 55 to 64 | 1 | 3 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 6 |
| 65+ | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Total | 132 | 53 | 146 | 57 | 23 | 11 | 6 | 25 | 0 | 453 |

Note: the most common primary disabilities for the 453 participants shown above were Intellectual Disability (200) and Autism (140).

Primary or Secondary Disability of FASD – 31 May 2020

Number of active participants with an approved plan with FASD as disability

| Age Group | State & Territory | | | | | | | | | Total |
|--------------|-------------------|------------|------------|------------|-----------|-----------|-----------|-----------|----------|--------------|
| | NSW | VIC | QLD | WA | SA | TAS | ACT | NT | OT | |
| 0 to 6 | 31 | 16 | 41 | 20 | 4 | 1 | 0 | 11 | 0 | 124 |
| 7 to 14 | 201 | 67 | 200 | 76 | 29 | 20 | 5 | 43 | 1 | 642 |
| 15 to 18 | 73 | 19 | 80 | 42 | 10 | 8 | 2 | 25 | 0 | 259 |
| 19 to 24 | 49 | 7 | 40 | 32 | 11 | 9 | 2 | 13 | 0 | 163 |
| 25 to 34 | 29 | 10 | 37 | 6 | 10 | 2 | 2 | 6 | 0 | 102 |
| 35 to 44 | 13 | 7 | 10 | 1 | 6 | 0 | 1 | 1 | 0 | 39 |
| 45 to 54 | 8 | 3 | 10 | 0 | 1 | 0 | 1 | 0 | 0 | 23 |
| 55 to 64 | 1 | 4 | 2 | 0 | 0 | 1 | 0 | 0 | 0 | 8 |
| 65+ | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Total | 405 | 133 | 420 | 177 | 71 | 41 | 13 | 99 | 1 | 1,360 |