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Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability

Danila Dilba Health Service

***Submission on Children and Young
People with Disability in the NT***

11 November 2020

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1. Acknowledgments

This submission was compiled by the Danila Dilba Health Service policy team with input from staff across our organisation, including general practitioners, nurses, Aboriginal health practitioners, social and emotional wellbeing staff and youth workers. We were also grateful for the input and support of the Top End Health Service Paediatric Department in preparing this submission. Finally, we are immensely grateful to our clients who have allowed us to share their stories, in the hope of achieving systemic change and improving outcomes for Aboriginal families and children with disabilities across the Northern Territory.

2. Executive Summary

Danila Dilba Health Service (**DDHS**) is an Aboriginal Community Controlled Health Service, delivering comprehensive primary health care to Aboriginal and Torres Strait Islander People in the Greater Darwin Region.

The focus of this submission is on the systemic failure to identify and address the complex needs of First Nations children with disabilities, particularly those with neurodevelopmental impairment or developmental delay. As this submission and associated case studies demonstrate, lack of support for families of children with disabilities can lead to a perpetuating cycle of parental neglect, engagement of child protection services, school-disengagement and ultimately, entrenchment in the criminal justice system.

Our submission focusses on the benefits of delivering a comprehensive primary health care model, integrating education, early assessment, multi-disciplinary and specialist treatment and therapeutic interventions in a holistic wraparound model. Our experience demonstrates that Aboriginal Community Controlled Health Services are well placed to coordinate and deliver these services, leveraging off existing relationships of trust to ensure continuity of care and support throughout the client journey.

Throughout our submission we make the following recommendations:

1. The Commonwealth Department of Health should make available consistent, long-term funding for Aboriginal Community Controlled Health Services, to coordinate and deliver culturally appropriate assessments for First Nations clients of all ages as part of an integrated comprehensive primary health care model.
2. The National Disability Insurance Agency should embed the role of 'community connectors' and other culturally appropriate supports into the core operation of the National Disability Insurance Scheme (**NDIS**) through sustainable and recurrent resourcing of appropriate community controlled organisations.
3. The Commonwealth Government should fund Aboriginal Community Controlled Health Services to provide integrated allied health support as part of a comprehensive primary health care model.
4. The Commonwealth Government should undertake widespread consultation about the independent functional assessment scheme before it is rolled out more broadly. This should involve specific consideration of the suitability of the scheme for First Nations children and families.
5. The Commonwealth Government should ensure that the NDIS is available to fund the provision of support for children in detention in a consistent way. In particular, the availability of providers of these therapeutic supports for children in detention should be reviewed to ensure that NDIS plans are actually implemented in detention.
6. The Commonwealth Minister for Health should:
 - a. make the necessary directions under section 19(2) of the Health Insurance Act 1973 (Cth) to enable the payment of Medicare benefits for medical services provided to children and young people in detention in the Northern Territory; and

- b. take all necessary steps to ensure that supply of pharmaceuticals to children and young people in detention in the Northern Territory is provided under the Pharmaceutical Benefits Scheme.
- 7. The Northern Territory Government should review the workforce capabilities of youth detention centres, prioritising funding for the recruitment of:
 - a. Senior personnel and a multi-disciplinary work force with relevant qualifications and minimum of 4 years experience working with adolescents; and
 - b. First Nations staff, particularly into senior leadership positions.
- 8. Evidence-based FASD training should be developed and delivered in the Northern Territory for all staff working with children in detention.
- 9. The Commonwealth and Northern Territory Governments should coordinate to provide funding for the development and implementation of a therapeutic secure facilities for children with high needs relating to their disabilities, including children in the justice system. These should be developed in partnership with local Aboriginal Community Controlled Health Services.

3. Introduction

DDHS is Darwin's only Aboriginal Community Controlled Health Service (ACCHS), established in 1991 with a single clinic in the Darwin CBD. Since then, DDHS has successfully developed into a large, sophisticated organisation that provides comprehensive health and wellbeing services to 15,000 clients through eight clinic locations across the Greater Darwin area. DDHS enjoys a high level of trust and engagement with the local Aboriginal and Torres Strait Islander community of whom 80 per cent are counted as regular clients of the service.

The DDHS vision is outlined in our strategic plan 2017-22; 'that the health, well-being and quality of life of Aboriginal and Torres Strait Islander Australians equals that of non-Indigenous Australians.'

To achieve this vision, DDHS has adopted a comprehensive and integrated approach to the delivery of primary health care. Our service is culturally safe and locally relevant. Our services are integrated in our clinics, which are located close to where our clients live. DDHS offers services across the life course of our clients from maternal and child health to in-reaching services to residential aged care facilities. DDHS works in partnership with other organisations, researchers and community members, alongside the mainstream health sector to best meet the needs of our clients.

DDHS is grateful for the opportunity to provide input to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (**Disability Royal Commission**). As the sole ACCHS in the greater Darwin region, we are well-placed to assist the Disability Royal Commission with its inquiry, particularly regarding the unmet needs of First Nations people with disabilities in the Northern Territory.

Our submission emphasises the importance of early assessment and ensuring that children with developmental delay or disabilities and their families receive timely diagnosis and appropriate therapeutic and capacity building supports that they need to grow and thrive. Through case studies, we highlight the multi-faceted and complex needs of children and families who very frequently 'fall through the cracks' of agencies tasked to support them (including NDIS, health, education and child protection services). We would be happy to provide further information to the Disability Royal

Commission on these challenges and would be grateful for the opportunity to provide evidence at the Northern Territory hearings once they have been scheduled.

4. Background

4.1 Our role and services

DDHS provides a range of services to children, families and clients relevant to this submission and to the Disability Royal Commission's inquiry:

- **Comprehensive primary health care and social and emotional wellbeing services** for parents and families, with integrated services including social and emotional wellbeing support, and a collaborative midwife lead model of antenatal care.
- **Family support and strengthening through the Australian Nurse Family Partnership Program (ANFPP)** which is a nurse led, sustained home visiting program that supports women pregnant with a First Nations child to improve their own health and the health of their baby;
- **Primary health care and social support services for young people at Don Dale Youth Detention Centre (DDYDC)**. Since July 2020, DDHS has had a primary health care clinic based at DDYDC with a full-time general practitioner, psychologist and registered nurse and an after-hours on-call service. We also have two youth workers on-site six days a week to provide social and emotional wellbeing services and programs to young people.
- **Youth Diversion** (police diversion) in partnership with YWCA, for young people engaging with the justice system, and **youth after hours activities** for young people at risk of this engagement.
- We work in partnership with the Top End Health Service (**TEHS**) Paediatric Department to improve specialist services for First Nations children in the Darwin/Palmerston region. We have recently recruited a full-time paediatrician with the vision of developing a **collaborative child health care model**, using a multidisciplinary team to deliver much needed and timely diagnostic and therapeutic services to vulnerable children and their families.
- **Disability Royal Commission Counselling Service** which provides counselling and support services for people participating in or affected by the proceedings of the Disability Royal Commission.
- **NDIA 'Community Connectors' program** which provides assertive outreach to First Nations people in a culturally safe way to break down barriers that prevent our clients from accessing the NDIS. This includes linking potential participants with the local NDIS partner, assisting clients to complete Access Request Forms (**ARF**) and providing follow-up on submitted forms. Following the assessment process, the program supports participants to understand their NDIS Plans, ensure those plans are meeting the client's needs and to link the client with an appropriate support coordinator.
- **NDIA Information, Linkages and Capacity Building** aims to build the skills and capacity of children, young people and their families through a child development framework. The service consists of weekly skill building sessions for children and young people with a disability, weekly sessions for their parents, families and carers and individual support for families and children to access the NDIS where eligible. The service equips participants with the foundational skills on which further learning and capacity can be built.

- **Health Justice partnership with Northern Territory Legal Aid Clinic (NTLAC)** to improve access for DDHS clients to legal services through integrated referral pathways and legal clinics held at DDHS. We have also recently been funded to support a full-time integrated family lawyer position at DDHS to improve access to legal supports for Aboriginal people impacted by domestic and family violence.

4.2 Developmental vulnerability of First Nations children in the NT

The developmental trajectory of First Nations children in the Northern Territory is being compromised by a complex layering of pervasive disadvantage, intergenerational trauma, poverty, violence, overcrowding, and alcohol and substance abuse.¹

This narrative does not apply to all First Nations families. Many are strong and care for their children, steeped in the cultural bonds that nurtured First Nations children for tens of thousands of years. The unfortunate reality is, however, that many First Nations children grow up in an environment impacted by the factors inextricably linked to a higher prevalence of developmental delay and neuro-disability.²

Relative to other **MMM 2** geographic areas, Darwin's First Nations population is:³

- half as likely to have obtained a post-high school qualification;
- more than 10 percentage points more likely to be unemployed or not in the labour force;
- twice as likely to reside in a property which required one or more additional bedrooms;
- five percentage points more likely to be earning below \$20,800 annually; and
- 13 times more likely to report experiencing homelessness or marginal housing.

By the time they start school, nearly half of all First Nations children in the Darwin region are developmentally vulnerable on one or more domains.⁴ Furthermore, the proportion of children being identified as 'vulnerable' or 'at risk' rose between 2012 and 2018 in the Australian Early Development Census. DDHS has 975 regular-client children aged 0-4, an increase of 75% over 4 years. Most clients live in the suburbs of Moulden, Karama, Woodroffe and Gray, suburbs which also had the highest prevalence of developmental vulnerability in the AEDC in 2018.⁵

Evidence suggests that without early intervention and the timely provision of culturally appropriate, therapeutic supports, it is more likely that children will experience disengagement from school, behavioural difficulties, maltreatment,⁶ incarceration,⁷ mental illness and suicide.⁸ It is therefore reasonable to believe that a lack of access to necessary services is contributing to the following outcomes for Aboriginal people:

¹ Royal Commission into the Protection and Detention of Children in the Northern Territory, final report 2017, Volume 2A page 236.

² The First Thousand Days; An Evidence Paper, Centre for Community Child Health, 2017.

³ Deloitte Access Economics, Funding analysis of the Danila Dilba Health Service, June 2019.

⁴ Australian Early Development Census, 2018.

⁵ Australian Early Development Census, 2018.

⁶ Sullivan, Patricia M., and John F. Knutson. "Maltreatment and disabilities: A population-based epidemiological study." *Child abuse & neglect* 24.10 (2000): 1257-1273

⁷ Snow, Pamela C. "Speech-language pathology and the youth offender: Epidemiological overview and roadmap for future speech-language pathology research and scope of practice." *Language, speech, and hearing services in schools* 50.2 (2019): 324-339.

⁸ Beitchman, Joseph H., et al. "Seven-year follow-up of speech/language impaired and control children: Psychiatric outcome." *Journal of Child Psychology and Psychiatry* 37.8 (1996): 961-970.

- Declining school attendance: The First Nations school attendance rate in the NT fell from 70.2 per cent in 2014 to 66.2 per cent in 2017.⁹
- Persistent over-representation in the youth justice and care and protection systems.¹⁰
- The highest rate of deaths by intentional self-harm for 5-17 year-olds for any capital city in the country at 6 per 100,000 (Darwin).¹¹

There is also strong research to suggest that developmental delay and neurodevelopmental impairment contribute to the gap in life expectancy that many First Nations children will unfortunately face.¹²

Quality early childhood development programs are a key, cost-effective intervention strategy to address and offset the effects of adverse early childhood development. Such programs are proven to support cognitive, social, communicative, physical and emotional development and thereby improve the long term health, education and employment outcomes for young children from disadvantaged families.¹³ They also have been shown to prevent the onset of significant cognitive disability.¹⁴

DDHS has experienced significant growth in demand for its child health services over the last 4 years:

Indicator	30-Jun-16	30-Jun-20	% Increase over 4 years
Regular Clients (Aged 0-4)	572	975	70%
Services Provided (Aged 0-4)	5335	10013	88%
Kids tested for Anaemia (6-59 months old)	376	576	53%
Kids identified as Anaemic by testing (6-59 months old)	127	195	54%
Kids checked for Growth Faltering (0-59 months)	577	930	61%
Kids identified with Growth Faltering (0-59 months)	23	37	61%
Kids with ear checks (3m - <6 years)	640	844	32%

⁹ Closing the Gap report, 2018, chapter 3.

¹⁰ NT Government, Department of Territory Families, Annual Report 2018-19.

¹¹ ABS 3303.0 Causes of Death, Australia, 2018, table 11.3 'Intentional self-harm, Number of deaths in children aged 5-17 years by age and capital city areas/remainder of state, 2014-2018'

¹² Greg O'Brien, 'Adult outcome of childhood learning disability' *Developmental Medicine & Child Neurology* 2001, 43: 634-638.

¹³ Campbell, F. A., Wasik, B. H., Pungello, E., Burchinal, M., Barbarin, O., Kainz, K., ... & Ramey, C. T. (2008). Young adult outcomes of the Abecedarian and CARE early childhood educational interventions. *Early Childhood Research Quarterly*, 23(4), 452-466.

¹⁴ Odom, S.L., Boyd, B.A., Hall, L.J., Hume, K.A., Volkmar, F.R., Paul, R., Rogers, S.J., and Pelphrey, K.A. (2014). Comprehensive treatment models for children and youth with autism spectrum disorders. In F.R. Volkmar, R. Paul, S.J. Rogers, and K.A. Pelphrey (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (4th ed., pp. 770-787). Hoboken, NJ: John Wiley & Sons.

What Works Clearinghouse. (2014). *What Works Clearinghouse: Procedures and Standards Handbook Version 3.0*. Washington, DC: U.S. Department of Education, Institute of Education Sciences.

Kids with full health checks (MBS 715) (0-4 years)	308	507	65%
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The proportions below indicate First Nations developmental vulnerability on one or more domain as assessed in the first year of school in the Australian Early Development Census in 2018. Below are reported IARE's within the DDHS service region:

AEDC 2018	Aboriginal children developmentally vulnerable on one or more domains	Aboriginal children assessed in AEDC (first year of school)	% Aboriginal children developmentally vulnerable on one or more domains
Tiwi - Lyons - Leanyer	10	18	55.6
Moil - Wagaman - Wanguri	8	16	50.0
Litchfield	15	32	46.9
Palmerston	58	132	43.9
Karama	8	19	42.1
Total	99	217	45.6

The average above can be extrapolated as a crude measure of First Nations children in the region who are developmentally vulnerable on one or more domain due to the proximity of these IAREs to others where results were not published.¹⁵

As outlined throughout this submission, DDHS has identified significant gaps in the provision of assessment and treatment services for children with disabilities and their families and carers. DDHS also understands the barriers that are preventing these families from accessing the comprehensive and holistic services that are required to support children with disabilities, preventing neglect, abuse and pathways into child protection and justice systems.

4.3 Pathways into the child protection system

There is a significant over-representation of First Nations children in the care and protection and youth justice systems in the NT. In 2019, 80% of the out of home care population and 99% of the youth detention population were First Nations children.¹⁶ The prevalence of neuro-disability in these populations is well-known with more than 50% of the youth detention population and around 30% of the out-of-home care population having been diagnosed with a neuro-disability,¹⁷ with many more yet to be assessed.

¹⁵ Note: some key IARE areas including Ludmilla do not have published data as confidentiality thresholds had not been passed or other anomalies prevented publication. <http://phidu.torrens.edu.au/current/maps/atsi-sha/iare-single-map/atlas.html>

¹⁶ Northern Territory Government Department of Territory Families, Territory Families Annual Report, 2018-19.

¹⁷ Carol Bower et al, 'Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia' BJM Open (19 February 2018) <http://bmjopen.bmj.com/content/8/2/e019605>.

There is a recognised relationship between early childhood trauma, delayed or impaired development and substantiated child protection notifications.¹⁸ We are concerned that many of the Territory's most developmentally compromised children are being removed from families and communities and placed in out-of-home care in Darwin due to systemic failures to support their families and carers and to understand their complex needs.¹⁹

5. Identifying disabilities or developmental delay

5.1 Barriers to early assessment and diagnosis

While the formal diagnosis of some neuro-developmental and behavioural disorders like Fetal Alcohol Spectrum Disorder (**FASD**), Attention Hyper Deficit Disorder (**ADHD**), Intellectual Disability (**ID**) or other complex Learning Disorders may not occur until the child reaches primary school, early intervention and assessment of developmental delays and vulnerabilities is critical to ensure access to appropriate services and support and successful long-term outcomes. Multidisciplinary and functional assessments are essential to identify and understand the complex needs of children with developmental vulnerabilities and ensure timely access to relevant supports.

The NDIS has a national approach to early childhood early intervention (**ECEI**) that gives children aged 0-6 years quick access to NDIS support for issues like developmental delay, without the need for a diagnosis. Older children must generally be assessed and have a diagnosis of a 'significant and permanent' disability, such as FASD or ID, to be eligible for NDIS funding. However, support for families to access the scheme in the 0-6 years age group, or to access the diagnostic assessments required to determine a 'significant and permanent disability' for children older than 7 years is crucial.

As the case study below demonstrates there are significant challenges accessing assessments for vulnerable children and their families. We are concerned that children and families are often not empowered or supported to understand and navigate the complex referral and assessment process and are thus unable to access the support that they need in a timely manner.

Case Study

In September 2020, Aboriginal 5-year old twins Ethan and Larissa* attended the DDHS Palmerston Clinic with their mother Patricia* following a referral from the children's school, who were concerned about their behaviour and development. Both children have a history of trauma, suspected in-utero alcohol exposure and their mother was a victim of domestic violence.

More than a year earlier, Ethan had had been referred to the Children's Development Team (CDT) and public paediatric outpatient service at the Royal Darwin Hospital for assessment due to concerns regarding severe language delay, limited social skills and disruptive behaviours. He received a diagnosis of global developmental delay and the Paediatrician recommended ongoing frequent speech therapy, occupational therapy and physiotherapy, as well as educational support. Following this diagnosis, Ethan was placed in the special needs class at school. It seems an application was also made for him to access therapy through NDIS – however as far as their mother is aware, this has not yet occurred.

¹⁸ Suzanne Lim, Childhood Trauma, Attachment and Family Violence – A Speech Pathology Perspective (Darwin 2019)

¹⁹ Department of the Chief Minister, 'Story of our Children and Young People; Northern Territory 2019', 38, 54 accessed at: https://dcm.nt.gov.au/__data/assets/pdf_file/0006/760254/story-of-our-children-and-young-people.pdf

Upon reviewing the file, the DDHS GP has made several calls and attempts to understand the status of the NDIS application and access to therapy. The NDIS indicated that they have no record of Ethan. DDHS then called the private service who are supposed to be providing therapy, who confirmed that there is a service agreement in place with NDIS for Ethan, and that he requires further assessment before this support can be provided. There are long delays accessing this further assessment through existing publicly funded pathways. In the interim, Ethan is not receiving any therapy to address the concerns raised by the paediatrician 12 months earlier.

Ethan's twin Larissa has not yet been assessed and has no diagnosis, however her teachers are also concerned she is falling behind. The school referred Larissa (and the family) to DDHS to follow up about concerns regarding her hearing. The DDHS GP reviewing the case has now referred Larissa for assessment by the publicly funded allied health service – CDT. However, there is a long wait before this will occur and in the meantime, Larissa is not receiving any therapy to address the school's concerns.

Patricia is concerned about her children and their development and wants to learn the skills to support them and make sure they grow up strong and healthy.

*This case study is drawn from a current client of DDHS. Some details and names are changed to maintain privacy.

5.1.1 Complex referral pathways

There are multiple services in Darwin that can provide input to support the diagnostic assessment process. These include the Children's Development Team (publicly funded allied health service run by the NT Department of Health), school psychologists, private providers and non-for-profit organisations. However, there are significant challenges coordinating and accessing the assessment processes for children who need them, particularly given the silos and lack of communication between private service providers and government departments.

Children with complex neurodevelopmental and behavioural needs often require assessments from a variety of medical and allied health services. Unfortunately there is no 'one stop shop' in Darwin where all the diagnostic assessments required for an individual child can take place. This often leads to a 'piecemeal' service where a child may get 'a little from here' and 'a little from there', and responsibility for navigating this complex pathway is often left with vulnerable families who may have little understanding of the process. This means that despite GPs ensuring that they make all the necessary referrals, families can find it challenging to organise appointments, attend appointments and gain access to the assessment reports. Another difficulty is that many of our vulnerable, high-needs clients often experience insecure housing, living with extended family members and moving from one household to another. It can therefore be difficult to gather together the relevant pieces of information from a variety of locations and arrange appropriate and ongoing follow up appointments or assessments.

5.1.2 Prohibitive costs

Given the expertise and multidisciplinary team required to undertake private diagnostic assessments, costs can be prohibitively high for children and families who are unable to access these services through the public system. The NDIS generally does not fund comprehensive, multidisciplinary diagnostic assessments, and although sometimes they are funded through other means (e.g. if the child is in care and protection or the justice system), cost continues to be a barrier for many children and families accessing the assessments that they need.

5.1.3 *Wait times*

Due to large numbers of referrals and a large backlog of clients, wait times can be extensive both in the public and private system. Our clinicians estimate that wait times from initiation of referral to completion of a complex neurodevelopmental assessment by CDT to be greater than 18 months in the Darwin region at present. Due to client demand, there is also an extensive wait for assessment through private providers like PATCHES, who only have a small team in Darwin.

Furthermore, as mentioned above, for many clients and families, this diagnostic process may never complete due to a failure of coordination, funding or other factors.

5.1.4 *Lack of culturally and linguistically appropriate assessments*

Staff have raised significant concerns regarding the lack of culturally appropriate diagnostic assessment processes and interventions. These concerns have been echoed by the CDT.

The assessments used for making diagnoses are developed around western values and worldviews. They are typically administered in standard Australia English and are interpreted by a non-First Nations clinician. For example, DDHS have had clients who were measured against U.S. normative data across a number of domains including social, home living, health and safety, leisure, communication and community - all of which are culturally and linguistically variable. These questions are not culturally relevant to the daily lives of First Nations people generally, and in particular to people who come from remote communities and do not speak English as a first or second language. They are therefore not reliable measures and present a risk in wrongly indicating a disorder due to cultural difference.

Some culturally appropriate tools, including the ASQ-TRAK tool, have been developed and are being utilised by some services, however these are not being widely used by public and private assessment providers.

5.2 Early adulthood diagnostic gaps

If young people do not get a formal diagnosis (e.g. ASD or ADHD) during childhood or prior to about their 16th birthday, it becomes almost impossible to get this diagnosis formally confirmed in Darwin. TEMHS previously delivered an adult ADHD service, however this was discontinued at the start of 2020. This means that now there are currently no local publicly funded services for assessment and diagnosis of this condition for young adults in the Top End.

PATCHES are the only private provider with capacity to deliver comprehensive, multidisciplinary diagnostic assessments in the Darwin-Palmerston region. Given the prohibitive costs of these assessment, as outlined above, most young people in this cohort will miss out on getting assessment altogether. This means that these young people are unable to access the therapeutic support and services that they need.

Case Study

Daniel*, a 21-year-old man presented to DDHS in early 2020 with his mother due to concerns about a lack of motivation, poor social engagement and limited life skills. He had been sporadically attending mainstream bulk billing practices in Darwin for the past 8 years.

Daniel lived with his mother and was unable to perform even basic tasks of daily living, such as heating up a meal in the microwave or getting himself ready to attend an appointment. Any task

requiring forward planning or problem solving could only be achieved with his mother's direct input or prompting. Daniel was also experiencing significant anxiety symptoms related to social interactions, and he struggled to make and maintain relationships outside of his immediate family. His life was spent playing computer games and reading fantasy stories on the internet.

Daniel had previously received a tentative diagnosis of ADHD (inattentive type) as a child from a visiting Paediatrician, however, this diagnosis was never confirmed nor was any treatment initiated. Daniel had struggled at school and had very low academic achievement throughout his formal education. He has never entered the workforce.

Following a series of detailed assessments by the DDHS GP and primary health care team, Daniel was referred to the Top End Mental Health Service for diagnostic clarification. This assessment concluded that Daniel probably has a diagnosis of Autistic Spectrum Disorder (previously misclassified as ADHD), but a definitive diagnosis was not able to be made due to a lack of specialist diagnostic services available for adults with Autistic Spectrum Disorder in the Northern Territory.

Daniel is unable to receive further diagnostic assessment by specialist psychiatrists or psychologists due to an inability to access these services through the public system. Daniel has also not been able to receive any therapeutic inputs due to a lack of local expertise in adult Autistic Spectrum Disorder. Sadly, if he was <18 years of age then he would have access to the necessary services through the Child and Adolescent Mental Health Service.

This delineation of available services based on age is clearly a major service gap impacting vulnerable subsets of the population.

*This case study is drawn from a current client of DDHS. Some details and names are changed to maintain privacy.

5.3 DDHS role in supporting families through diagnostic assessment processes

DDHS believes that taking a holistic approach to child health by integrating early assessment and therapeutic services into primary health care will achieve the best outcomes for First Nations children and families. This was recognised by the NT FASD Strategy:

Within current resources, there will be a renewed focus on ensuring that primary health care staff are educated so that abnormalities can quickly be recognised and assessed. NT Health will increase the use of telehealth services for specialist advice when developmental concerns in children are identified, particularly in remote areas.²⁰

5.3.1 Background

Recognising the benefits of integrating these services into our broader service model, over the past few years DDHS has worked in partnership with the Top End Health Service (TEHS) Paediatric Department to improve specialist services for Aboriginal children in the Darwin/Palmerston region. In 2014, we established our own paediatric specialist service at the Palmerston Clinic in partnership with the Royal Darwin Hospital (RDH), which hosted visiting registrars and specialists. By 2018, we recorded a 26 per cent increase in paediatric specialist referrals and it became clear that our paediatric clinic needed to be reviewed to develop a more sustainable model.

²⁰ NT FASD Strategy at p 20.

Building on learnings from the DDHS paediatric clinic, in February 2019, with the assistance of the NT Department of Health funding²¹ and funding as part of a research project with PATCHES Paediatrics,²² DDHS established an Assessment of Behaviour and Child Development Clinic (**ABCD Clinic**) to support families and children with learning, behavioural and development issues.

These assessment processes, including for FASD, are complex and multidisciplinary and involve ruling out vision and hearing problems, neuropsychological assessment, as well as assessments by paediatricians, OT, physios and speech pathologists. For our clients, given the impact of trauma and overlapping vulnerabilities (as outlined above) we consider it critical that this process is embedded in a primary health care setting. The model strives to ensure cultural safety by providing integrated services and supports through the trusted Aboriginal Community Controlled Health Service setting. The ABCD Clinic was established with the aim of:

- Supporting First Nations families, children and carers to establish diagnoses and develop a support plan for children with neurodevelopmental and behavioural difficulties including FASD;
- Strengthening capacity of specialist and PHC staff in assessment, planning and ongoing primary health care for children with development and behaviour difficulties;
- Engaging children and their families in PHC and specialist follow ups and to identify children who are eligible for NDIS funded services and support them in the process of NDIS applications and access;
- Improving access to allied health services for DDHS child clients.

The collaborative model sought to combine the expertise of DDHS staff with knowledge of community and primary health care, together with paediatricians and registrars with an interest, knowledge and skill in development, behaviour, assessment and management. As outlined above, there are multiple overlapping vulnerabilities affecting many of our clients and their families. One of the key learnings of the ABCD assessment model was that addressing the social determinants of health - poverty and homelessness – cannot be uncoupled from the goal of completing the assessment process.

Case Study

Leanne*, a DDHS client, is the carer for her three grandchildren. One of the children was suspected of having autism, one was suspected of having ADHD, and all three had a history of trauma and suspected in-utero alcohol exposure. The children all came into Leanne's care with fecal incontinence and difficulty in learning and regulating behaviour. At this time, Territory Families were also involved as the school had made reports of concern regarding the children and possible neglect. Leanne was terrified of losing the children, whom she loved and cared for dearly.

At this time, the family came to the attention of the ABCD Clinic project officer through a referral from Leanne's regular DDHS clinic. Given the complexity of the case, it was decided that it was necessary to convene a case conference to develop an assessment and treatment plan. Through engagement with her local clinic, Leanne was supported to keep the assessment process on track,

²¹ Arising out of the NT FASD Strategy.

²² A nationally funded research and service development project, with a vision of building a private public assessment and planning service with sites across Australian. Funding for this research helped support an additional DDHS child health project officer position.

including referrals for hearing, vision and other relevant assessments. The children were engaged with several support services, including occupational therapy and play therapy to help address their complex trauma.

Working across the DDHS services, a social worker from our SEWB team was also engaged to assist Leanne with a range of other challenges, for example arranging furniture for the house.

*This case study is drawn from a current client of DDHS. Some details and names are changed to maintain privacy.

5.3.2 ABCD Clinic Learnings

Our ABCD Clinic strives to ensure continuity of care and so DDHS has prioritised the allocation of resources to engage and assist families through the assessment and diagnostic process by building on relationships of trust. A project officer was recruited to organise appointments and provide clinical and family support on clinic days. The paediatric registrars and paediatric nurse engage with the family to develop a relationship of trust and provide clarity about the processes.

However, in its current form, the ABCD clinic still requires some of our most vulnerable families and their children to attend multiple appointments both at DDHS and off-site with allied health therapists/psychologists to which they have been referred. The ABCD clinic does not have all the necessary allied health services in-house and relies on referrals to external services. We have been able to engage external providers of hearing, eye, speech, physio and occupational therapy (OT) services, however again, referrals to these services take time and the complexity of needing to attend multiple sites at different times to complete all assessments means diagnosis is much less likely to occur in a timely manner. Thus children and their families are often delayed in accessing important treatment and support.

By way of comparison, the Central Australian Aboriginal Congress (**Congress**), an ACCHS in Alice Springs, has a Child and Youth Assessment and Treatment Service team, established in April 2018. The team has grown substantially over this time and now includes a team leader, two neuropsychologists, two speech pathologists, one OT, one Aboriginal Family Support Worker and a Clinical Case Coordinator. This service sees six children over a six-week period for a differential assessment. Though, as Congress noted in their submission to this inquiry, there are long wait times for these assessments (up to 18 months), they are able to offer a 'one stop shop' model, adapted to meet the needs of clients.

DDHS strives to ensure holistic engagement and integrated services across all our clinics, building on relationships of trust to assist and empower clients to navigate complex referral pathways and systems. A comprehensive model of care like that which Congress is able to offer through the Child and Youth Assessment and Treatment Service Team, would enable children and families to access all relevant assessments and supports to meet their complex and overlapping needs (e.g. vision, hearing, impact of trauma and other developmental concerns) as well as assisting with other challenges like accessing safe accommodation.

5.3.3 Proposed DDHS Child Development Clinic – 'DDHS Kids'

If adequately resourced to do so, DDHS would be very well-placed to develop capacity to provide diagnostic and therapeutic services as part of a comprehensive primary health service. We would also be able to expand our existing early recognition and therapeutic support programs.

To this end, building on our learnings from the ABCD clinic model, DDHS has applied for funding to expand our targeted child health and developmental services across the greater Darwin region.

While the ABCD clinic has helped to increase DDHS child-client access to specialist paediatric services, the level of need has far exceeded the limited resources currently available.

Ongoing sustainable funding of the proposed 'DDHS Kids' team will assist the DDHS primary health care team to coordinate the assessment and care of children with complex neurodevelopmental and behavioural needs, addressing the challenges outlined above.

Recommendation (1): The Commonwealth Department of Health should make available consistent, long-term funding for Aboriginal Community Controlled Health Services, to coordinate and deliver culturally appropriate assessments for Aboriginal clients of all ages as part of an integrated comprehensive primary health care model.

6 Access to therapeutic interventions and support

As outlined above, a child who has (or is suspected of having) a disability, or neurodevelopmental or behavioural issues, is at greater risk of neglect or abuse. These challenges are compounded where parents or caregivers are not educated to understand the child's disability and therapeutic services and appropriate community supports are not available to support them. In this context, early access to allied health intervention is *essential* so that the child (and their parent or caregiver) accesses therapy to help them manage behaviours, build capacity (e.g. in speech and language) and develop essential life skills. This is important to help support the child's education, regulation, behaviour and social skills going forward.

6.1 Challenges accessing therapy through NDIS

Children aged 0-6 years with developmental delay should be able to access NDIS supports through the ECEI scheme. Older children who are assessed and have a diagnosis of a 'significant and permanent' disability, such as ASD, FASD or Intellectual Disability, should also be eligible for NDIS funding. However, our staff have experienced great challenges assisting clients to access therapy and treatment through the NDIS even where children or young people meet NDIS criteria. In our experience, often clients are not empowered to understand the system or to access the supports they are entitled to.

Even after a child has received a diagnosis, there can still be a lengthy wait until the child begins to receive supports under the NDIS. DDHS service-level examples have highlighted that the time between first referral and being considered 'access met' under the NDIS could be as long as 2.5 years.

DDHS has a health justice partnership with NT Legal Aid Commission (**NTLAC**) to help connect clients to legal assistance if they need it. NTLAC have provided training for DDHS staff regarding NDIS referrals and have also provided assistance for clients and families struggling to gain access to supports through the NDIS. However, we continue to be concerned by the fragmented nature of the scheme and challenges navigating it.

Case Study

DDHS client Angela* and her partner Thomas* are kinship carers for their 8-year old grandson Malcolm, whose mother lives in a remote Aboriginal community in Central Australia. Angela and Thomas are an ageing couple who also have complex health needs and are care-coordinated clients at DDHS.

Malcolm has a diagnosed language disorder, speech sound disorder, low average cognitive function and adaptive behavioural function. He has an NDIS plan, however his grandparents do not know

what support is being provided under the plan. The plan has not been provided to DDHS, the referring paediatrician or Malcolm's school, who have all been attempting to understand the supports being provided by NDIS and to advocate for funding for necessary therapy. In a recent report the Paediatrician suggested that respite care should be provided under the NDIS plan as Malcolm is a high needs child being cared for by his ageing grandparents.

DDHS recently received a request for information from Malcolm's NDIS Coordinator of Supports (COS). Upon request, the COS provided DDHS with a report about Malcolm's NDIS plan, which essentially confirmed the GP's suspicion that no supports are actually being provided. The report notes that the COS is providing "support as required to strengthen the participant's ability to design and build their supports with an emphasis on linking broader systems of support across a complex service delivery environment." There is no evidence of any therapy actually being provided or any planning for respite care. Despite requests from Malcolm's grandparents to help them get the supports they need, both DDHS and Malcolm's school are being left out of planning processes and have had no communication from services providers about what is being provided under the plan.

*This case study is drawn from a current client of DDHS. Some details and names are changed to maintain privacy.

6.1.1 Role of primary health care providers in coordinating supports

DDHS are concerned by the lack of feedback from and communication between NDIS service providers and the primary health care team. As the case study above demonstrates, there is almost a complete lack of communication between service providers and health services in most instances. This leads to potential risks for clients and an inability to coordinate comprehensive care. There is also an apparent lack of transparency or oversight in many cases, where key support services (like DDHS and the school in the above example) seem to have been excluded from the process.

Primary health care providers, in particular general practitioners, should play a key role in assisting clients to access the NDIS and overseeing the implementation of their plans. The Royal College of General Practitioners notes:

GPs are an essential link for patients with disability in accessing the NDIS and helping them to navigate through it ... Once a plan has been drawn up, the GP can provide valuable feedback as to the adequacy of the plan and whether it sufficiently meets the need of the individual. At times the GP may need to advocate for their patients to have a revision of the plan.²³

There is a need for specialist support coordination for our clients. To this end, DDHS welcomes key aspects of the Government's response to the 2019 Review of the NDIS Act and the new NDIS Participant Service Guarantee (**'The Tune Review'**) recommendations including the expansion of the NDIA's Information, Linkages and Capacity (ILC) Building program and the National Community Connectors Program (NCCP). DDHS has been successful in obtaining a grant under the former and is in the process of registering as a service provider for the latter. While both programs will help to improve our client's access to assessment and the NDIS, both programs are intended to run for a very limited timeframe and this will undermine the achievement of the desired outcomes.

The ILC program is set to run for two years to 30 June 2022. At the time of writing this submission in November 2020, a funding agreement has yet to be finalised, reducing the limited service delivery period to less than two years. Likewise, the NCCP provides funding for two staff positions for a

²³ <https://www1.racgp.org.au/newsgp/professional/gps-role-in-linking-patients-with-the-ndis>

period of only twelve months. Once recruitment and onboarding processes are finalised, the NCCP for instance, will have a period of months to achieve the systemic change identified by the Tune Review and required in order to achieve a structural improvement in access for First Nations people to the NDIS.

The ability of Aboriginal Community Controlled organisations like DDHS to achieve the desired outcomes of these programs will be significantly impacted by the short and non-recurrent nature of these programs. Furthermore, despite the recent publication of the draft Indigenous Evaluation Strategy by the Productivity Commission which foresees a whole-of-government commitment to embedding and resourcing culturally appropriate evaluation for services for First Nations people, neither of these programs provide dedicated resourcing for evaluation.

Recommendation (2): The National Disability Insurance Agency should embed the role of ‘community connectors’ and other culturally appropriate supports into the core operation of the NDIS through sustainable and recurrent resourcing of appropriate community controlled organisations.

6.1.2 Need for capacity building supports

Where therapy is provided, there is often a focus on the behaviour of the young person, particularly where concerns are initially raised by schools or engagement with the justice system. Our experience tells us that we must extend the conceptualisation of the challenges for these children and families beyond behaviour management to include broader skills development (capacity building) in a culturally appropriate and responsive way.

In particular, the DDHS SEWB Team have noticed a trend in counselling referrals for children who are displaying perceived difficult behaviours and mental health concerns. A review of their files often reveals a multitude of underlying neurodevelopmental difficulties, including cognitive impairment and communication disorder. Unfortunately, the focus on behaviour management often means the underlying difficulties are ignored and the intervention that occurs is reactive, e.g. school suspensions, behaviour management plans and crisis responses. As a DDHS speech pathologist notes:

In a system that does not understand them, a child with a disability becomes known as “a bad kid” and they start to see themselves in this way too. It is unlikely that children with these difficulties will ‘catch up’ to their peers. In the example of a language disorder, the gap between the child and their typically developing peers continues to widen. This is because the expectations and demands continue to increase as the child progresses throughout school and into adulthood.

Where children are not provided with timely and appropriate intervention, they are at risk of disengagement at school, behavioural difficulties, maltreatment, incarceration, mental illness and suicide. In particular, the parents and carers of children with FASD or other neuro-developmental impairments need to be able to support them in the development of life and education skills, particularly in the context of challenges in daily activities including learning, attending, sitting still, regulating and impulse management.

Case Study

Samuel* is a 7 year old boy with a diagnosis of FASD, ADHD and suspected cognitive impairment. He is in foster care, being cared for by a couple. Initially they had the view that as they provide a safe predictable environment, he would ‘settle’ and manage the demands of school and everyday life. His

challenging behaviours, including many ‘meltdowns’, were often conceptualised as ‘part of his personality’ and history of trauma.

Working with a DDHS child psychologist, the carers were able to understand these challenges in the context of his diagnoses and were able to adjust expectations and responses to how he learned. When the difficulties overwhelmed him, it was helpful for the carers to see him from the perspective of how he experiences the world. For example, they realised he needed reminders because of his difficulties with memory, rather than because he ‘didn’t listen’.

Consequently the carers became advocates at his school when reference was made to his behaviour – reframing that for teachers as being part of his diagnoses. They were also much more able to work with his high levels of arousal *pre-emptively* rather than reactively, which helped him develop a sense of safety in different settings. They also reflected his ‘excitement’ more regularly, which tended to keep levels of arousal in a more ‘calm alert’ state cognitively. Consequently in his therapy he more quickly developed motor skills (particularly fine-motor), was able to play at one game longer (improved attentional capacity) and manage disappointment when things did not work out.

*This case study is drawn from a current client of DDHS. Some details and names are changed to maintain privacy.

6.1.3 Lack of culturally appropriate services

It has been our experience that even where a child is assessed and approved access to NDIS, there is very poor access to allied health for treatment and other services in the Darwin-Palmerston region. In many cases, once a FASD or other diagnosis is made, NDIS may provide funding for support coordination to arrange treatment and therapy but access is still an issue, let alone access to culturally safe care. It is our experience that many of our most vulnerable clients and families are also not accessing Allied Health services in the Darwin region.

For our client base, these services should be integrated into our comprehensive model of care to ensure continuity of care. There are already Aboriginal and Torres Strait Islander allied health services within Australia. One example is the Aboriginal Children’s Therapy Team (ACTT) in Dubbo, Western NSW. ACTT is funded by Indigenous Australian Health Promotion (IAHP), Commonwealth Department of Health. The eligibility criteria for the service is:

- 0-8 years
- Not eligible for NDIS
- Dubbo postcode
- Confirmation of Aboriginality (COA)

The team comprises of 1.5 Speech Pathologists, 1 Occupational Therapist, 0.2 Psychologist (outsourced privately), 1.5 Aboriginal Community Support Worker and 1 Therapy Assistant. At present there is a significant waiting list for the service, including at least 50 people long for Psychology and 70-80 for Speech Pathology. Often children attend for one discipline e.g. Speech Pathology, and the assessment process will identify vulnerabilities in other developmental domains which then sparks internal referrals to others, e.g. OT, Psychology.

In addition to ACTT, Dubbo also has a Community Health Centre with an Allied Health Team. Some Indigenous families will choose to access this mainstream service over the ACTT. This highlights the potential demand for a First Nations allied health services in Darwin. The challenge for ACTT has been to manage through-put, as there hasn’t been any limit on the number of sessions.

ACTT was established around 2010-2011 based on research that showed Aboriginal people were not accessing the mainstream allied health service in Dubbo. The team have a flexible service model and provide additional supports not offered by the Community Health Centre, e.g. transport. ACTT also has a “bridging role” in linking eligible children with Dubbo’s ECEI partner, Mission Australia.

Recommendation (3): The Commonwealth Government should fund Aboriginal Community Controlled Health Services to provide integrated allied health support as part of a comprehensive primary health care model.

6.2 Independent Functional Capacity Assessments

The Tune Review raised concerns regarding challenges people with disabilities face accessing diagnostic assessment. In response to the Tune Review, the Government has proposed to roll out ‘independent assessors’ to undertake functional capacity assessments to support NDIS access, planning and review. We are concerned that this response will not meet the particularly complex needs of our clients outlined above.

We reiterate concerns raised by several disability advocates that the Government’s response is not consistent with the Tune Review’s recommendation that the NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments.²⁴

As other disability advocates have noted, it is also very concerning that tender documents indicate that time spent face-to-face with a client to undertake these assessments could be as little as 20 minutes.²⁵ Short, stock standard testing is not likely to be sufficient to gain an understanding of our clients’ needs – including cultural needs, for example, the ability to continue to participate in ceremony or other cultural obligations. As outlined above, working with vulnerable children and families in a comprehensive and culturally appropriate way (including the use of interpreters and/or cultural liaisons) requires a commitment of time to build trust and rapport and to be able to gain a proper understanding of the client and their needs.

We understand that the proposal will also require existing participants to have an assessment for reviews at critical life points (e.g. when leaving school or moving out of home), and then gradually every single participant will need to have one of these assessments when they have a plan review.²⁶ This is inconsistent with the Tune Review, which was recommended only for *prospective* participants not those already on the scheme.

Finally, the Tune Review recommended consultation prior to the shift to independent assessments. The NDIA is being criticised for a lack of consultation in the implementation of this approach. Though the results from the first stage of the pilot (November 2019 – April 2019) were reported by the NDIA to have largely positive outcomes, absent from the pilot results is any data from the second pilot, which ran from November 2019 to June 2020, was paused due to COVID-19 and will now be restarted. There is very little information publicly available about the cultural backgrounds and contexts of the client group that were involved in the first pilot. In particular we are concerned that there has been little or no consideration of the needs of First Nations participants, particularly from remote areas.

Recommendation: The Commonwealth Government should undertake widespread consultation about the independent functional assessment scheme before it is rolled out more broadly. This

²⁴ At 4.37.

²⁵ <https://everyaustraliancounts.com.au/questions-for-minister-robert-about-ndis-independent-assessments/>

²⁶ <https://everyaustraliancounts.com.au/testing-times-in-the-ndis/>

should involve specific consideration of the suitability of the scheme for First Nations children and families.

6.3 Barriers for children and young people who do not meet diagnostic criteria

For Children who are 7 and over (who are ineligible for ECEI) it is extremely difficult to get access to the NDIS scheme without evidence of a 'significant and permanent' disability. We are also concerned for children approaching their 7th birthday who gained access to the ECEI scheme due to developmental delay, however this diagnosis alone is unlikely to see continual access to the NDIS beyond their 7th birthday. Unfortunately, the education system also relies on diagnosis to fund additional supports in the classroom.

Case Study

Liam, a 7-year-old boy was referred to the DDHS SEWB Team by his Paediatrician for psychological therapy. The client came into out of home care from remote Northern Territory, with a background of domestic violence. His carer reported that his behaviours were becoming difficult for her to manage, e.g. screaming, throwing things and breaking things. School Psychology reports also indicated that his behaviour had been a problem for his teachers at school, including aggression towards others, poor attention, hyperactivity and impulsivity.

Liam had been diagnosed with ADHD and placed on medication which was somewhat helpful in reducing aggressive and impulsive behaviours. He was also taking Melatonin because he hadn't been sleeping. Liam was continuing to find school difficult and was not meeting his academic milestones. Assessment by the school Psychologist indicated borderline cognitive delay and low to extremely low scores in adaptive behaviour. There were also concerns about his speech and language development. He was on the waiting list for Occupational Therapy and Speech Pathology assessment at CDT at the time of referral.

Liam previously had an NDIS plan under the ECEI program. NDIS supports finished when he turned 7 because he did not have evidence of a significant and permanent disability. In light of his 'borderline' IQ results, a repeat cognitive assessment was recommended for two years time "when he has had consistent schooling and his English speaking is fluent" to see if he meets criteria for Intellectual Disability and thus access to NDIS and educational supports.

In the meantime, despite his evident need, Liam has no access to funding.

*This case study is drawn from a current client of DDHS. Some details and names are changed to maintain privacy.

7 Disability needs of children in care

There is no accurate published data about the prevalence of FASD or developmental impairment among children in the care system in the NT, though anecdotally it is expected to be high. The NT Royal Commission discussed the issue of disability among children in care, noting that:

- At 30 June 2016, there were 112 children with a disability in out of home care in the Northern Territory.
- Of these children, 44% had an intellectual or learning disability and 37% had a physical disability.

- In 2015–16, 72 children with disability who were in care were on a long-term order.²⁷

The prevalence of neurodevelopmental impairment in particular was recognised by the NT FASD Strategy,²⁸ which acknowledged the expected high prevalence of FASD among children in care:

Another priority group is children in out of home care. Early assessment for neurodevelopmental impairment and linking these children with support services may prevent future contact with the juvenile justice system. The Territory Government will facilitate the assessment of all children in out of home care.

The risks of failing to provide these children with timely and appropriate intervention are well-known: disengagement at school, behavioural difficulties, maltreatment, incarceration, mental illness and suicide.²⁹ Despite this, we are concerned that many children in care are not accessing the diagnostic assessments, therapeutic interventions or support that they need in a timely way.

Through our work at DDYDC in particular, we have been concerned to observe that the vast majority of children coming into detention are in the care of Territory Families prior to their detention. This highlights the deficits of the current child protection systems in supporting children to access appropriate assessments and supports.

Case Study

Jimmy*, from a remote community in the NT, was born prematurely and diagnosed with failure to thrive. He has a history of developmental delay, learning problems and poor social skills. He has been in the care of Territory Families almost from birth, and has experienced a history of abuse, neglect, disrupted attachment, multiple care placements and parental substance dependence.

Jimmy was diagnosed with FASD with neuro-developmental impairments, as well as Attention Deficit Hyperactivity Disorder (ADHD). At this time, an application was made for access to the NDIS, which was approved. However, the plan was never implemented and Jimmy did not access any supports.

He was remanded in detention for criminal offending before his plan was implemented. Despite the FASD and ADHD diagnoses, he was held on remand in detention for over a year, unable to access the therapeutic supports he needed.

8 Disability needs of children in the justice system

There is a recognised high prevalence of neurodevelopmental impairment among children in the justice system. A recent study at Banksia Hill Detention Centre in Western Australia (**The Banksia Hill Study**) found that 89 per cent of young offenders have a severe neurodevelopmental impairment, and 39 per cent were diagnosed with FASD.³⁰ Whilst we cannot yet provide rigorous estimates of the prevalence of FASD at DDYDC, early indications are that it is at least as high as that found in the Banksia Hill study.

²⁷ Royal Commission Final Report, Chapter 33, p 440.

²⁸ NT FASD Strategy p 23-25.

²⁹ INSERT.

³⁰ Carol Bower et al, 'Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia' *BJM Open* (19 February 2018)

<http://bmjopen.bmj.com/content/8/2/e019605>.

8.1 Barriers to assessment and diagnosis

DDHS clinical staff at DDYDC have continued to raise concerns regarding lengthy delays progressing diagnostic assessment for young people in detention. In addition to all the issues accessing assessments outlined above, there are additional challenges for children in detention. Our team have observed a high degree of fragmentation in the coordination of assessment and lack of clarity regarding responsibilities of different government agencies – particularly where children are in the care of Territory Families when they come into detention. These challenges are compounded as children are often in and out of detention quite quickly (often within a few days).

We are particularly concerned about lengthy delays in accessing assessments where children and young people are on remand. We have several case studies to highlight these concerns, however given the small numbers of children in detention we would prefer to provide these confidentially to the Royal Commission.

8.2 Appropriate therapy and support for children in detention

We are particularly concerned about the lack of appropriate therapy or support for children with FASD or other neurodevelopmental impairments while in detention and upon release. Children with neurodevelopmental impairment in the justice system require specialised services and supports, including for example communication intermediaries that can support effective communication with judges, lawyers, service providers and detention staff. We have observed that these are not being provided on a regular basis.

8.2.1 Access to NDIS for Children in Detention

Until recently, no NDIS supports were provided to children in detention, due to advice received from NDIA staff to the effect that people in detention (including children) do not typically receive supports until they are released. Although NDIS services are now available for some children in detention, access to NDIS continues to be sporadic and uncoordinated. We have also raised concerns regarding the limited engagement or involvement of the primary health care team who know these children and their health needs best.

There is a clear need for clarity on entitlement to NDIS for children in detention, and a holistic process for these children including proper assessment on entry to detention with a clear pathway to full assessment if required.

Recommendation (5): The Commonwealth Government should ensure that the National Disability Insurance Scheme (NDIS) is available to fund the provision of support for children in detention in a consistent way. In particular, the availability of providers of these therapeutic supports for children in detention should be reviewed to ensure that NDIS plans are actually implemented in detention.

8.2.2 Access to Medicare for Children in Detention

If adequately resourced to do so, DDHS would be very well-placed to develop capacity to provide diagnostic and therapeutic services for children both in detention and post-release as part of a comprehensive primary health service. We would also be able to expand our existing early recognition and therapeutic support programs as outlined above.

To this end we wrote to the Commonwealth Minister for Health requesting that the Commonwealth make available Medicare benefits and the Pharmaceutical Benefits Scheme to our clients in Don Dale under a 19(2) exemption, for which our service is eligible as an Aboriginal Community Controlled

Health Service. This request is consistent with the NT Royal Commission's recommendation that the Commonwealth Minister for Health:³¹

- a. make the necessary directions under section 19(2) of the Health Insurance Act 1973 (Cth) to enable the payment of Medicare benefits for medical services provided to children and young people in detention in the Northern Territory
- b. take all necessary steps to ensure that supply of pharmaceuticals to children and young people in detention in the Northern Territory is provided under the Pharmaceutical Benefits Scheme, and;

We note that the Commonwealth did not support this recommendation, on the grounds that Prisoner health care remains the responsibility of state and territory governments under corrective services legislation.³² We were disappointed to receive a response from the Minister Hunt declining our request on similar grounds.

Our view is that allowing the use of Medicare for young people in detention is a policy decision that can be accommodated under the *Health Insurance Act 1973 (The Act)*. All Aboriginal Community Controlled Health Services and all remote state government Aboriginal health clinics already hold a 19(2) exemption allowing billing under Medicare. DDHS currently holds an exemption for all our primary health clinics across the Darwin-Palmerston region, except DDYDC.

The rationale for the 19(2) exemption is contained in the factsheet regarding s (19(2)).³³ In short, the 19(2) exemption recognises the high level of health needs of Aboriginal people and the fact that Aboriginal people do not access Medicare through private general practice at the same level as the rest of the population. In this context, access to Medicare revenue is an opportunity to better support health among vulnerable young people.

The inability to access Medicare revenue and access to pharmaceutical benefits for the clinic at DDYDC limits our capacity to provide comprehensive primary health services that meet the complex needs of children in detention. Additional funds generated through Medicare would allow us to improve health services for vulnerable young people including:

- Enabling us to undertake comprehensive, culturally appropriate assessment to identify the therapeutic and developmental needs of vulnerable young people.
- A range of social and emotional well-being services in addition to the funded psychologist position, including group-based therapies, play therapy, music therapy.
- Engagement of traditional healers as appropriate for the young person.
- Culturally safe allied health input.
- Alcohol and other drug detoxification and rehabilitation support.
- Improved post release health planning and liaison with health care providers in the young person's home location.

³¹ NT Royal Commission, Recommendation 15.4.

³² Commonwealth Department of Social Services, 'Commonwealth Response to Royal Commission' (Last Updated 23 October 2019) at <https://www.dss.gov.au/families-and-children/programs-services/children/royal-commission-into-the-protection-and-detention-of-children-in-the-northern-territory>

³³

- In-reach services from DDHS to let the young people get to know and build trust with community clinic staff prior to release, giving Darwin and Palmerston based young people a trusted and seamless primary health care service whether in detention or in the community.

In addition, DDHS could utilise Medicare funds generated in detention to provide additional supports and services to young people in contact with the justice system but not in detention through our Community Youth Diversion program or to self-fund early intervention family support services.

Recommendation (6): The Commonwealth Minister for Health should:

- make the necessary directions under section 19(2) of the Health Insurance Act 1973 (Cth) to enable the payment of Medicare benefits for medical services provided to children and young people in detention in the Northern Territory
- take all necessary steps to ensure that supply of pharmaceuticals to children and young people in detention in the Northern Territory is provided under the Pharmaceutical Benefits Scheme.

8.3 Workforce skills and capabilities and training for detention staff

We have observed the difficulty that youth detention staff and management face in trying to appropriately manage children with FASD or undiagnosed neurodevelopmental impairments. It is well-known that children and young people with FASD and other neuro-developmental impairments often have difficulty understanding, following instructions and often have poor emotional regulation. To the untrained eye this may be interpreted as ‘bad behaviour’ or wilful ignorance of instructions.³⁴ The Royal Commission into the Protection and Detention of Children in the NT (NT Royal Commission) found that:

The environment of youth detention in the Northern Territory on the whole did not provide the structured, regular, predictable and therapeutic environment required for children and young people with FASD.³⁵

It is our assessment that many existing responses to challenging behaviours in DDYDC may be counterproductive and even lead to further escalation of some situations. This is not meant as a criticism of the individual staff members at DDYDC or their management, but more a reflection of the significant paradigm shift that must occur in order to appropriately care for many young people in detention.

In particular, we note that a number of the children involved in significant incidents, whose freedom of movement and association in the facility is restricted to ‘manage’ their behaviour, have been diagnosed with FASD or are currently being assessed for this.

³⁴ See Carol Bower et al, ‘Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia’ *BJM Open* (19 February 2018) <http://bmjopen.bmj.com/content/8/2/e019605>; Foetal Alcohol Spectrum Disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce Hayley M. Passmore (Australia).

³⁵ Royal Commission Final Report, Chapter 15, 351.

8.3.1 Staffing and Qualifications

It has been positive to see that since the NT Royal Commission many new youth justice officers (YJOs) have been recruited and new staff are provided with a six-week induction that includes trauma informed training. Despite these improvements, we have observed that workforce and recruitment strategies are continuing to fail, as evidenced by constant attrition of YJOs, absenteeism and turnover generally.

Specifically, we are concerned that YJOs are inherently conflicted in their roles and functions, compromising their ability to meet young people's complex needs and in turn fuelling staff attrition and absenteeism. We have observed that YJOs are expected to perform a security role, which involves day to day management of young people (managing lock downs, providing food and managing movement through the centre), despite the presence of full-time security guards on site. YJOs are also expected to support the wellbeing and broader education or development of young people. It is clear that some staff, particularly those without relevant training or qualifications in child development, teaching, social work or youth work are less comfortable with performing the latter function.

By comparison, evidence based therapeutic youth justice models overseas have fundamentally different staffing models. In Spain, for example, youth justice facilities are run by non-government organisations. The largest of these is the Diagrama Foundation. Diagrama have a proven track-record of working with young people with complex needs. These needs are identified through Diagrama's comprehensive case management and assessment processes. The assessment then informs the development of a suitable plan for each young person and informs how staff – a highly qualified team of social workers and educators – work with young people in order to meet their needs.

DDHS and the Aboriginal Medical Services Alliance NT (AMSANT) facilitated a visit from Diagrama to the NT in October 2019. The Diagrama CEO, David McGuire and his team visited DDYDC and ASYDC, as well as supported bail and other facilities in the NT. A report detailing their findings and recommendations 'A Blueprint for Change in the NT' is published on the DDHS website.³⁶ The team raised concerns regarding the staffing model and noted:

"It was good to see that many new YJOs have been recruited, some with excellent qualifications, and with the ability to understand and relate well to young people. We were also pleased to hear that new staff are provided with a six-week YJO induction that includes an understanding of trauma-informed practice and cultural competence.

However the role of the YJOs does not appear to have changed consistently in line with this and we saw clear differences in how people saw their role. We were particularly impressed by some of the staff who have taken the initiative to lead activities with young people, such as music recording and sports. Others, though, were less comfortable with an ethos that was not security focused and did not see it as central to their role to form strong relationships with young people or to lead activities and engage in young people's broader education. This is a potential waste of some staff members' skills."³⁷

In comparison, Diagrama have one role specifically related to welfare and engagement with young people and one for security. The welfare staff are responsible for leading and running the daily life of young people in the centres, including daily living (e.g. eating, cleaning and setting standards of

³⁶ Diagrama Foundation, Blueprint for Change (2019) <https://ddhs.org.au/resources/blueprint-change-diagrama-foundation-report>

³⁷ Ibid, at p 24.

behaviour. These staff need to be able to build good relationships with young people, motivate them to engage, be proactive and act as role models. These staff are highly skilled professional staff, with qualifications in teaching, social work or psychology and the ability to work with children with complex needs.

Recommendation (7): The Northern Territory Government should review the workforce capabilities of youth detention centres, prioritising funding for the recruitment of:

- a. Senior personnel and a multi-disciplinary work force with relevant qualifications and minimum of 4 years experience working with adolescents; and
- b. First Nations staff, particularly into senior leadership positions.

8.3.2 Training for Staff - Reframe

Although management and staff at DDYDC are becoming increasingly aware of the prevalence of FASD and neuro-developmental impairment, there is still insufficient knowledge about how to work with and achieve good outcomes for the children and ensure good order in the detention centres. In light of this, we looked into evidence-based training programs that could be of benefit to the NT's custodial workforce.

We are drawn to the 'Reframe' training program being rolled out in Western Australia, with great outcomes. Following the conclusions drawn in the Banksia Hill Study, researchers at the Telethon Kids Institute developed this training program for custodial workforce about how to work with children in detention with neuro-impairment.

As the Banksia Hill team noted:

it is vitally important that frontline professionals engaging with vulnerable populations of children and young people are aware of neurodevelopment impairments and the resulting behaviours, as well as equipped with strategies to help work with affected young people. This is particularly relevant to professionals in the police, justice, child protection, education, health and community services sectors.³⁸

The evidence-based Reframe training about FASD and other neurodevelopmental impairments has been tailored specifically for the youth justice workforce. The training was trialled and evaluated with over 100 justice professionals in WA. It has been found to be a highly effective method of improving participants' understanding of FASD and its implications.³⁹

Recommendation (8): Evidence-based FASD training should be developed and delivered in the Northern Territory for all staff working with children in detention.

³⁸ Telethon Kids Institute, Reframe: Workforce training on the behavioural implications of Fetal Alcohol Spectrum Disorder (FASD) and other neurodevelopmental impairments (2019)

³⁹ Hayley M Passmore et al 'Reframe the Behaviour: Evaluation of a training intervention to increase capacity in managing detained youth with fetal alcohol spectrum disorder and neurodevelopmental impairments' (2020)

<https://www.tandfonline.com/doi/abs/10.1080/13218719.2020.1780643?forwardService=showFullText&tokenAccess=7HY3MNM5DIZHA7UTY6JU&tokenDomain=eprints&doi=10.1080%2F13218719.2020.1780643&doi=10.1080%2F13218719.2020.1780643&doi=10.1080%2F13218719.2020.1780643&target=10.1080%2F13218719.2020.1780643&journalCode=tppl20>

8.4 Lack of appropriate secure facilities for children with complex needs

There is a dire need for a secure therapeutic residential facility in the Northern Territory to accommodate and rehabilitate young people with FASD and other neurodevelopmental conditions. It is abundantly clear to our team that given the complex health and developmental needs of some children in detention, they require a secure therapeutic facility, not a detention centre. We are concerned about the entrenchment of young people with neurodevelopmental impairment (particularly FASD) in detention without access to therapeutic supports to meet their complex needs.

In particular, we are concerned that young people under 12 who are suspected of being *Doli Incapax* (that is, not criminally responsible) or over 12 who are suspected of being 'not fit to plead' or 'not fit to stand trial' due to mental impairment,⁴⁰ are held in detention. We have been particularly concerned by cases in which young people with neurodevelopmental impairments who have been found unfit to plead or not guilty by way of mental impairment, are kept in custody at Don Dale because there are no appropriate alternative options for them to live. This is contrary to a legislative requirement that a person who is not guilty by way of mental impairment be accommodated in an 'appropriate place', namely a therapeutic facility.⁴¹

The Western Australian Office of the Inspector of Custodial Services has recommended that:

'community based alternatives to custody orders for people who are found unfit to stand trial but require some degree of supervision'

We have done significant research into this area to explore alternative living options for young people with severe neurodevelopmental and trauma related impairments. These models aim to divert young people away from the criminal justice system and to provide therapeutic support services that cater specifically to the needs of the child. As there is very little evidence of best-practice in this area in Australia, we believe we should look carefully to effective international approaches. We are particularly drawn to the evidence based therapeutic secure care units developed by the Diagrama Foundation.

Diagrama's centres have therapeutic units both for those with significant mental health conditions and for young people in the justice system who have mental health issues.

In the NT, there have been some attempts to implement a therapeutic secure residential care model in the out-of-home-care context. This is relevant as many of the children in detention are also in care of Territory Families. In April 2009, the Department of Children and Families (now Territory Families) announced a commitment to fund the establishment and operation of secure care services for children with complex needs. However, the model was never properly implemented.

Building on the learnings of effective interstate approaches to secure therapeutic residential care, like the Sherwood House Model (NSW) it is clear that these facilities must be run by highly skilled, multidisciplinary teams that can provide comprehensive supports to meet children's needs. More work needs to be done to develop and implement an appropriate secure care facility for children in the NT with complex needs. While we continue to advocate for this, we have been met with little response from government.

⁴⁰ Senate Standing Committee on Community Affairs. Report on the Inquiry into 'Indefinite Detention of People with Cognitive and Psychiatric Impairment in Australia.' Chapter 2.

⁴¹ See s 43ZA(2A) Criminal Code

Our experience delivering health and social support services at DDYDC has indicated that there is a clear need for culturally appropriate, therapeutic secure facilities as an alternative sentencing option for young people with complex needs that require intensive support and care. It is absolutely clear to our staff that several of the children at DDYDC today should be in a secure therapeutic facility, not a detention centre.⁴²

Case Study

Patrick* is a young person who was detained at Don Dale Youth Detention Centre. Patrick had been diagnosed with Foetal Alcohol Spectrum Disorder and a history of trauma starting from abandonment at birth and multiple placements whilst in the care of Territory Families.

In mid-2018, an incident occurred while Patrick was at Don Dale, resulting in him being kept away from other young people to manage his behaviour and 'risk' to other staff and young people. Complaints were made to the Children's Commissioner on his behalf, but nothing was done. Two weeks later Patrick was involved in a further serious incident that resulted in further serious criminal charges and a further sentence of imprisonment.

It was not until after this incident that an assessment revealed Patrick has FASD with "very low" mental functioning, on top of his diagnoses for major depression and substance misuse disorder. Shortly after this, lawyers applied on Patrick's behalf to the NDIS for access to therapeutic supports in detention. However, the application, which should be processed within 21 days, went unanswered for months. Patrick's lawyers applied for the case to be reviewed by the Administrative Appeals Tribunal and he was finally granted access to NDIS.

Shortly after this Patrick turned 18 and was transferred to the adult correctional centre. He is still serving a term of imprisonment as a result of the incident he was involved in while at Don Dale.

Recommendation (9): The Commonwealth and Northern Territory Governments should coordinate to provide funding for the development and implementation of a therapeutic secure facilities for children with high needs relating to their disabilities, including children in the justice system. These should be developed in partnership with local Aboriginal Community Controlled Health Services.

9 Conclusion

Our submission highlights the systemic failure to identify and address the complex needs of First Nations children with disabilities, particularly those with neurodevelopmental impairment or developmental delay. As our submission and associated case studies demonstrate, lack of support for families of children with disabilities can lead to a perpetuating cycle of parental neglect, engagement of child protection services, school-disengagement and ultimately, entrenchment in the criminal justice system.

Our submission explores the benefits of delivering a comprehensive primary health care model, integrating education, early assessment, multi-disciplinary and specialist treatment and therapeutic interventions in a holistic wraparound model. Our experience demonstrates that Aboriginal Community Controlled Health Services are well placed to coordinate and deliver these services,

⁴² We have several case studies regarding current clients at DDYDC, however given the small number of children in detention we would prefer to provide these confidentially to the Royal Commission.

leveraging off existing relationships of trust to ensure continuity of care and support throughout the client journey.