



Jarjum Health Planning Project for Lifetime Wellbeing

IMPROVING THE HEALTH OUTCOMES FOR ABORIGINAL CHILDREN IN OUT OF HOME CARE

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1. Project overview and summary statement

Project overview

The project was developed to improve the health outcomes of Australian Aboriginal children presently under Ngunya Jarjum Out-Of-Home-Care (OOHC) case management and families serviced through the Ngunya Jarjum Gumaguy (Family preservation) program.

The project sought to gain increased understanding of the prevalence of chronic health conditions, including notification of disability assessment in health reporting found across approximately 150 health files of Aboriginal children and adolescents who are currently under Ngunya Jarjum OOHC case management.

Further to this, the intention of the project, via its design, was to develop increased knowledge of the NDIS system for casework staff and their managers, as well as caregivers. Particularly the process undertaken by caseworkers for new applications, including awareness of the various types of supporting evidence required by the NDIS National Access Team.

To reach other intended project aims, various activities were undertaken, such as the development of several casework tools to increase knowledge, informing practice and assist caseworkers in the process of gathering health information. Further, instructional material was correspondingly developed to support their use. This was communicated to OOHC caseworkers and managerial staff, via the presentation of three workshop style learning activities. Other activities undertaken to guide the project to completion are described in *project highlights* and *project outcomes* reported below.

Summary Statement

The report outlines the various activities, contextual to the projects aims, that were undertaken in the implementation of the project to reach project aims. Below is outlined the various results and outcomes of the project. This is followed by description of the projects scope. To communicate the environment in which the project was undertaken, across ecological, social, and cultural spheres. Description of its scope further communicated the contextual positioning and extent of Ngunya Jarjum's service delivery across its identified catchment area, including the number

of OOHC cases that were under Ngunya Jarjum case management at the time of its implementation. This is followed by an outline of the projects identified success criteria and description of related activities undertaken to meet performance criteria. Including the generation of new knowledge and practice, that arose via processes and activities undertaken to meet performance indicators and ensure delivery of project aims.

The project budget and its expenditure, which often follows description of success criteria, is provided as an attachment to this report as per acquittal guidelines.

The report then progresses to describe the project highlights, to provide context and insight to defining events throughout implementation. The highlights reported, provided the project with unforeseen and unplanned results and benefits, unique to the described events. This is then followed by an outline of the challenges and risks faced by the project, as the changing circumstances and impacting events within the environment of the project's implementation.

The challenges and risks faced, while navigating the project to completion, provided opportunity for the design of new supports, conceived in remedy to the various challenges that were faced, including well publicised natural disasters. The opportunity to undertake new design, as solutions-building to reduce the impact of challenges and risks, this approach provided further project outcomes. The following section reports on project results and outcomes, which is presented in four distinct parts.

Part 1: Outlines the results that arose from comparative thematic analysis of Ngunya Jarjum chronic health and disability data.

Part 2: Describes new interagency collaboration as a further project outcome and KPI.

Part 3: Recounts the shaping of new policy and service design, as a project outcome and KPI, ensures through embedding practice in procedural policy, that new professional knowledge directly translates to new practice.

Part 4: Introduces the various tools to assist caseworkers developed during the project. The development of caseworker tools was undertaken in addition to the development of the Family Chronic Health Information Gathering Tool.

This section of the report is then followed by an outline of the various structural and procedural challenges met in the project, and the lessons learnt to further inform our understanding of their complexity, and their resolution. Project recommendations are then introduced, based on project results and outcomes, and lessons learnt along the way. In summary, the report's conclusion

is presented at the end of the report. An appendix of supporting research is included to support observations made regarding the major diagnostic groups, as findings, via data analysis (pages 11 to 17).

2. Results and outcomes of the project

As part of the project, various activities were undertaken to meet its identified aims, this included NDIA service scoping across the Northern Rivers of NSW. The development of a family chronic health information gathering tool and informing the Ngunya Jarjum OOHC team of the project and its outline. The use of the NDIA service sector to better meet the various needs of eligible children, included the identification of two age-related priority groups within current NDIS participants in OOHC. Priority group 1 were children between the ages 0 to 6 years and, priority group 2 were teens between ages 15 to 18 years, who are undertaking their journey towards adulthood and its various challenges, including transitioning out of OOHC.

Further outcomes for the project included changes to Ngunya Jarjum OOHC policy to ensure chronic health planning is embedded into daily casework practice. This included seeking to better understand and work with National Disability Insurance Scheme (NDIS) processes, NDIS local area partners, and key regional NDIS service providers to inform project alignment. This knowledge influenced and continued to shape the development of Ngunya Jarjum health policy, now embedded into daily business practice.

This further incorporated building interagency relationships to share the project and its aims, and to seek sector feedback via further consultation, although this was reduced due to both COVID-19 restrictions and recent flooding across the Ngunya Jarjum catchment area.

A primary Key Performance Indicator (KPI) of the project was to improve the health outcomes of Aboriginal and Torres Strait Islander children including improved access, and improved quality of support from comprehensive and culturally appropriate primary health care providers. This included a project goal of approximately 90% of all NDIS eligible children to have, either active NDIS applications, or have been granted NDIS access and have approved NDIS planning with funded supports in place. We are able to report, that at project completion, all eligible children (100%), with disability/health reporting under current Ngunya Jarjum case management, either have existing NDIS access and support planning, or have active NDIS applications submitted and in progress as a result of the project.

In this process, new NDIS procedural knowledge was gained particularly regarding supporting documentation, including evidence of identity and residence, multidisciplinary health reporting of clinical assessment clearly identifying both primary disability and other co-occurring secondary conditions. Further, evidence of case management and authorised consent for allocated caseworkers and other key OOHC staff is required. Establishing agency OOHC case management is an additional component to standard NDIS application requirements. This includes the NDIA verifying both accredited case management and allocated caseworker consent. This additional component adds further time and potential added complexity to the process, particularly when children have pre-established NDIS plans that include caseworker consent as “guardian”, as viewed in NDIA eyes, from family members, other agencies, or organisations. Due to NDIA legislation regarding confidentiality, OOHC caseworkers are required to provide appropriate supporting evidence to establish new case management, like that required for new OOHC NDIS applications. Report recommendation/s encourage further exploration of the role and identity of ‘guardian’, particularly as children in out of home care are under the parental care of the Minister in accordance with the Child and Young Persons Care and Protection Act NSW 1998. This is particularly important in the context of NDIS plan management, with potential to reduce likely bottlenecks in service delivery to children in OOHC.

Other outcomes of the project included the successful brokerage of a newly identified role within Northcott’s regional NDIS Early Child Early Intervention (ECEI) Intake Team. Further detailed accounts of results and outcomes are outlined in section 8 below.

3. Project Scope

The project’s scope included both Ngunya Jarjum’s regional operational area and included the available health information as a dataset, drawn across the approximate 150 files of children in current Ngunya Jarjum case management. Ngunya Jarjum is the peak Aboriginal Out of Home Care service across the Northern Rivers of Far North Coast NSW. This catchment area includes seven local government areas (LGAs) plus Urbenville town as part of Tenterfield LGA.

The Traditional Owners and Custodians of the Land, as the environmental and operational scope of service delivery includes the various Bundjalung Nations, the Yaegl, and Githabul First Nations peoples. Northern NSW is estimated to currently include 13,666 persons identified as Aboriginal, or approximately 4.7% of the total population. This includes variously linked Aboriginal communities with approximately 40% of community membership being under 15 years of age. In

comparison approximately 19% of the non-Aboriginal population are under 15 years of age. Further, the proportion of local Aboriginal community members over the age of 65 years is little over 3%, whereas in comparison with the non-Indigenous population where 13% are 65 years or over. The organisation is accredited without condition through the Office of The Children's Guardian of NSW.

As an Aboriginal organisation, we are proudly community-driven and controlled. It is acknowledged that children often enter with little or unknown family health history. This includes disconnection from family, community, and Country of belonging. As an organisation, Ngunya Jarjum actively reconnects children to their biological family of origin within the scope of case planning. This provides opportunity to further engage extended family members in planning support for chronic health conditions, disease, and disability.

4. Success Criteria

Various Key Performance Indicators (KPIs) were identified as integral to the project and its aims. KPIs included various activities such as NDIS service scoping, the development of a family chronic health information gathering tool, and communicating to the Ngunya Jarjum team the project, its outline and intended aims. Further indicators included implementation of the family chronic disease information gathering tool this included its introduction and practical application to caseworkers via online workshops. Further identified indicators were the effective use of the NDIS service sector to better meet the needs of eligible children. This was successfully achieved with the outcome of 100% of eligible children possessing either a current NDIS planning and funded supports or actively have a NDIS application in progress. Further to this indicator, two priority groups were identified, priority group one 0-7 years and group two 15-18 years. These groups were identified to prioritise access to early child early intervention funded supports for group one and to further prioritise those adolescence 15-18 years to better ensure support planning includes preparation and increased readiness to undertake the transition to adulthood with the added psychosocial challenges of living with different abilities. Other project actions included changes to Ngunya Jarjum OOHC policy which embedded family chronic health into support planning for children. Further changes to Ngunya Jarjum OOHC policy was undertaken to incorporate NDIS access and funded supports to improve disability care, this too has been embedded into policy as daily business practice under Standard 9: Health. We are further exploring adaption of the client record management system used to host Jarjum records, to explore likelihood of funds being allocated to include disability monitoring and chronic health screening as Jarjums enter care arrangements.

Other activities to meet identified indicators included gathering a sound understanding of local NDIS partners and key NDIS service providers across the region. This included working with Northcott ECEI local area partners and various well established NDIS service providers including Aruma, Magenta, Red Inc, and Gulgen Care who are an Aboriginal service provider located in Lismore. This also included contact with other Aboriginal allied health professionals particularly those with current Indigenous Allied Health Australia membership.

Another performance indicator was building Aboriginal interagency relationships which was successfully undertaken in the brokerage of a newly identified liaison role within the Northcott ECEI early childhood intake team. Further outcomes of the project included undertaking Health/Disability data analysis, offering further refinement to future disability support planning, and the development of various chronic health tools to assist caseworkers in their work.

5. Schedule and Budget Performance

As per financial report attached.

6. Project Highlights

Interagency collaboration

As mentioned briefly above, a highlight of the project has been the successful brokage for an Aboriginal-identified liaison to assist Ngunya Jarjum caseworkers undertake NDIS applications for children aged 0-6years. This was established with the assistance of NDIS local area partners Northcott (previously *The NSW Society for Crippled Children*). Northcott is a not-for-profit organisation responsible for the NDIS Early Child Early Intervention (ECEI) program in the Northern Rivers of NSW. This included the coordination of a successful interagency visit undertaken by a Northcott Early Childhood NDIS Intake Coordinator. During the visit, casework staff were able to meet with and seek answers regarding the application process. It is commendable that both Northcott/Local NDIS partners and Ngunya Jarjum were able to secure this new support for the OOHC NDIS application process. Particularly considering both organisations at the same time, experienced the loss of their places of business in Lismore during recent NSW floods.

An interagency visit was undertaken by Mr Conor Ellem, Northcott/NDIS Early Childhood Intake Coordinator from Wednesday 17th to Friday 19th August 2022. Mr Ellem was able to meet with key OOHC staff (management & caseworkers) at the newly relocated Ngunya Jarjum office in Lismore.

At that time Ngunya Jarjum staff were able to gain further clarity regarding the application process and further grow the ongoing relationship between Ngunya Jarjum and local NDIS area partners Northcott/NDIS ECEI. Feedback from casework staff confirm that the visit was beneficial and assisted in their understanding of current applications in progress and application processes.

Supporting diagnostic assessment

During the project in my role as Health Coordinator, I was able to facilitate the process of diagnostic assessment in two complex cases. One case stands out as an exemplar in this regard. During the project, I undertook post-graduate training for qualified health and allied health professionals in autism diagnosis presented by Professor Tony Attwood and Dr Michelle Garrett.

As Health Coordinator, my prior experience as a social worker includes PhD research, where Professor Attwood, Adjunct Professor of Clinical Psychology, Griffith University, acted as an external supervisor to my doctoral project, which focused on building a strengths-based autism model of support. These post-graduate courses facilitated the initial screening of autism-associated characteristics in two individuals using the Australian Scale for Autism Spectrum Conditions (ASASC, 2013) questionnaire, which indicated the young person may meet diagnostic criteria prior to further referral to their clinical psychologist.

Case 1

The first case concerned a young man, who turned 18 years during the project and subsequently left OOHC case management. The young man has chosen to live with his maternal aunt and her partner.

The initial screening process included using the Australian Scale for Autism Spectrum Conditions (ASASC) questionnaire to gain greater clarity of their cognitive profile and individual characteristics. Both his caseworker and I followed the initial screening through interview with the young man and his kinship carers to seek further confirmation regarding some of his answers. At that time, we obtained the young man's consent for further referral for clinical assessment via his psychologist.

Further, both his caseworker and I met with his psychologist prior to his leaving care to ensure his health care and support would continue. This included his caseworker raising awareness concerning potential guardianship of his financial affairs, which the young man's psychologist agreed to speak with him further about. He turned 18 years during the project and subsequently left OOHC case management. Case management has been handed over to Lifestyle Solutions, who provided NDIS supported independent living options with keyworker support via the Supported Independent Living (SIL) program. His previous OOHC caseworker further reports he is still engaging with psychological support and is pending clinical assessment for autism.

Case 2

The second case highlighted here, concerned a 15-year-old adolescent who has an ongoing history of profound withdrawal, including non-engagement with services, non-attendance to his high school, and reduced social contact limited to a small circle of family members due to anxiety and depression. Both anxiety and depression are demonstrated to have a higher degree of comorbidity with individuals who possess the lived experience of an Autism Spectrum Condition (ASC), than for members of the general population who do not experience neurodiversity (Attwood, 2006; Baron-Cohen, 2008; Botha & Frost, 2020; South & Sunderland, 2022).

In this process I was able to engage and coordinate the services of the young man's previously consulted Clinical Psychologist, and a Speech Pathologist who works closely with his psychologist, and who the young man had not previously seen. This was undertaken to facilitate further ASD-associated assessment of verbal and non-verbal communication via multidisciplinary consultation.

In this young person's experience, due to social withdrawal, previous attempts to engage with clinical services had failed. The Clinical Psychologist was known to the young man, as they had been consulted at another practice while the young person was under the case-management of another organisation. This prior knowledge facilitated assessment, both his medical history and presentation were known to his psychologist, and Foetal Alcohol Spectrum Disorder had previously been assessed for in his case, and he was found to not meet DSM-5 diagnostic criteria for FASD.

This multidisciplinary approach was successful after several attempts to do so, due to recent floods and the changing availability of the multidisciplinary team. His Clinical Psychologist and Speech Pathologist both confirmed the young person met ASD (DSM-5, 2013) criteria.

Additional to the diagnosis process, an application for NDIS funded supports was made and the young man has gained access and now has NDIS planning in place to better support their health-related outcomes across their life. In this process, a Family Group Conference (FGC) was organised

and hosted by an external FGC facilitator, where I was invited to speak to the young man gathered family members and educators. The FGC was facilitated well, and subsequently provided a supported process to reach mutually agreed outcomes and responsibilities, including increased family support for both the young person and their carer.

After gaining consent from the young person's kinship carer to address the group, I briefly introduced ASD as a condition, and in relation to a request to his educators for further educational support as "reasonable adjustment", under disability equity. The issue of truancy arose due to a lack of school attendance and non-engagement. Issues identified around truancy were able to be resolved as a direct result of formal diagnosis and recent NDIS access. Further discussions took place around the need to remain sensitive to potential triggering that re-engagement with schooling may likely pose in this case. In remedy, it was mutually agreed with the young man's family representatives and his educator's to initially trial online lesson delivery and online personal tutoring support. This included his school organising use of a student laptop and other resources to support his re-engagement. Although an appropriate outcome, at the time of this report, the young man's social withdrawal continues and is an ongoing concern requiring monitoring through case management.

7. Challenges and risks faced by the project

There were several challenges and risks that impacted upon and created various challenges for the project. Below I outline events as they arose, which impacted on the communication and engagement of key community stakeholders and sector-based agencies. The loss of business locations and business operations, due to recent disaster, and the subsequent reduction of available staff across the sector in the Northern Rivers influenced the way the project was undertaken. For instance, reduced network coverage across the Northern Rivers, displacement of carer families, the reduction of available staff across sector-based organisations, and being solely reliant upon online communication and phone, when available, during the events described below. These impacts gave rise to the development of various tools and online workshops as further supports for casework staff and OOHC managers.

For instance:

- i. To further understand the two age-related streams of the NDIS application process and the need for supporting evidence regarding the reporting of child's/young

- person's health/disability status, including required evidence by the NDIS to establish case management and authorised consent for allocated caseworkers.
- ii. The identification of chronic health conditions, including both congenital and acquired chronic health and disability, to provide further refinement in gathering and clarifying health information in their case management.

COVID-19: Late 2021 to Mid-2022

During the later months of 2021 to approximately mid 2022 saw various local government areas (LGA's) in the Northern Rivers and other areas of the State continue to experience COVID-19 lockdowns. Due to these various lockdowns both travel and engagement with community within and across Local Government Areas in the Northern Rivers were reduced and for various lengths of time prohibited. We adapted the program delivery accordingly through use of online meetings and research as a result.

Floods: Late February 2022

On Monday February 28th, 2022, North-East NSW and South-East QLD experienced the largest flood throughout the Northern Rivers in recent recorded history. For four consecutive days prior to the floods heavy rain inundated the Northern Rivers. In that period, people prepared for a flood that was estimated to be two meters below February 2022 levels. People throughout the region moved their household contents to the second floor, if that option was available, and cars and other belongings to areas that had not previously been in threat based on initial information provided by the Bureau of Meteorology. On the 28th 557mm fell on Lismore area, SES volunteers were reportedly overwhelmed by the increasing number of emergency calls for help, some residents across various LGA's in desperation self-organised a flotilla of small boats to save people where possible.

Floods: Late March 2022

Approximately one month apart, a second weather event brought heavy rains and flooding back to the Northern Rivers again. Albeit the second flood waters were not as high as the first,

arguably its impact socially and emotionally, at a local level, only added to the loss of morale and hope for the future experienced by many people Indigenous and non-Indigenous alike.

The Northern Rivers community was subsequently unprepared and under-resourced to meet the various challenges ahead.

The 2022 floods have been estimated by the Insurance Council of Australia to have cost approximately \$4.8 Billion in insured claims as reported by the National Insurance Broker's Association (NIBA, 2022). The uninsured damage caused by the floods across urban and rural communities in the Northern Rivers is currently unknown.

Due to the impacts outlined above, many children in OOHC and their Carer's have been directly impacted by these events. Subsequently, it became increasingly important during the project to remain mindful of the potential risk for re-traumatisation that may likely occur during a time of community devastation and initial recovery. In response to these challenges the project continued to undertake a trauma-informed approach to reach its remaining goals by working at the pace of community throughout the period and allowing time for caregivers to prioritise household needs within the context of the project for example housing, family, and community priorities.

8. Project Outcomes

Below is described the various project outcomes that were achieved during the project.

These outcomes as results of the project are presented in four parts outlined directly below, followed by their detailed description.

- Project outcomes, part 1: Review of Ngunya Jarjum chronic health/disability data.
- Project outcomes, part 2: New interagency collaboration.
- Project outcomes, part 3: Shaping new policy and service design.
- Project outcomes, part 4: Tools to assist caseworkers.

Project outcomes, part 1: Review of Ngunya Jarjum chronic health/disability data

The Australian, National Strategic Framework for Chronic Conditions (2017) uses, "chronic conditions", as the term describing a wide range of health conditions including:

- Chronic complex health conditions

- Mental illness
- Trauma
- Disability
- Genetic disorder

The review of data included the broad scope of conditions outlined above.

Prior to undertaking the health and disability data review. It was respectfully acknowledged that all children in OOHC, including those children and young person's presently under Ngunya Jarjum case management, have experienced varying degrees of trauma. Both prior to their removal (resulting in removal from parental care), and unfortunately for some as an added consequence of their removal. It was further acknowledged, in relation to known chronic health impacts, including early cognitive development, that for individuals who have experienced early childhood trauma its relative impact may be both significant and lifelong.

Arguably, both diagnosed and undiagnosed children in OOHC are included in this group. Ngunya Jarjum OOHC, as a regional specialist in culturally informed care, has approximately 150 children supported by current case management.

Cultural considerations when working with trauma:

Due to the impacts of trauma, and the history of previous government sensitivity concerning trauma. Culture and healthy self-identity are abiding concerns in health support. Historically, government policies have actively sort to dismantle aboriginal cultures, remove Aboriginal peoples from their Lands, and separate and displace Aboriginal peoples, and their families, from their communities of origin. Aboriginal peoples may experience intergenerational and transgenerational trauma due to both the effects of negative enculturation as the "colonised", and more recently epigenetics, which advances an embodied memory and continued impact of trauma across generations (Singh *et al.*, 2017; Salmond *et al.*, 2019). The Aboriginal and/or Torres Strait Islander SEWB model (Gee *et al.*, 2014) supports reconnection to Indigenous life domains to assist the development of a positive self-concept, and the construction of healthy self-identity/s, as protective factors in health care.

A recommendation is made to further ensure that additional cultural practices are available as community-valued cultural elements and embedded learnings used in the development and support of healthy personal cultural identities. It is envisaged that the development of a structured cultural program will further support cultural community identification, community inclusion and participation. While correspondingly reducing potential experiences of limited or partial-acceptance

and inclusion due to difference and nonunderstanding, including potential experiences of shame, stigma, and isolation, and the increase of health impacts due to disability minority stress as further potential risk factors.

Method

Below the various stages undertaken in the review of chronic health/disability data is briefly described. This includes, the data source, selection criteria, data collection, coding, and method of analysis, including its findings. described via the presentation of major diagnostic profiles and their relevant comorbidity with other conditions. Both the findings and lessons learned along the way informed the various recommendations made below.

Data collection

An initial list of children/young persons was provided by the OOHC manager and was added to via consultation with caseworkers in review of their cases. NDIS-related health information was drawn from those existing Ngunya Jarjum health files to identify and understand the various diagnostic profiles of children was undertaken to gain greater clarity regarding diagnostic categories to gain refinement to future health planning and further supports. Health data was obtained from the three groups below.

- i. who either had pre-existing NDIS plans or,
- ii. who were already in the process of their application being submitted for access to the scheme or,
- iii. were in the process of gathering independent health reports, undertaken by their caseworker with Health Coordinator support when required, to better support their NDIS application.

Coding

Data collected was then coded under diagnostic profiles arising as theory-driven data informed *priori*. As new health conditions were revealed from the data, new diagnosis-informed coding categories were established. Cases selected, via the criteria above, commonly had one or more reported conditions.

Analysis

Once data was coded under presenting diagnostic profiles, several major groups were revealed for further comparative thematic analysis. Patterns of comorbidity, where several conditions co-occur, and which superimpose upon the functionality of individual cases were observed.

Findings

Neurodevelopmental conditions

Analysis, in general, revealed that a broad collection of neurodevelopmental conditions were the largest diagnostic groups represented in Ngunya Jarjum NDIS-related data at the time of project conclusion.

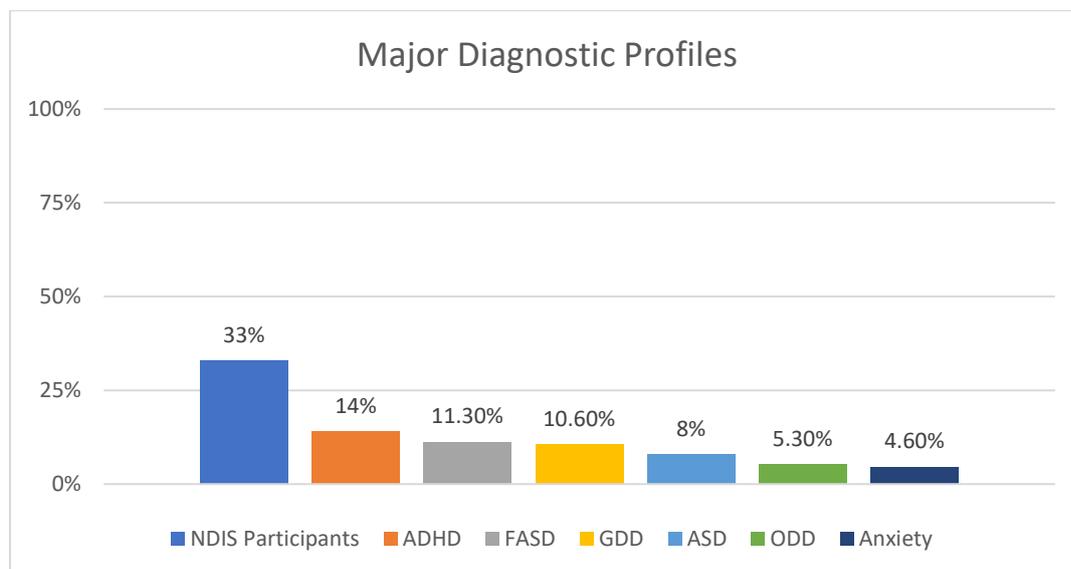
Of this broad category, the largest group with confirmed diagnoses were those children who had previously been assessed for Attention Deficient Hyperactively Disorder (ADHD). Of note, ADHD as a single standalone condition, is currently not recognised by the NDIS as a “primary disability” and does not by itself qualify individuals for access to NDIS funded supports. Where ADHD does co-occur with other conditions viewed as primary disabilities, ADHD-associated executive functioning support needs are funded. As domain-specific areas of support are often shared with other co-occurring neurodevelopmental conditions.

The second largest diagnostic group were cases where Foetal Alcohol Spectrum Disorder (FASD) had previously been assessed. This group was closely followed by those cases which recorded prior assessment for Global Developmental Delay. For consideration, these findings may be viewed cautiously and potentially misrepresenting FASD prevalence, as children who are less than 6 years (with or without sentinel features and a confirmed prenatal history of alcohol exposure) are not generally diagnosed with FASD in Australia.

Differential diagnosis of FASD requires other neurodevelopmental conditions to be considered and excluded prior to confirmation of meeting FASD criteria via paediatric assessment. Some children who may experience domain-associated delay or impairment in comparison to age-related trajectories may remain broadly diagnosed as experiencing developmental delay or disorder. Particularly if limited evidence of sentinel features are observed, and where no confirmation of prenatal exposure can be firmly established.

These two groups were then followed by other diagnostic categories for instance, autism spectrum disorder (ASD), speech/Language delay, hearing impairment, motor skills delay, anxiety, oppositional defiance disorder (ODD), sleep disturbance, and behavioural/emotional regulation, obsessive compulsive disorder (OCD), several rare genetic microdeletions and/or microduplications via microarray assessment, and depression. Speech and/or language delays, motor delay, attention hyperactivity, impulse control, emotional regulation, and other learning challenges function as early flags in relation to age-related benchmarks. These delays and other challenges are often the reason for further paediatric assessment, where criteria for Global Developmental delay, FASD, ASD and Attention Deficit Hyperactivity Disorder (ADHD) diagnostic profiles are often later assessed. As this was observed, in general, to be the case based on the historical occurrence of assessments and diagnoses, the focus was on major diagnostic categories mentioned directly above, acknowledging that speech/language and motors delays, including difficulty with maintaining attention are often observed to be characteristic to their diagnosis. Although ADHD is not viewed by the NDIS as a primary disability, the Ngunya Jarjum/NDIS dataset revealed that as a diagnosis it is often found to commonly co-occurred with other diagnoses such as FASD, Global Developmental Delay (GDD), and ASD, and may accordingly function as a flag, which may in individual cases, suggest the need for additional monitoring and further clinical assessment. Therefore, a recommendation has been made relating to this project finding.

Below is presented the recorded number of major diagnostic categories across the 45 NDIS cases individually assessed, or approximately 33% of children under current case management met selection criteria. Of note, most cases recorded more than one diagnosis.



Analysis revealed approximately 1 in 3 children (33%) of the sample group placed in OOHC under Ngunya Jarjum case management are either NDIS participants or applicants living with a disability.

Further approximations are given below.

- 1 in 7 children (14%) have a diagnosis of ADHD.
- 1 in 9 children (11.3%) have a diagnosis of FASD.
- 1 in 9.4 children (10.6%) have a diagnosis of GDD.
- 1 in 12.5 children (8%) have an ASD diagnosis.
- 1 in 18.8 children (5.3%) have a diagnosis of ODD.
- 1 in 27.7 children (4.6%) have an anxiety diagnosis.

Additional to the identification of diagnostic groups figured above, a lack of reported trauma-associated conditions is apparent in the dataset. Trauma-associated conditions may include, reactive attachment disorder, disinhibited engagement disorder, post-traumatic stress disorder (PTSD), acute stress disorder and adjustment disorder's (DSM-5, 2013).

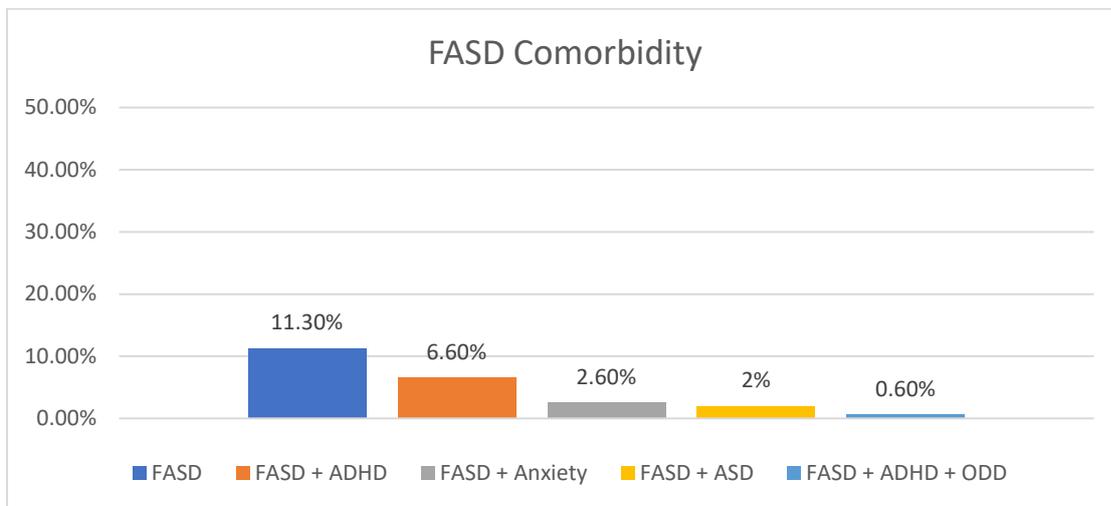
Given the very reasons for assuming a child or young person into State care, this lack of trauma-related data suggests that undertaking further enquiry and assessment of trauma-impacts would be beneficial. Therefore, a recommendation of the project outcome report is designed to address this finding. Further to the seven cases of reported anxiety diagnoses, only one case in the dataset reported formal PTSD diagnosis, one case of diagnosed Complex Development Trauma was reported, and a single case of emotional dysregulation as a form of childhood depression was identified.

This suggests that trauma, a chronic health condition, and trauma-associated impacts for children and adolescents in OOHC may often be assumed by medical and other health professionals, and therefore not formally identified during assessment. Potential support for this observation is found in several cases where medical reports or other correspondence, including referral, mentioned trauma as a concern, although no further formal assessments of trauma-associated conditions and impacts were reported, bar the cases mentioned above. It could be further argued that the finding of minimal health assessment and reporting of trauma, and its impacts for children in OOHC, may represent an unintended gap in health services.

Correspondingly, this also suggests a potential current lack of available therapeutic supports for children and adolescents who may be living with disability, including unrecognised trauma and

trauma-impacts in OOHC. Additionally, the lack of trauma reporting found in the dataset, further suggests that some children and adolescents currently in OOHC, and who do not have other disability diagnosis (n=105), may currently be experiencing unidentified, and correspondingly unsupported, trauma-associated conditions and/or trauma-related impacts. As potential risk-factors, non-acknowledgement and non-support of trauma, may for some children be increasingly challenging, burdensome, and disabling in various ways, and life-long as chronic health impacts. Further supporting research is found in the appendix attached to this report.

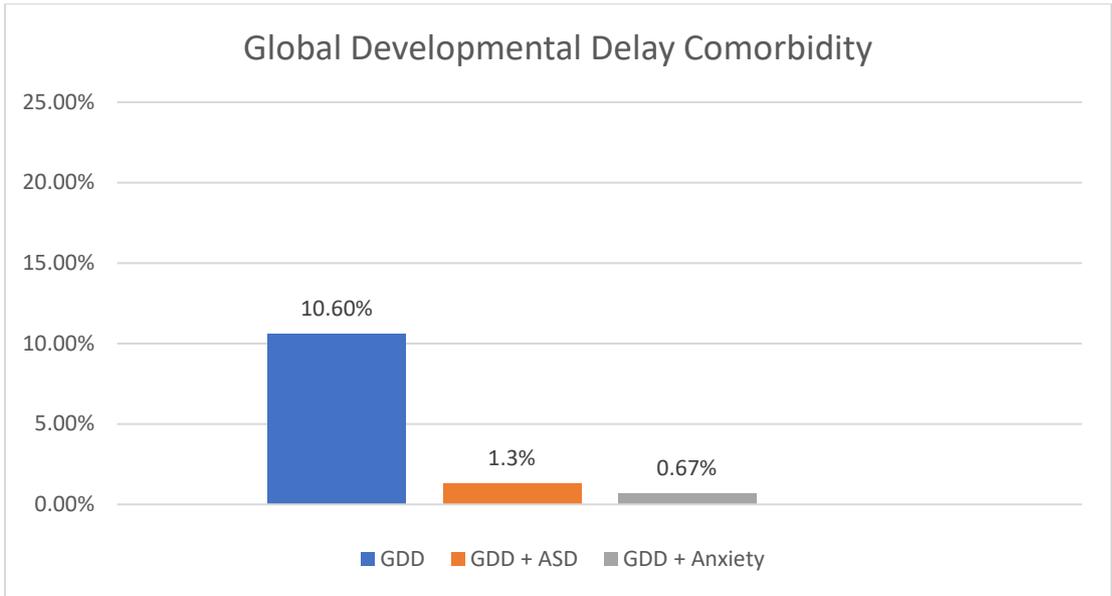
FASD comorbidity is presented below.



**Please Note: Chart is adjusted out of 100%, although 50% is shown in the legend to facilitate visual presentation.*

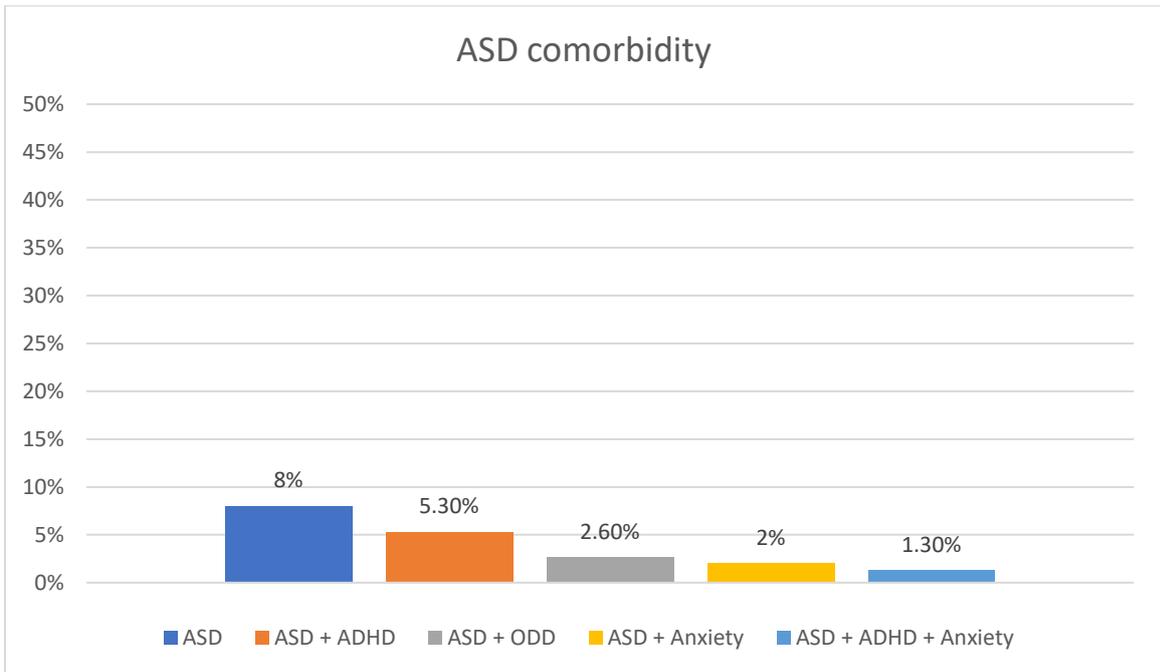
Excluding the observation of FASD-associated sentinel features, FASD as a condition is both neurodevelopmentally and behaviourally indistinguishable from other neurodevelopmental conditions. Further, speech and language delays as a presenting characteristic, are commonly found to occur across all neurodevelopmental conditions.

Below, Global Developmental Delay (GDD) is presented for comparison, with similar comorbidity as FASD above.



**Please Note: Chart is adjusted out of 100%, although 25% is shown in the legend to facilitate visual presentation.*

GDD results, as mentioned above, may include children who have FASD.



**Please Note: Chart is adjusted out of 100%, although 50% is shown in the legend to facilitate visual presentation.*

The findings above are consistent with the literature regarding ASD comorbidity with other conditions such as ADHD, ODD, Anxiety, and OCD (Attwood, 2007; Baron-Cohen, 2008).

As briefly mentioned above, in some cases, unique morphology and/or neurobiology had previously been reported by specialists. In some health cases this included medical correspondence

and reports, of prior genetic microarray testing whose findings have revealed several cases for ongoing clinical consideration and review. Presented below is a table outlining the occurrence of reported rare conditions within the dataset.

Other Rare Chronic Conditions	
Diagnosis	Occurrence
Arachnoid cyst within sylvian fissure (Right frontal)	1
Cardiac Conditions	3
Cerebral palsy (hemiplegic)	1
Chromosomal atypical change/microduplication at 16q13.11	2 (familial)
Chromosomal atypical change at 15q15	1
Chromosomal atypical change/microdeletion at 1q21.1	1
Chromosomal atypical change/microdeletion at 7q35	
Class II division I dental malocclusion Superimposed on mandibular retrusive skeletal II base.	1 (familial)
Class II division 2 dental occlusion (Severe)	1 (familial to above)
Hydrocephalus (with VP shunt) and Arnold-Chiari malformation	1
Hypothyroidism	1
Intellectual disorder/disability (IQ <70)	3
Spina bifida	2
Pectus excavatum (Funnel chest)	1

Further description of the rare chronic health conditions above has been omitted from the report due to their detail, the cases highlighted above are identified for continued health monitoring and referral. Part 2 of outcomes and results, is presented below.

Project outcomes, part 2: New interagency collaboration

As part of the projects KPI's, interagency relationship-building was identified as a project aim. In response to the changing conditions This included the identification of an Aboriginal staff member within Northcott's regional NDIS ECEI Intake team to take on the added role of ECEI Aboriginal OOHC liaison, as a preferred contact for caseworkers and other staff, and to ensure prioritisation of OOHC NDIS ECEI access requests, to offer further guidance to Ngunya Jarjum staff, and expediate expected application turnarounds.

The collaboration between Northcott, as the local NDIS ECEI partner, and Ngunya Jarjum included an interagency visit by the identified Early Childhood Intake Coordinator to Lismore. During the visit, caseworkers and other staff were able to meet and discuss NDIS processes and new applications. This was one of the projects highlights, and we thank Northcott for their openness and willingness to establish and foster mutually beneficial collaboration, including new service access and support.

Project outcomes, part 3: Shaping new policy and service design

NDIS access

As part of the outcomes of this project has been the writing up of both NDIS access streams in a step-by-step presentation of the various stages and components necessary to establish a NDIS application, with corresponding supporting evidence as required by the NDIA. This incremental process has been embedded as daily business practice under Standard 9: Health, in Ngunya Jarjum OOHC policy.

NDIS planning review process

Once NDIS access has been gained, NDIS Planning is undertaken to align identified support needs of participants with appropriately funded supports. A one-page guide to this process was developed to assist caseworkers through the review process. The guide included information on potential alternatives to the formal review of a participants NDIS Planning and funding.

For instance, where a child's or young person's diagnosis and/or life circumstances may change, further and/or other funded supports may now be warranted. This process includes caseworkers' gathering and submission of further supporting evidence, notifying the respective change to the NDIS review team, prior to the acknowledgement that a planning review is appropriate in that individual case.

Alternatively, the addition of extra needed supports can in some cases be made directly to their local NDIS Planner. Who may be able to include their purchase as an additional required funded support to the participants plan, or as a cost already funded for within the scope of their current planning.

The tool was developed to communicate the procedural knowledge above, and to reduce caseworker workload, and time taken to obtain access to needed supports.

Help Us, Help Your Jarjum!

A further outcome of the project has been increased service alignment and design, post-development of the Chronic Health Information Gathering Tool, introduced in Part 3 below. The gathering of chronic health information at the time a child is assumed into care, provides a potential opportunity to caseworkers; based on the premise that providing health care and support is a mutually shared aim between both Ngunya Jarjum staff and family members. Naming this approach up as “*Help Us, Help Your Jarjum!*”, was proposed to convey this mutual aim to family members and the wider community at first take.

A further aim of this approach is to potentially reduce initial concerns regarding case-management and service engagement with the family, in sharing common ground regarding health and health care aims. This was envisaged to be best positioned as part of the initial relationship-building phase of ongoing case management, placing health and chronic health information gathering as an embedded initial step, and as scaffolding to further support that process. Further, that chronic health information is monitored and updated annually by caseworkers.

Project outcome’s part 4: Tools to assist caseworkers

Identifying Chronic Conditions

This tool introduces chronic health conditions through highlighting the difference between chronic and acute health conditions, and further the difference between genetic health conditions (inherited and/or unique), which may impact on an individual’s respective developmental trajectory and/or ability in certain domains. Further clarity was given to both inherited (congenital) and acquired chronic health conditions and disability. The tool further cites information highlighting the prevalence of eight identified chronic health conditions that impact Australians the most. This included statistics revealing the impact of chronic health management on Australian Health systems. This tool was intentionally developed to assist the understanding and identification of chronic health and chronic health impacts for caseworkers, carers, and family members alike. It further

intentionally raises awareness of the importance of chronic health and chronic health management, including knowledge that early identification and early support are protective factors.

Family Chronic Health Checklist

This tool was developed based loosely on a design for use by a professional health partner. It provides a means to record information collected by caseworkers, via interview with family members. The checklist can also be left with family members who may prefer that form of communication or option. Information gathered via the checklist is designed to be uploaded to each child's health profile of documents and findings embedded into the child's case plan for healthier lifestyle choices. To reduce likelihood, or age of onset, of genetically predisposed chronic health conditions such as (but not restricted to) type 2 diabetes, kidney disease, heart conditions, eye, and ear chronic health concerns etc.

Chronic Health Information Gathering Tool

This tool was designed to include health information of individual children/young person's, including the chronic health information of their family of origin, and their carer's, as the basis to inform caseworkers ongoing chronic health and disability support planning across identified psycho-physical, socio-cultural, and socio-economic domains.

The information gathering tool, includes an introduction to support planning, including Social Niche Theory, an ecological strengths-based approach used in social work and other human services to inform practice and to better guide the process of strengths-based capacity building. A brief introduction to the affirmative model of disability, was included, which advances that disability, or living with different abilities, is not necessarily a tragedy nor are people living with different abilities (in certain domains) limited to a so-called "half-life", due to their difference. A brief introduction to disability rights, to raise continued awareness, and as a potential caseworker tool for client advocacy and empowerment was included.

The information gathering tool for ongoing support planning, is further informed by the Aboriginal and Torres Strait Islander Social and Emotional Wellbeing (SEWB) model, highlighting connection and re-connection to and across Indigenous Australian personal and social life domains. The SEWB practice lens was incorporated to inform First Australian support planning across life

domains and individual areas of identified support. Implementation of the tool included its design, development of instructional materials for its use, three online workshops for OOHC caseworkers and managers, ensuring OOHC staff had a copy of the tool for each child under their case management.

ASD and FASD Comparison Tool

This tool was developed as a brief comparison of commonly observed ASD and FASD characteristics to assist caseworkers in early identification, as a protective factor, and in raising referrals to health professionals for further assessment. The tool included respective prevalence estimates in Australia, and naming conventions used by health professionals that caseworkers and other OOHC staff may likely encounter in their work.

9. Lessons learnt during implementation

Various invaluable lessons were learnt during project implementation, generating new knowledge and new processes to negotiate the various environmental, social, structural, and correspondingly procedural challenges that arose as lesson's to be better understood for solution-building, where presenting challenges were repurposed as new opportunity, and reframed as new design principles guiding the development of project-informed recommendations supporting new practice.

For instance, in seeking to better understand why NDIS ECEI application delays continued to increase, it was important to deepen the working relationship I had begun to build, at project outset with Northcott's Tweed Heads and Lismore offices, and with members of the Northcott regional NDIS ECEI Intake team. In attempting to find solutions to best resolve both access and support delay's due to the impact of recent floods, such as loss of business locations, reduced communication, and reduced availability of staff. It was meaningful that the increased of environmental and social stressors, once mutually acknowledged as shared experience within the current operating environment. This led to the establishment of a dedicated new OOHC liaison role, for an Aboriginal staff member of Northcott's regional NDIS ECEI Intake team that I had been working closely with through these events.

Both the environmental circumstances, and the shared wider community spirit which arose as a community-based local recovery response to disaster, undoubtedly further provided the rationale and identified need for new collaboration. In reflection, I believe this was achievable

through undertaking an Indigenous approach to collaboration based on shared experience. This included the mutual recognition of the practical need to reduce mutually shared, and recently increased workloads for a reduced number of available staff.

Citizenship Requirements:

A recent additional requirement requested by the NDIS National Access Team, further to the provision of an Australian birth certificate, has been the necessity to provide further evidence of a child's citizenship status, and the citizenship status of their biological parents if their parents were born after 1986.

While we can obtain birth certificates in most cases for children in OOHC, this requirement cannot always be met as documentation confirming the citizenship status of child, including the citizenship status of their biological parents may not be available or able to be accessed should parents be uncontactable, uncooperative, deceased and/or not understand purpose of the requirement clearly.

Further requirement for parents born after Aug 1986 asks, we further supply confirmation of Australian citizenship details of at least one of the child's grandparents to satisfy eligibility. For Aboriginal families and communities this is often unrealistic and unnecessary as we continue to battle against the impact of previous Governmental policies and practices influencing identity. As such, for children in out of home care a recommendation exists below to accept the NSW Children's Court Order as satisfactory confirmation of citizenship for the purpose of access to NDIS.

The Minister for Community Services in NSW allocated responsibility for the Child and Young Persons (Care and Protection) Act, delegates agencies to provide out of home care services for children in NSW requiring safety. We are one such allocated Agency as accredited through the Office of the Child's Guardian.

These structural and procedural barriers are overtly systemic, presenting increased barriers which may deny, limit, or forestall participant access. These added challenges highlight the need for further awareness raising, rights-informed discussion and advocacy for change within the sector.

10. Recommendations

The recommendations made below have been informed by the various project outcomes described above, and invaluable lessons learnt along the way. Their purpose is to proposed project-

informed improvements to service design, service delivery, service engagement, and increased chronic health and disability identification and support.

The recommendations below, further support previously identified service directions, adding further traction to their momentum. The recommendations outlined below are made in response to data findings, the lessons learn, and/or other project outcomes. These sources have shaped recommendations, and provide their rationale, context, and intention. Further the recommendations are made to address present needs. Several highlight, *their ability*, as a design principle, to guide continued innovation in service design, and further support increased growth and efficacy of services.

Project recommendations

- 1. That caseworkers undertake further disability support training for targeting understanding of FASD and GDD, including ASD and ADHD (neurodevelopmental) such as the Centre for Community Welfare Training (ACWA/CCWT) course, Challenging Behaviours in Children and Adult with Intellectual Disabilities.*
- 2. That all children and adolescents living with a disability under present case management, be accessed for potential trauma-associated conditions and trauma-related impacts, to offer further therapeutic support and offer further refinement to current professional knowledge and inform best practice.*
- 3. Those children and adolescent, who do not have a diagnosis, and who are experiencing developmental, psychosocial and/or educational challenges, be initially screened for trauma-related impacts prior to specialist referral for further assessment.*
- 4. That Ngunya Jarjum seek future registration as a NDIS provider, to oversee and coordinate culturally informed best practice.*
- 5. That Ngunya Jarjum further develop culturally informed service design through the development of a structured cultural education program for children and young persons that includes workshops by elders and tutors in language, story, arts, crafts, song, music, and dance, through the introduction and instruction of practice activities designed to communicate cultural knowledge and build upon a variety of skills, both personal and social.*

6. *That children with clinical assessment of speech/language and motor delay, are further referred for cognitive assessment to gain greater clarity of their cognitive profile in the process of their NDIS application and/or the refinement of required planned supports.*
7. *That children with allied health assessments of speech/language and motor delay, be referred for paediatric assessment of global developmental delay prior to age 6 in preparation for their application to the NDIS ECEI program.*
8. *That children at age 6 years who have a prior confirmed assessment of global developmental delay, with or without sentinel features, with a confirmed history of prenatal exposure to alcohol and other drugs (AOD) be referred for further paediatric assessment for FASD, as an identified protective factor at 6 years + via the child's or young person's doctor, AMS, or NSW Health Pathways.*
9. *That included in planned supports, where diet and specific dietary needs are supported in the literature for identified diagnostic groups, be further supported via consultation with qualified dieticians as part of NDIS funded supports.*
10. *That children/young person's support planning include re-connection to those life-domains outlined in the First Australian Social and Emotional Wellbeing model, with the addition of connection to future social opportunity.*
11. *That correspondence and advocacy be undertaken with the NDIA, raising concerns regarding NSW State legislation regarding "guardianship" of children in OOHC under the Minister's parental care, and the development of an "alternate means", to meet NDIS citizenship criteria, such as the provision of Final Court Orders to evidence NSW State Care.*
12. *Development of a database/network of allied health professionals, and other disability service providers, who meet Ngunya Jarjum culturally appropriate service standards, is established and maintained via service agreements.*

13. *That further consultation take place between regional Lands Councils, Aboriginal Medical Services (AMS's), and other key regional Aboriginal Controlled Community Organisations (ACCO's) be scoped for potential new pathways towards further skill acquisition and development and support of children/ young people living with different abilities in OOHC, taking a whole of community-approach.*
14. *That young people living with different abilities in OOHC, and their carers are linked to external regional disability support groups, to reduce experiences of isolation as a protective factor, and to foster further knowledge and support practice.*
15. *That education and awareness of a child's/young person's different abilities, and their disability rights, as a balance of rights (private & public), and the basic skills of self-advocacy, is introduced as a protective factor to young people in OOHC prior to their turning 18 years of age.*
16. *That the education and awareness of a child's/young person's different abilities, including their fundamental disability rights, as a balance of rights, is extended to Carers, and established as part of Carer induction, (if disability is known), and as part of ongoing case management as disability/health reporting is obtained.*
17. *That recognition of their intrinsic right, and potential, to become socio-cultural and socio-economic contributors is further understood and acknowledge by Carers and actively nurtured.*
18. *That disability information and resources, positive accounts of disability, service supports, and opportunities be regularly communicated through business and community networks.*

11. Conclusion

In summary, despite the projects implementation during regional COVID-lockdowns across LGA's and two natural disasters (floods), it was able to meet project aims and performance indicators through an alignment of supporting factors.

Firstly, the projects aims and corresponding KPI's were clearly communicated and articulated well into activities within and across the various KPI-defined areas of the project. These worked to co-informed each other as the project progressed. This gave rise to the generation of new knowledge that directly informed project recommendations to inform new practice; to support the continuing professional development of staff in chronic health and disability support; and facilitate new service design and delivery.

Further, the project was appropriately funded by the Australian Commonwealth Department of Health and Aged Care, Indigenous Australians Health Programme. Additionally, their project management team were sensitive to the environmental and social impacts experienced during project implementation, remaining responsive and supportive throughout.

The Ngunya Jarjum supervisory team and other staff members, including senior management, actively supported and advised the project through its various stages, and at times of increased challenge due to impacting events. Additionally, employment selection criteria for the projects Health Coordinator role aligned well with my prior experience. These supporting factors worked together to ensure the delivery of project outcomes.

Submitted:



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Appendix

Trauma

Based on the findings reported above, particularly in reference to the approximately 150 children/young person's presently in Out of Home Care under Ngunya Jarjum, arguably have experienced varying degrees of trauma. Additionally in some cases early experiences of trauma may be coupled, via various triggers, with potential experiences of re-traumatisation due to the impact of early trauma and neglect prior to their court ordered removal from their families of origin. The trauma-based experiences of Aboriginal Australian children in Out of Home Care are an important consideration and line of enquiry and referral for further diagnostic assessment and ongoing therapeutic support.

Recently, Radford *et al.*, (2017) reported that in their study, which included both urban and rural Aboriginal communities in NSW, a clear finding that highlighted the relationship between early childhood stress and adversity as being highly associated with later life onset of dementia, Alzheimer disease and other mental health conditions. The authors (2017) further reported that higher levels of childhood stress and adversity were also associated with lower emotional health outcomes including reported higher levels of depression, higher levels of anxiety, post-traumatic stress disorder (PTSD) and attempted suicide. Additionally, Radford *et al.* (2017) highlighted that the findings of their study were neither isolated nor limited to the reported lived experience and observable health impacts of Aboriginal Australians. The authors (2017) cite the pivotal study undertaken by Felitti *et al.*, (1998) that found similar impacts in North America. Felitti *et al.*, (1998) reported a robust correlation between childhood neglect and abuse and family breakdown and household disfunction to many of the leading causes of illness and mortality in adults. These findings above amplify those reported by Danese *et al.*, (2009), whose research showed clear parallels between early adverse childhood experiences and the increase of health-related risk factors in adults for age related disease including conditions such as depression, inflammation and

inflammatory response and the clustering of various metabolic risk markers. Radford *et al.* (2017) cite the work of Anda *et al.*, (2006) which reported there is strong evidence drawn from neurobiology and epidemiology which observes the clinical impact and lifelong enduring effects of childhood abuse and related adverse experiences on the cognitive development and developmental trajectory of children who have been adversely impacted. These findings are further supported by the research review undertaken by Teicher *et al.*, (2016) which also reported on the enduring neurobiological impacts of early childhood abuse and neglect on cognitive development.

When working with Aboriginal Australians, particularly in mental health support undertaken as social and emotional wellbeing, both care and sensitivity is advised, particularly on how culture may shape a young person's presentation. Including how a young person's understanding and presentation of mental health concerns may indicate the appropriate cultural means of support and subsequent recovery trajectory of Aboriginal Australians who have experienced the enduring impacts of childhood abuse and neglect.

Westerman (2020) offers the first clearly defined empirical validation of culture-bounds syndromes within Australian Aboriginal communities. This pivotal study, although limited to participants in Western Australia, included the reported lived experiences of both urban (N=34) and rural (N=31) Aboriginal community members, highlighting the way in which Aboriginal culture can influence individuals particularly in how they may behave or act, including their enculturated understanding of their own experience and how it may or may not be understood or accepted by their kinship group or wider community. For instance, Westerman (2020) raises awareness that cultural beliefs and corresponding practices such as being "sung" or being "cursed" are reported concerns for Aboriginal Australians who may be experiencing a mental health condition/s according to contemporary Eurocentric diagnostic criteria (DSM-5 & ICD-11).

Westerman (2020) further advances that the trauma and grief that may be experienced through the loss of a loved one is often accompanied in Aboriginal Australian communities by an appropriate

length of “sorry time” where individuals are given time to grieve, mourn and heal. Where the trauma and grief of loss is not appropriately addressed or supported, individuals may reportedly develop a variety of psychosomatic complaints including sadness and depression.

Another culturally shaped practice is “sorry cutting” where cutting is undertaken as an expression of a person’s grief during “sorry time”, although misunderstanding may arise if viewed solely through a Eurocentric lens to be a practice of self-harming behaviour. Such views of self-harming fail to recognise that “cutting” in various Aboriginal groups included well defined practices that may superimpose themselves during times of grief such as “cutting” being used as a means to maintain clan or tribal inclusivity through being marked in similar ways. Further, a common practice among many Aboriginal communities in Australia where the undertaking of “lore markings” to signify completion of a rite of passage, or specific markings related to specific traditional roles within the organisational hierarchy of kinship groups. Additionally, the practice of “cutting” may be used as a form of physical payback or punishment such as being speared as an example. Westerman (2020) highlights that experiences of trauma, grief, or separation may act as potential triggers for culture-bounds syndromes.

The findings above support the importance of early identification and early therapeutic support which is mindful that any intervention or planning needs to undertake a lifelong support approach to psychosocial and disability support planning.

Further, it is recommended that therapeutic approaches strategically include the various skills and psychoeducation required to best provide both dementia and mental health prevention and care. Such approaches are characterised as including and being sensitive to culturally informed psychosocial therapeutic supports that are trauma-informed and shaped by a holistic approach to first Australian health, for instance the Aboriginal and Torres Strait Islander, Social and Emotional Well-Being (SEWB) (Gee *et al*, 2014). Including the importance to establish and maintain positive and informed networks of personal support. To better ensure individuals are self-aware of their personal

strengths and present challenges and the various supports they may require to successfully meet challenges and further experiences of hardship that they may be presented with at the various points of transition (from education to employment, from youth to adulthood, including aged care etc.) throughout their lifetime.

Neurodevelopmental conditions

Arguably, the early identification of neurodevelopmental conditions supports improved outcomes for First Australian children. Luke *et al.* (2021) highlight that the early identification of neurodevelopmental risks is complex due to various neurodevelopmental conditions such as some conditions like cerebral palsy, foetal alcohol spectrum disorder and autism spectrum disorder may present with shared characteristics particularly in common domains of developmental delay.

For instance, according to established diagnostic practice diagnosis of FASD, with or without characterised morphology, does not take place until 6 plus years of age. Children below 6 years of age with observable development delay and learning difficulties may subsequently receive an umbrella diagnosis of developmental delay until later assessment can be undertaken to clarify the type and degree of delay within and across domains.

ADHD

Attention deficit hyperactive disorder is identified as a common childhood neurodevelopmental condition which is diagnostically characterised by inattention, impulsivity and hyperactivity which is often associated with observable educational and social impacts. Individuals who receive a diagnosis of ADHD are often prescribed psychostimulants as a first approach to ADHD management. Ghosh *et al.* (2015) in their large retrospective study included 186,468 children, adolescence and young adults who were born in Western Australian between the years 1980 to 2005 of that large, selected group, approximately 2% (n=3677) of individuals included in the study had records of prescription psychostimulants for ADHD management. Of the 3677 approximately 155 (19.5%) of individuals had at least one Aboriginal parent. The authors further report that children and young persons with both Aboriginal parents were 65% less likely in metropolitan areas and 72% less likely in rural remote areas to have stimulant medication. The study advances that lower stimulant use for ADHD management for children and adolescence suggests that Aboriginal

parents may perceive ADHD symptoms as typical childhood behaviour and further that Aboriginal parents, due to various reasons, may have a negative attitude towards the medication of children and young persons. This suggests that there are ethnic and demographic differences in psychostimulant use. Subsequently, a recommendation arising from the research cited above potentially highlights the need to discuss the relative benefits of medication with kinship carers of those children and young persons in OOHC including the communication of potential benefits for young persons who may be affected.

FASD

Foetal/Fetal Alcohol Spectrum Disorder is acknowledged as a complex neurodevelopmental condition caused by alcohol exposure prior to birth. As mentioned by Hamilton *et al.* (2021) alcohol as a substance unobtrusively crosses the placenta approximately 1-2 hours after consumption foetal blood alcohol concentrations have been measured to be nearly as high as those recorded by a maternal blood assessment and further foetal alcohol levels remain higher for longer than in the mother's blood. Alcohol is known to cause damage to developing babies, particularly the developing brain and the degree of damage depends on the stage of pregnancy that exposure occurs, the frequency of exposure and the level of exposure, this is further compounded with both the variances of both the mother's and pre-natal child's genetic and/or metabolic factors.

The authors (2021) in their review of FASD research highlight that FASD occurs across all parts of Australian society where alcohol is consumed. The authors highlight via citing data from the Australian Bureau of Statistics (2019) and further, the Australian Institute of Health and Welfare (2011) that alcohol use is reported to be in general less common among First Australian women, than non-indigenous women. Although, where alcohol consumption was reported by First Australian women, consumption is often at higher levels.

Hamilton *et al.* (2021) further raises awareness that our present understanding of FASD cannot be separated from the historical context of alcohol use in Aboriginal and Torres Strait

Islander communities. The authors (2021) further advance that co-factors relating to alcohol use is often tied to colonial dispossession, historical violence, and the impact of intergenerational trauma, including the social and economic determinates of alcohol use.

FASD is noted by Hamilton *et al.* (2021) to often be associated with a wide variety of co-occurring other conditions, the most common were found to be within the broad categories of congenital malformation and mental health and associated behavioural challenges, The authors further report that the highest prevalence co-occurring conditions include:

- Visual impairment
- Chronic serious otitis media (serious and prolonged middle ear infections)
- Hearing loss (conductive and sensorineural)
- Mental health and behavioural challenges due to alcohol and other drugs
- Expressive and receptive language delay or disorder
- Conduct disorders

Bower and Elliott (2020) in the Australian Guide to the Diagnosis of Foetal Alcohol Spectrum Disorder (FASD) outline Australian diagnostic criteria for FASD diagnosis presented in the table below.

Australian diagnostic criteria for FASD diagnosis

Diagnostic Criteria	Diagnostic Categories	
	FASD with 3 sentinel facial features	FASD with less than 3 sentinel facial features
Pre-natal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains Brain structure/neurology Motor skills Cognition Language Academic achievement Memory Attention Executive function including impulse control and hyperactivity Affect regulation	Severe impairment* in at least 3 neurodevelopmental domains	Severe impairment* in at least 3 neurodevelopmental domains

Adaptive behaviour, social skills and/or social communication		
Sentinel Facial Features Short Palpebral Fissure Smooth philtrum Thin upper lip	Presence of 3 sentinel facial features	Presence of 0, 1, or 2 sentinel facial features

**Please note: severe impairment is characteristically defined as being either a global score or major subdomain score on a standardised validated neurodevelopmental scale that is less than 2 below the mean, or less than the 3rd percentile.*

Domains and Neurodevelopment Impairments

Domain	Impairments that may be present
Brain structure/neurology	Microcephaly, structural brain anomalies, seizures or other functional anomalies (with no other known cause)
Motor skills	Impaired fine motor skills (manual dexterity, precision), gross motor skills (balance, strength, coordination, ball skills and agility), graphomotor (handwriting) skills and visuo-motor integration
Cognition	Low IQ, impaired verbal and non-verbal reasoning skills, processing speed
Language	Impairment in expressive and/or receptive language
Academic achievement	Problems with reading, mathematics, and/or literacy (including written expression and spelling). Includes specific learning disorder according to DSM-5 criteria
Memory	Impairment in overall memory, verbal memory, and visual memory
Attention	Concentration, task focus and work organisation
Executive function including impulse control and hyperactivity	Problems in organising and controlling one's own thoughts and behaviours in order to fulfil a goal with maximum efficiency. For the purposes of FASD diagnostic criteria, also includes impulse control and inhibition response, hyperactivity, working memory, planning and problem solving, shifting and cognitive flexibility
Affect regulation	Depressive and anxiety disorders meeting DSM-5 criteria
Adaptive behaviour, social skills or social communication	Impaired life skills which may affect how well an individual can live independently in a safe and socially responsible manner and how they cope with everyday tasks. Includes autism spectrum disorder according to DSM-5 criteria

The table above is adapted from Hamilton *et al.* (2021) potentially provides caseworkers and other OOHC staff with a checklist of concerns that can be used in the decision-making process for supports, including referral for further clinical diagnostic assessment.

Hamilton *et al.* (2021) report that in their review of Aboriginal-focused FASD research, that stigma and shame were important considerations to remain aware of in the screening for and diagnosis of FASD. Including awareness that intergenerational shame can potentially be experienced by Aboriginal Australians. The authors (2021) advance that this is important particularly for those at the interface of traditional and contemporary Eurocentric culture and institutions as this may impact upon service engagement and use of FASD supports and resources. The authors (2021) highlight that fundamentally the goal of FASD screening and diagnosis is as a protective factor, that can help to further develop understanding within families to recognise that their child/ren may be experiencing neurodevelopmental impairments which they are struggling with.

Of note, as reported by Rice *et al.* (2022), community-led innovation has taken place in the Kimberley region of Western Australia concerning FASD where the Marulu strategy was developed in answer to the concerns of female Aboriginal leaders in the Fitzroy Valley. In that study (2022) Female Aboriginal leaders noted and raised awareness that the occurrence of FASD in their community may limit children's capacity to learn and pass on languages, stories, dances, and traditions that are held to be essential and necessary for the preservation of their culture to the next generation. The Marulu strategy was developed to best support the process of diagnosis, and the prevention and management of FASD and early life trauma in their community. Rice *et al.* (2022) described their use of various psychometric assessment tools cited in their study including:

- **Strong Souls Inventory:** specifically designed to assess the social and emotional wellbeing of Australian Aboriginal adolescents. Found here

- **Post-Traumatic Stress Disorder Checklist:** for the DSM-5 edition, a self-reporting measure to identify symptoms as mentioned in DSM-5 diagnostic criteria
- **Revised Adverse Childhood Experiences:** although representatives of the Fitzroy Valley community elected to not include questions concerning sexual abuse as it was felt to be too invasive or burdensome for those adolescence involved.
- **Self-description questionnaire self-concept subscale:** although negatively worded questions were emitted based on recommendations from a prior report.
- **Measure of Indigenous racism experiences (MIRE);** is developed specifically to assess the self-reported experiences of racism by Aboriginal and Torres Strait Islanders.
- **School Connectedness Scale:** developed by the United States Longitudinal study of adolescent health and previously used in the Australian Young Mind Matter survey.
- **Hunter Opinion and Personal Expectation Scale;** developed to provide an overall measure of an individual's hopefulness.

Other assessment tools were used in their study which included several that measured parent and peer attachment, appearance and body-self relations, sexuality, drug use, suicidality and depression which may not be appropriate for adolescence who have experienced early trauma in Out of Home Care. The List above provides various resources that OOHC staff, and allied health professionals may find helpful.

Autism

Autism is a lifelong neurodevelopmental condition that has not been well researched in Indigenous communities across Australia. Lilley *et al.* (2020) highlight that their recent study is the first to break ground in seeking to better understand the experience and attitudes towards autism that Aboriginal and Torres Strait Islander communities currently hold. Their study included families with a total of 16 children with an autism diagnosis living in various diverse regions of Australia. Their study raises awareness that on one hand various participants in their study described

experiences of shame related to perceived autism associated behaviour which often generated negative feelings and a sense of stigmatisation including the social isolation of families. In contrast, this study also highlighted a common experience of inclusive attitudes, a sense of looking after each other and a developing acceptance of autism-difference.

This study further highlights the importance of positive ideas and attitudes towards those living with the increased hardship of autism advancing that we can all learn from these positive attitudes and suggest that further research may likely support that positive attitudes towards autism may support improved outcomes for children and adults who live with the difference of autism in Aboriginal communities. Based on the initial evidence provided by Lilley *et al.* (2020) it is recommended that a positive ecological strength-based autism approach be undertaken that includes the psychoeducation of autism as neurological difference unique to each individual.

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2022 Jarjum Lifelong wellbeing final report

Final Audit Report

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