

# “PEOPLE DON'T KNOW WHAT GOOD LOOKS LIKE”

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CREATING EQUITY FOR PEOPLE WITH  
DISABILITY IN THE FITZROY VALLEY

SEPTEMBER 2021

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# **“People don’t know what good looks like”**

Creating equity for people with disability in the Fitzroy Valley

September 2021



## TABLE OF ABBREVIATIONS

ACCO	Aboriginal Community Controlled Organisations
ASGS	Australian Statistical Geography Standard
EACP	Evidence, Access, and Coordination of Planning
FASD	Fetal Alcohol Spectrum Disorder
ILC	Information, Linkages and Capacity
KAMS	Kimberley Aboriginal Medical Service
KMHDS	Kimberley Mental Health and Drug Service
MWRC	Marninwarntikura Women's Resource Centre
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
RCC	Remote Community Connector
RECS	Remote Early Childhood Services
TAFE	Technical and Further Education
USYD	University of Sydney
WA	Western Australia

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# EXECUTIVE SUMMARY

The National Disability Insurance Agency (NDIA) commissioned Marninwarntikura Women's Resource Centre (MWRC) to undertake an intensive consultation with the Fitzroy Valley community in Western Australia (WA). MWRC in collaboration with researchers from The University of Sydney (USYD) conducted interviews with people with disability, their parents/carers and key stakeholders, including disability service providers in the Fitzroy Valley. We also supported 20 people with disability to navigate the NDIS processes. The purpose of the consultation was to determine how to improve the lives of people with disability, with a focus on the roll-out of the National Disability Insurance Scheme (NDIS).

**The project aimed to explore the following:**

Aim*	Description
1. What does an 'ordinary life' look like for people with disability in the Fitzroy Valley?	The NDIS Support Catalogue does not necessarily describe the types of supports required to meet the needs of Aboriginal people living in remote towns and communities.  To identify relevant supports for these people the Agency and Local Co-Design Partner will work with community to define an 'ordinary life' in the context of their environment.
2. What are people's experiences with the NDIS and disability services in the Fitzroy Valley?	MWRC would like to capture people's experiences with disability services in the Fitzroy Valley, particularly since the roll-out of the NDIS began.
3. What are the facilitators and barriers to delivering disability services in the Fitzroy Valley?	MWRC would like to identify stakeholders' views on the key factors that help and hinder delivery of disability services in the Fitzroy Valley.
4. How could the NDIS roll-out be improved in the Fitzroy Valley?	MWRC wants to understand how the NDIS roll-out could be improved in the Fitzroy Valley.
5. What are the community's collective goals for people with disability?	The NDIA wants to better understand the collective disability goals of community. The NDIA, in partnership with the Local Co-Design Partner, will support participants and community members to define a set of collective disability goals to guide the NDIA and providers in identifying relevant supports for individual participants, including culturally appropriate supports.
6. What are the disability priorities for targeted action?	The NDIA would like to better understand how the NDIS can make a positive difference in the local community, and which actions should be prioritised in the short-term to build sustainable delivery models for disability supports.

*\*The NDIA proposed and wrote aims 1, 5 and 6 and the MWRC/USYD Team added aims 2, 3 and 4.*



This report outlines: key NDIS policies; the historical context of the Fitzroy Valley, particularly in relation to disability services; the consultation methodology and key findings; and provides recommendations to Commonwealth, State and Local Government Services, Aboriginal Community Controlled Organisations (ACCOs) and Private Health and Disability Services, on how to improve the efficacy and efficiency of services and outcomes for people with disability in the Fitzroy Valley.

## WHY IS THIS REPORT NEEDED?

Since the introduction of the NDIS in January 2017 there has been a failure in delivering services to people with disabilities in the Fitzroy Valley.

**As evidenced by this report there are numerous barriers for Aboriginal people living across the Fitzroy Valley to access NDIS plans and support services.**

Cultural knowledge and understanding by disability service providers, the employment and upskilling of local Aboriginal people and, long-term funding is absent.

Existing services are generally using drive-in drive-out models. This means they are covering large distances in short time frames and generally do not have the relationships with people in communities to enable access and support. This is costing the NDIS a lot of money in travel for limited-service delivery. The onus to support people to navigate the NDIS has fallen to unfunded ACCOs.

National statistics provide evidence of the high incidence of disability amongst Aboriginal people compared with the general population and are less likely to access support services due to significant barriers to access across the service system.

MWRC has a long history of collaboration with community members across the Fitzroy Valley and identified experts to foster knowledge and understandings of issues and to identify practical solutions. MWRC has been advocating for the needs of Aboriginal people living with disabilities across the Fitzroy Valley resulting in being invited to undertake this consultation.





**We walked alongside 20 people with disability and their families to help them navigate the NDIS process. This process helped us identify the facilitators and barriers people with disability experience.**

## **WHAT DID WE DO?**

The project partners (MWRC and USYD) implemented a co-design project to explore the aims of the project.

1. We invited people with disability living in the Fitzroy Valley and their parents/carers to participate in semi-structured interviews. We focused on people with disability who have accessed or attempted to access NDIS-funded disability services because two of our aims look at people's experience with the NDIS and disability services.
2. We walked alongside 20 people with disability and their families to help them navigate the NDIS process. This process helped us identify the facilitators and barriers people with disability experience.
3. We invited staff from disability services and other stakeholders to participate in semi-structured interviews. These interviews aimed to identify barriers and facilitators to delivering disability services in the Fitzroy Valley.



## WHAT DID PEOPLE SAY?

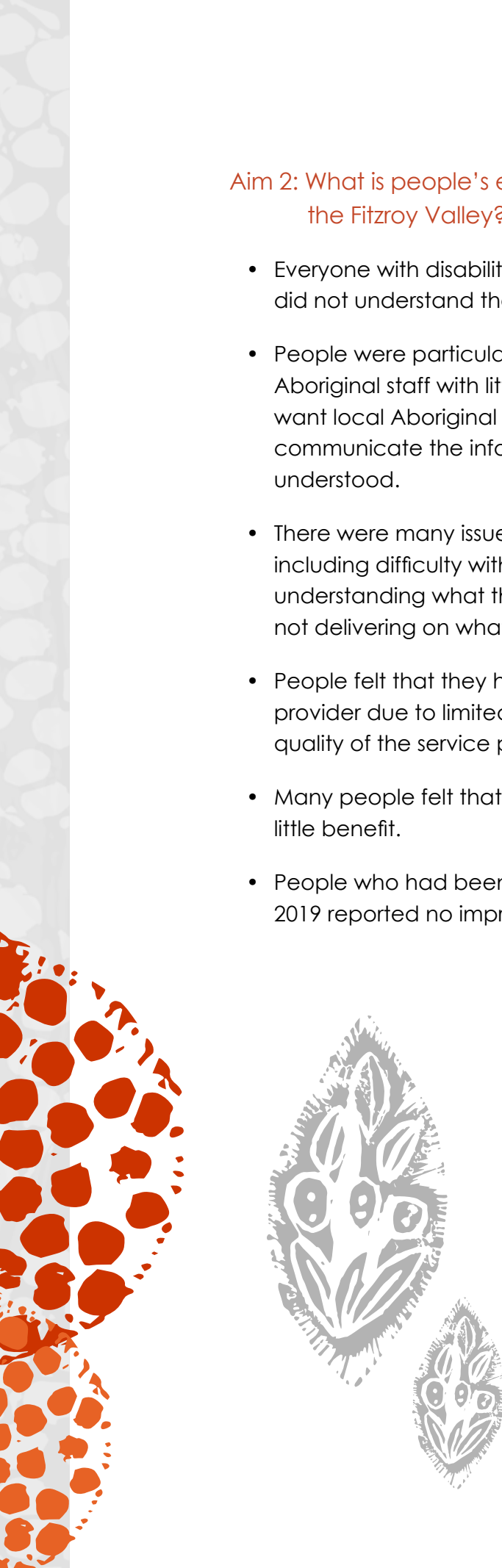
### Aim 1: What does an ordinary life look like in the Fitzroy Valley?

- Every person with disability interviewed wants to live in the Fitzroy Valley and reported many benefits to living in a regional town/community and being close to family, culture, and country.
- Martuwarra, the Fitzroy River is very important for people and a source of recreation, food, healing, and a way of managing emotions and stress. The river is not currently accessible to anyone with mobility limitations.
- Most people with disability live at home with a birth parent or relative. Most participants reported overcrowding in their home and the negative impacts this has on their mental health as well as safety, access to food and potentially leading to homelessness.
- Very few people have been able to access minor modifications to their house to support their disability.
- Parents of children with disability reported struggling to access crucial early intervention services for their child through their NDIS plan.
- There is no supported residential housing in the Fitzroy Valley for people with disability. Several primary carers of adults with disability expressed their concern about what will happen to their child as they age and when they pass away.
- Many of the participants interviewed require in home support. This support is almost exclusively provided by other family members. Out of the 30+ people we interviewed or supported only one family member was funded by NDIS to provide in-home support.
- There are very limited options for adults with disability to access daytime activities outside the home. This impacts people's wellbeing who identified their lives as "hard and boring".
- Increased access to respite care and weekend trips away to neighbouring towns (Broome, Derby, Kununurra) is something many people were interested in but only few had benefited from.
- There is no after school, weekend or school holiday programs for children with disability in the Fitzroy Valley, meaning no respite for families or opportunity for them to gain full-time employment.



## Aim 2: What is people's experience with the NDIS and disability services in the Fitzroy Valley?

- Everyone with disability interviewed/supported and their carers said they did not understand the NDIS or NDIS plans.
- People were particularly frustrated by having to interact with non-Aboriginal staff with little or no cultural knowledge or understanding. They want local Aboriginal staff to work alongside these staff to translate and communicate the information in a way that is culturally appropriate and understood.
- There were many issues with the current support coordination services, including difficulty with contacting the support coordinator; not understanding what the support coordinator said, support coordinators not delivering on what was agreed; and too much paperwork.
- People felt that they had little to no choice or control over their service provider due to limited options. Concerns were also raised about the quality of the service provision.
- Many people felt that signing up to the NDIS meant a lot of work for very little benefit.
- People who had been on the national NDIS since it began in the Valley in 2019 reported no improvement over the past 24 months.



**The four case studies provide a snapshot of what daily life is like for people with disability in the Fitzroy Valley, including the barriers and difficulties people face accessing services.**

### Aim 3: What are the facilitators and barriers to delivering disability services in the Fitzroy Valley?

#### **The things that work:**

- Services based in the Fitzroy Valley or providers who have partnerships with local services.
- Working alongside Aboriginal people as community navigators.

#### **What is needed?**

- Locally based support coordination to enhance face-to-face support and ensure timely follow-up; support workers based in the Fitzroy Valley; repairs for wheelchairs; respite options; day programs and after school care programs; psychologists and neuropsychologists to provide emotional, behavioural, and cognitive supports; and other nutritional, allied health and therapeutic supports.

#### **What are some of the barriers facing the delivery of services?**

- Services not being based in the Fitzroy Valley; lack of housing for staff; low health and disability literacy among the Aboriginal population; low cultural knowledge and understanding among non-Aboriginal staff; and siloed record keeping.
- Stakeholders reported that most of the barriers to delivering disability services in the Fitzroy Valley are not simply teething issues with the NDIS that will improve over time. Rather these barriers are systemic government issues that must be addressed for services to improve.

# RECOMMENDATIONS

## Aim 4: How could the NDIS roll-out be improved in the Fitzroy Valley?

**Recommendation 1:** The NDIA should invest in 5-year funding for the Remote Community Connector program and implement the Evidence, Access, and Coordination of Planning program in the Fitzroy Valley to ensure access to the scheme is streamlined and efficient.

**Recommendation 2:** The NDIA must continue the Remote Early Childhood Services program to ensure children can thrive in their early years and reach their full potential, which may reduce reliance on the NDIS in the long-term.

**Recommendation 3:** The NDIA should ensure locally based support coordination and specialised support coordination services are available to break down barriers to accessing disability services and reduce underspend and travel costs.

**Recommendation 4:** The NDIA should invest in disability services and/or local services to employ, train and support locally based allied health assistants to reduce the overreliance on expensive specialised drive-in drive-out services.

**Recommendation 5:** As recommended in the NDIA's Rural and Remote Strategy, the NDIA should 'harness collaborative partnerships' by investing funds so disability services can engage ACCO's to successfully establish and integrate their disability service in the Fitzroy Valley.

**Recommendation 6:** The NDIA should implement strategies to ensure accountability of services in remote settings.

**Recommendation 7:** The NDIA should provide a clear process for extended family members to be paid support workers of people with disability when no services are available and support coordinators and planners should inform families of this process.

**Recommendation 8:** The WA Country Health Service, Kimberley Aboriginal Medical Service, Primary Health Network and Private Health Services in the Kimberley should establish a single accessible medical record for people in the region.

**Recommendation 9:** The WA Country Health Service should establish a team of clinicians to identify and support people with neurodevelopmental impairments. The earlier neurodevelopmental impairments are identified the better the outcome for the individual, meaning less reliance on government services in the long-term.



**Recommendation 10:** The Commonwealth and State Government need to invest in services to allow people to heal from and break the cycle of intergenerational trauma.

**Recommendation 11:** Staff from Commonwealth, State, Aboriginal Community Controlled and Private Organisations working in the Fitzroy Valley must understand how disability is perceived by Aboriginal people and adapt their perception of disability from impairment to strength focused.

**Recommendation 12:** The Commonwealth, State, Aboriginal Community Controlled and Private Organisations working in the Fitzroy Valley must ensure their staff have received formal cultural, early life trauma and neurodevelopmental disorder/FASD training.

**Recommendation 13:** Western Australian Government Services must work together to prioritise the housing shortage for disability workers in the Fitzroy Valley.

#### Aim 5: What are the community's collective goals for people with disability?

**Recommendation 14:** Western Australian Government Services should work together to develop a residential facility in the Fitzroy Valley for adults with disability.

**Recommendation 15:** Disability services should establish and run **day programs** for adults with disability so they can participate in the community, service providers can locate people with disability and family members can return to work.

**Recommendation 16:** State and Local Government should work together with communities to develop the infrastructure required for after school care and school holiday programs for children with disability.

**Recommendation 17:** The Commonwealth Government should provide funding to local services and organisations to enable them to offer supported work environments for people with disability to increase the number of people in the workforce.

## Aim 6: What are the disability priorities for targeted action?

All the above recommendations need to be implemented if we are to create equity and improve the lives of people with disability living in remote Aboriginal communities. However, some recommendations must occur before others. These are discussed below.

1. Disability services cannot establish themselves in the community without housing to employ staff. **Recommendation 13:** Addressing the housing crisis, therefore, must be a priority.
2. The NDIA have correctly identified and aimed to address the barriers Aboriginal people face accessing services with the Remote Community Connector (RCC), Remote Early Childhood Services (RECS) and Evidence, Access, and Coordination of Planning (EACP) programs (**Recommendations 1 and 2**). These programs, along with support coordinators (**Recommendation 3**), are crucial to the success of the NDIS in remote Aboriginal communities. However, the programs will only succeed if they are based locally and properly resourced. Locally based services will reduce cost in the long run as it eliminates the expensive travel costs and increases the service provision on-the-ground.
3. The first step in accessing the NDIS is to provide evidence of permanent and significant disability/functional impairment. It's not possible to understand or confirm neurodevelopmental impairments, like those associated with intellectual disability, dementia, or fetal alcohol spectrum disorder, without proper assessment by a psychologist/neuropsychologist. The WA Country Health Service are responsible for identifying and managing health and mental health conditions, including disability. The WA Country Health Service, therefore, must employ neuropsychologists to ensure the NDIS is accessible to everyone with disability (**Recommendation 9**).

## CONCLUSION

Aboriginal people across the Fitzroy Valley continue to display high levels of connection to culture and country despite the disruption from European colonisation. However, trauma, intergenerational trauma, poor health and wellbeing including disabilities, limited access to economic opportunities and, less than satisfactory living conditions continue to impact on people's day-to-day lives.



Remote Aboriginal communities are under-resourced to deal with the high levels of need.

**The systems and structures designed to support Aboriginal people are failing the people of the Fitzroy Valley and it is beholden on governments to do better.**

The systems and structures designed to support Aboriginal people are failing the people of the Fitzroy Valley and it is beholden on governments to do better.

The voices of Aboriginal people in the Fitzroy Valley tell a sad and all too familiar story of the failure of NDIS. People are facing multiple barriers to accessing plans and subsequent supports. The issues identified in this report will not improve without systemic change.

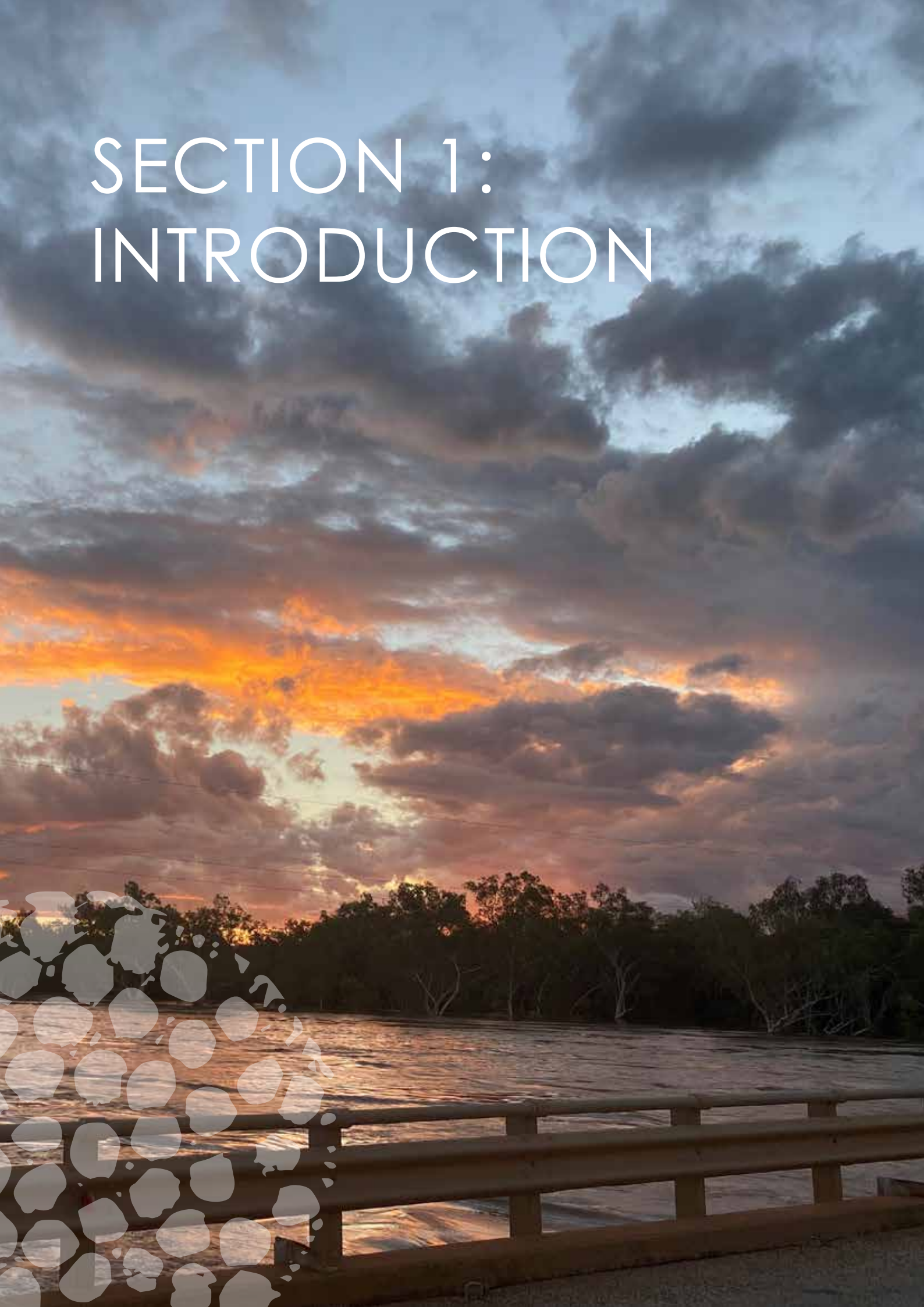
Aboriginal people in the Fitzroy Valley have a long history of coming together, bringing in expertise to identify what they need and want, and communicating this to governments and other stakeholders. MWRC and other local ACCOs have been instrumental in forging services that reflect what works for local people. This is consistent with the body of research identifying what works for Aboriginal people when considering programs and services.

This report asks government to re-evaluate the way the NDIA works in remote communities. It provides evidence of what will work for Aboriginal people in the Fitzroy Valley and what will reduce cost in the long-term. We urge governments to use evidence-based approaches to improve NDIS delivery for improved outcomes for Aboriginal people in the Fitzroy Valley. It demonstrates the commitment of MWRC and the benefits of working closely with community and other strategic partners to identify needs and implement local solutions.

The Fitzroy Valley is well positioned to become a pilot to trial approaches that reflect community need and aspirations delivered in a way that encourages participation and benefit to individuals and families. These findings will be transferable to other communities in consultation with, and reflective of, local services.

We commend the NDIA on funding this report and look forward to positive, co-designed solutions to support Aboriginal people living with disability in the Fitzroy Valley.

# SECTION 1: INTRODUCTION





The National Disability Insurance Agency NDIA commissioned Marninwarntikura Women's Resource Centre (MWRC) to undertake an intensive co-design consultation with the Fitzroy Valley community in Western Australia (WA). MWRC has a long history of working with The University of Sydney on internationally acclaimed research projects and chose to collaborate once again with researchers from The University of Sydney to co-lead consultation, collect data and write this report. The purpose of the consultation was to determine how to improve the lives of people with disability, with a focus on the roll-out of the National Disability Insurance Scheme (NDIS).

This report outlines some of the key NDIS policies; the historical context of the Fitzroy Valley, particularly in relation to disability services; the consultation methodology and key findings; and provides recommendations to Commonwealth, State and Local Government Services, Aboriginal Community Controlled Organisations and Private Health and Disability services on how to improve outcomes for people with disability in the Fitzroy Valley.

## THE NATIONAL DISABILITY STRATEGY AND NATIONAL DISABILITY INSURANCE SCHEME

### The National Disability Strategy

The first Australian National Disability Strategy was developed by the Commonwealth, States and Territories, through the Council of Australian Governments, and signed in 2011. The 10-year agreement committed **all governments** to "a unified, national approach to an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens." The National Disability Strategy is Australia's primary means for implementing its obligations under the United Nations Convention on the Rights of Persons with Disabilities<sup>14</sup>.

The strategy for the next 10 years is currently in development but aims to continue the commitment above and address the existing six outcomes of the strategy, which include:

1. Inclusive and accessible communities
2. Rights, protection, justice, and legislation
3. Economic security
4. Personal and community support
5. Learning and skills
6. Health and wellbeing

As part of the National Disability Strategy new avenues of funding and provision of disability services were explored. One of these avenues included an investigation into the feasibility of a social insurance model for disability services, which ultimately lead to the proposal and introduction of the National Disability Insurance Scheme (NDIS)<sup>10</sup>.

### **National Disability Insurance Scheme**

The NDIS is Australia's first national Scheme to support people with disability, their families, and carers. Jointly governed and funded by the Commonwealth, States and Territories, the NDIS provides funding directly to individuals. Estimates suggest that 4.3 million Australians live with permanent and significant disability, many of whom will require funding for supports and services.

The National Disability Insurance Agency (NDIA) is an independent statutory agency whose role is to implement the NDIS. A trial phase of the NDIS began in July 2013 with the national roll-out in July 2016<sup>10</sup>.

### **The NDIA Commitment to Aboriginal and Torres Strait Islander people**

The NDIA has a commitment to Aboriginal and Torres Strait Islander people (see below). Although it is acknowledged that this is only a first step, the lack of commitment of adequate resources or action to support this commitment, means this is nothing much more than words on a page.

## **“Our commitment is that:**

*All National Disability Insurance Agency staff will be trained to understand and engage with Aboriginal and Torres Strait Islander people and communities in a way that demonstrates respect and support for Aboriginal language, heritage, and culture or in the ‘proper way’.*

*Aboriginal and Torres Strait Islander peoples, their families, carers, and communities will be provided with culturally appropriate information to help them understand their rights and needs for disability support in preparation for the NDIS.*

*Our engagement approach will inform the way that we work with Aboriginal and Torres Strait Islander communities and influence the way we appropriately engage and deliver services to Aboriginal and Torres Strait Islander peoples with disability and their families; and*

*NDIA staff will listen, learn, build, and deliver. They will be supported in their work with Aboriginal and Torres Strait Islander peoples through the identification and sharing of previous knowledge, experience and lessons learned through the trial sites, states and territories and throughout transition of the NDIS” (p. 6)<sup>41</sup>.*

### **The NDIA commitment to rural and remote regions**

The NDIA had a Rural and Remote Strategy (2016-2019), promoting a vision that “People with disability in rural and remote Australia, including Aboriginal and Torres Strait Islander communities, are supported to participate in social and economic life to the extent of their ability, to contribute as valued members of their community, and to achieve good life outcomes”.

**To achieve this vision the strategy sets out five key goals:**

- 1. Easy access and contact with the NDIA**
2. Effective, appropriate supports available wherever people live
3. Creative approaches for individuals within their communities
4. Harnessing collaborative partnerships to achieve results
5. Support and strengthen local capacity of rural and remote communities

**According to their website, their “current approach to remote service delivery aims to deliver”:**

- Quality participant plans with the inclusion of supports that are culturally relevant.
- Improved social and economic outcomes for participants by addressing existing supply gaps at a local level, including the use of alternative commissioning for supports where required, and improved coordination between disability and mainstream services.
- **Coordination across all levels of government to maximise the outcomes of the Scheme**, recognising that the NDIS is part of a broader government service delivery ecosystem in remote communities.
- Access to specific service types or markets at a whole-of-region level through thin market trials and alternative commissioning approaches.
- Improved outcomes at a whole-of-community level by implementing a place-based approach that delivers participant outcomes and facilitates solutions.<sup>43</sup>

## **HISTORICAL CONTEXT OF THE FITZROY VALLEY**

*“Without truth of the structural origins of our powerlessness, the intergenerational trauma we suffer, the racism, the multiple inequalities, and poverty, governments will indefinitely respond to these issues as crisis demanding interventions. As if they are a fault of ours, isolated in the present, existing alone without cause.”(p.68) 7. - JJune Oscar AO, Aboriginal and Torres Strait Islander Social Justice Commissioner*

The Kimberley region of WA is culturally and linguistically rich and diverse. About 80% of the population are Indigenous people coming from over 30 language groups.

Aboriginal peoples across the region are interconnected through family and have one of the most sophisticated kinship systems in the world. Through this strong web of relationships intergenerational knowledge is transferred and responsibility bestowed on Aboriginal people living today to care and nurture country, family, and kin.

## IMPACT OF COLONISATION

In the Kimberley, the full onslaught of European colonisation began in the late 1880s. The occupation of lands through the dispossession and massacres of Aboriginal peoples by colonists was met with fierce resistance by Aboriginal peoples. This period of frontier wars is known as the 'killing times' by Aboriginal people today. Beyond this period, colonisation continued through discriminatory and assimilatory legislation, policies and practices that resulted in forced removal of Aboriginal children from their families, mass imprisonment, imposition of religion through missions, indentured labour, prohibition of use of Aboriginal languages and cultural practices and exploitation of the land for oil and minerals<sup>30, 58</sup>.

Since the 1960s there have been successive attempts through legislative and policy change to remove racially discriminatory practices and improve access to resources enjoyed by the broader population. The 1967 referendum, which resulted in Aboriginal people being counted as part of the Australian population, limited the state's control over the lives of Aboriginal people and heralded a new era of civil rights and self-determination.

In 1969, the introduction of the Pastoral Industry Award (with rights to equal pay) unexpectedly resulted in mass eviction of Aboriginal people from their traditional lands by pastoralists unwilling to pay equal wages. In the Fitzroy Valley this caused widespread homelessness and unemployment, and many were left to live in atrocious conditions on the fringes of the small settlements of Fitzroy Crossing, Halls Creek, Broome and Derby<sup>52, 53</sup>.

With fewer discriminatory practices against Aboriginal people, there was increased opportunity for Aboriginal people to buy and use alcohol. The binge-drinking culture of the white stockman spread into the Aboriginal communities who used alcohol to deal with awful living conditions, grief, loss of family and traditional practices and inherited generational trauma<sup>30</sup>.



These historic events have threatened the preservation and practice of Aboriginal culture and peoples' ability to continue living traditional lives on their land. Despite these overwhelming structural forces, and limited supports from government, many Aboriginal people have remained connected and culturally strong and, where practices were lost, people have continued to engage in revitalisation and resurgence efforts.

## THE FITZROY VALLEY TODAY

Fitzroy Crossing is a small Kimberley town, 400 kilometres east of Broome and 300 kilometres west of Halls Creek. Fitzroy Crossing is the service town for the Fitzroy Valley, which is home to five predominant language groups (Bunuba, Gooniyandi, Nyikina, Walmajarri and Wangkatjungka). People live in 37 communities, spread across a 200 km radius all classified as very remote<sup>3</sup>. Approximately 4,500 people live in the Valley of whom 80% are Aboriginal<sup>40</sup>. Fitzroy Crossing, the service town, remains a central point. The 37 or so communities of the Fitzroy Valley were developed from the late 1970s, as people sought to move away from the troubled town of Fitzroy Crossing, reconnect with country and, via extraordinary leadership, rebuild communities and families.

In 2010, Frances Morphy produced a detailed report on people, population, and place in the Fitzroy Valley. The survey she carried out resulted in a comprehensive head count and assessment of basic demographic data of the population and collected data to describe how the population lives<sup>40</sup>.

The report responded to the need for locally relevant and more detailed information that was not captured by the census, that is "demography in situ" or data that capture the unique features of particular regions and that is relevant to the people of those regions<sup>40</sup>.

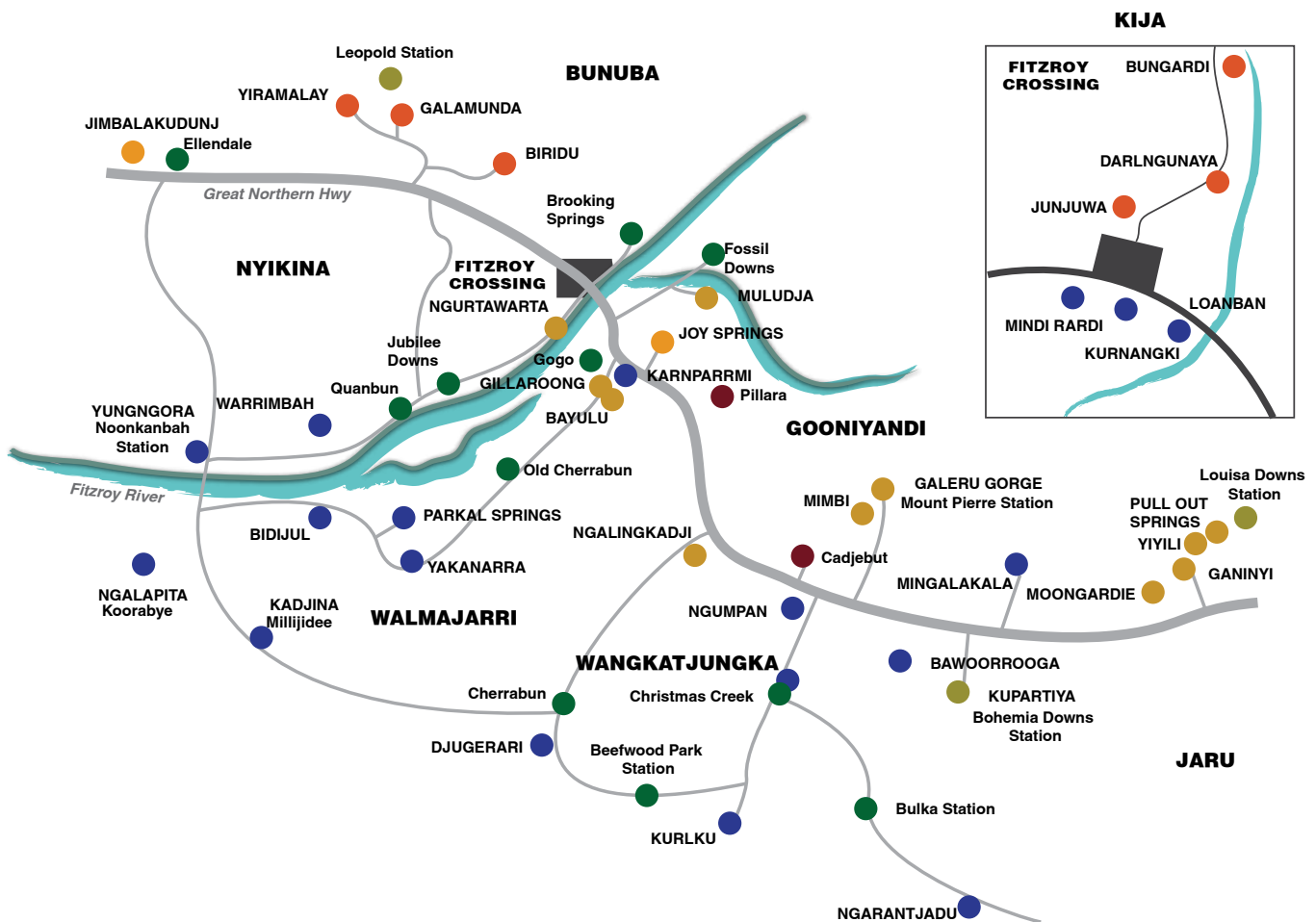
The need for such detailed population studies stems from concerns - not only with the broad-brush approach of the census but with undercounting. In the case of the Fitzroy Valley, this method of data collection recognises the Valley's self-identified regional boundaries which do not correspond with local government boundaries nor those of the census.

Further, census categories are born from Australian colonial assumptions of what is normal including definitions of family, households, and a simplified description of a person's relationship to place as either "resident" or "visitor"<sup>40</sup>. Research and lived experience suggest that these assumptions are not



relevant for Aboriginal people living in remote areas and the imposition of these definitions contributes to obscuring much of the richness of where people live and why.

In 2009, similar to national data, the bulk of the Fitzroy Valley population were in the 0-30 years age groups for both men and women. Population numbers decreased beyond 30 years of age and particularly beyond 60 years of age.



### Language Groups

- Gooniyandi
- Walmajarri / Wangkatjungka
- Bunuba
- Nyikina

### Other

- Aboriginal pastoral lease stations
- Pastoral stations
- Mine site

## HEALTH AND DISABILITY

It is well known that Aboriginal people carry a higher burden of disease and have poorer general health compared to the wider Australian population<sup>7</sup>. Life expectancy, health and wellbeing outcomes for Aboriginal people are the result of complex and interconnected environmental, socio-economic, and behaviour-related factors.

According to the 2018 Survey of Disability, Ageing and Carers 24% of Aboriginal and Torres Strait Islander people in Australia have a disability. However, this survey excluded people living in very remote areas where rates are likely higher given the poor living conditions and limited access to adequate health services.

The Wiyi Yani U Thangani report (AHRC, 2020) identified that despite the high occurrence of disabilities in Aboriginal and Torres Strait Islander people they are less likely to access support services. This is largely because of significant barriers to access across the service system.

Consultations confirmed significant gaps in the NDIS and its implementation; access barriers because of differing ways of conceptualising disability; barriers to understanding the complex processes; and a lack of available supports particularly for people living in remote and very remote parts of Australia<sup>7</sup>.



**24% of Aboriginal and Torres Strait Islander people in Australia have a disability**

# INTERGENERATIONAL TRAUMA, ALCOHOL RESTRICTIONS, AND FETAL ALCOHOL SPECTRUM DISORDER (FASD)

## Intergenerational trauma

The impact of colonisation described earlier in this paper is both historical and current. The Bringing Them Home report,<sup>33</sup> marked a significant contribution to understanding the impact of forced removal of Aboriginal and Torres Strait Islander children from their families. Its narrative more than two decades ago exposed the policies and actions of successive governments in reducing and controlling Aboriginal populations through legislative “protections”, and assimilation policies. The report drew the nation's attention to the fact that “Indigenous families and communities have endured gross violations of their human rights”. These violations continue to affect Aboriginal people's daily lives (including in the Fitzroy Valley) and have contributed to experiences of historical, intergenerational, and current trauma, an erosion of social and emotional and spiritual wellbeing, and economic and social disadvantage.

However, successive governments have failed to respond effectively through investment in appropriate, culturally embedded services and supports for Aboriginal children and young people, their families, and communities.

In 2021, many Aboriginal families across the Fitzroy Valley live with the legacy of inherited trauma and new traumas caused and compounded by the conditions of poverty, including unemployment, severe overcrowding, and inconsistent access to health care, education, and other services, alongside successive government policy changes, short-term funding cycles and imposed solutions designed in Canberra.

## Alcohol restrictions

In 2006 the Fitzroy Valley experienced 55 deaths including 13 suicides in 13 months with alarming reports of rising alcohol consumption, alcohol-fuelled violence and serious ongoing impacts on children and families. In 2007 Aboriginal women from the Fitzroy Valley were determined to address the excessive use and harm of alcohol in their community. These courageous women lobbied their community and the West Australian Liquor Licensing Board to impose a restriction on the sale of take away alcohol.



Evaluation of these restrictions demonstrated the enormous success of this community-led initiative, noting at the time significant improvements in community safety, health, education, and cultural engagement <sup>35</sup>. The community-led nature of this initiative is highly significant. The important and at times difficult journey was documented into a high impact film *Yajilarra* <sup>31</sup>.

Despite the complex challenges of responding to hazardous alcohol use, changing patterns of use and continued resistance from the alcohol lobby and licensed premises in the region, the alcohol restrictions remain in place 14 years later.

### **Fetal Alcohol Spectrum Disorder (FASD)**

Alcohol is a teratogen, a toxic substance that can cause harm to a developing fetus, including physical abnormalities and a range of neurodevelopmental deficits. The National Health and Medical Research Council advises that the safest option for women who are pregnant or planning a pregnancy is to avoid drinking alcohol. There is no known safe amount of alcohol or safe time to drink during pregnancy<sup>42</sup>.

FASD, a neurodevelopmental disorder, is caused by prenatal exposure to alcohol. FASD is a life-long condition; it is not curable but is preventable. Further, harm from prenatal alcohol exposure is compounded by complex early life trauma and conditions associated with disadvantage that are present in many vulnerable communities. According to the Australian Guide to the Diagnosis of FASD, a FASD diagnosis requires “evidence of severe impairment of brain function in at least three of [the] 10 specified neurodevelopmental domains” (p.14)<sup>8</sup>. These domains include brain structure, motor skills, cognition, language, academic achievement, memory, attention, executive function, affect regulation and adaptive behaviour, social skills and social communication<sup>8</sup>. Individuals with FASD commonly have difficulties with inhibition, self-regulation, understanding cause and effect and social cues. Compared to their counterparts, they are more likely to have attention deficit hyperactivity disorder, conduct disorder, experience depression, anxiety, drug and alcohol dependence, self-harm and suicide, and post-traumatic stress disorder; and are more likely to be suspended, expelled, or drop out from school, display inappropriate sexual behaviour, experience unemployment and have contact with social services and the justice system<sup>9, 39, 45-47, 54</sup>.

System-level barriers that hamper FASD prevention, diagnosis, and management include limited education about the risks of prenatal alcohol exposure, health professionals lack of FASD knowledge and training, and

lack of available diagnostic and intervention services and funding<sup>16, 23, 49</sup>. These barriers are likely contributing to these secondary outcomes<sup>46</sup>. **Early diagnosis, a stable and nurturing home and receiving developmental disability services early in life are the strongest protective factors for secondary conditions**<sup>54</sup>. Despite these outcomes, many children with FASD receive no NDIS support.

The recent inquest into the deaths of 13 Aboriginal children and young people in the Kimberley considered the possible role of FASD in the deaths<sup>29</sup>. Although none were formally diagnosed with FASD, due to limited presence of multidisciplinary teams, the inquest stated there was sufficient information from family to consider some may have FASD. The inquest provided seven recommendations regarding FASD, including recommendation 2 (p.270)<sup>35</sup>:

- a) *“that neurodevelopmental impairment (an umbrella term which includes behavioural, developmental and cognitive impairments) incorporating the criteria defined in the Australian Guide to the Diagnosis of FASD be recognised as a disability within the National Disability Insurance Scheme (“the NDIS”).”*
  
- b) *“that where FASD has actually been diagnosed at the appropriate level of severity, it is separately recognised as a disability within the NDIS.”*

Emily Carter the CEO of MWRC presented to this coronial inquiry and reiterated the issue that limited access to diagnostic and support services, plus the stigma often attached to the diagnosis contributes to the complex reasons for under diagnosis.

# COMMUNITY-LED STRATEGIES TO ADDRESS INTERGENERATIONAL TRAUMA AND FASD

## Marulu Strategy

Following implementation of community-wide alcohol restrictions, in 2008 community leaders partnered with health, education and local Community Controlled Organisations to launch the Marulu Strategy to address the impact alcohol was having on children in the region<sup>28</sup>. As part of the strategy the community worked with doctors and researchers to determine the prevalence of Fetal Alcohol Spectrum Disorder (FASD) and early life trauma; advocate for local diagnostic and management capacity in health and education services; and to enhance support for families living with FASD or early life trauma.

Marulu is a Bunuba word meaning “precious, worth nurturing”. The Marulu Strategy is evolving overtime and responding to changing needs, building new evidence, and creating exciting possibilities. The strength-based and trauma-informed approach in the Fitzroy Valley enables deep understandings, strong partnerships with leading experts and, comprehensive dynamic responses to the high levels of FASD and early life trauma in the region. The Marulu Strategy has become the leading Aboriginal-led response to FASD in the country.

## Lililwan Project

The Lililwan (Kimberley Kriol for little ones) FASD Prevalence Study was initiated in 2009. The study, conducted in 2010-2011, included all children aged 7-9 years living in the remote Aboriginal communities of the Fitzroy Valley, Western Australia<sup>24</sup>.

The project was successful because it was community-initiated and led and conducted by a genuine partnership between Aboriginal Community Controlled Organisations (Nindilingarri Cultural Health Service and MWRC), government (through funding of over \$2 million) and experts (through The USYD and the George Institute for Global Health). To summarise – extensive community consultation, local knowledge, adequate funding, and engaging experts helped address the complex issues.

The Lililwan Project research team interviewed over 127 mothers in the Fitzroy Valley who were pregnant before the alcohol restrictions were imposed in the Fitzroy Valley, then assessed neurodevelopment in 108 of their children. They found that the communities’ concern about the impact alcohol was having



on their children was well founded. Approximately 55% of children had been exposed to alcohol prenatally, 19% met criteria for FASD, which is one of the highest rates in the world, and 90% had experienced early life trauma. FASD severely impacted the growth, behaviour and learning abilities of children in the Valley<sup>26, 27</sup>. Of the children in the Fitzroy Valley born in 2002 or 2003:

- 1 in 5 children have FASD, one of the highest known rates in the world<sup>27</sup>
- 1 in 8 children have Fetal Alcohol Syndrome, the most severe condition in the FASD spectrum<sup>25</sup>
- Almost 10% of children with FASD have significant motor impairment
- There was a high prevalence of hearing disability
- Emotional and behavioural problems were common amongst those with and without FASD<sup>59</sup>

In response to these findings, women from the Fitzroy Valley advocated for funding to build an early childhood learning centre (Baya Gawiy Buga Yani Jandu Yani U Centre) to ensure children in the region get the best start to life. The early childhood unit includes a Child and Parent Centre that houses family play groups and visiting paediatric and allied health teams.

Nindilingarri Cultural Health Service used the Lirilwan Project findings to inform their Alcohol and Other Drug Health promotion program and MWRC used the findings to establish the Marulu Team, a group of local Aboriginal people who provide ongoing support to families with a child/children with FASD/early life trauma. The Marulu Team worked with two educators to develop the first Australian FASD and early life trauma training resource for teachers<sup>61</sup>. Project results informed National FASD strategy, community and health professional education and service development, and supported maintenance of alcohol restrictions.

### **Jandu Yani U (For all families)**

Key issues identified by parents and teachers in children from the Lirilwan Project were emotional regulation and behaviour challenges and behaviour challenges. MWRC leadership invited clinicians and researchers from The USYD and the University of Queensland to work with the Marulu Team to design tailored parenting supports to address these challenges<sup>2</sup>.

The team chose to adapt the evidence-based Indigenous Positive Parenting

program (Triple P) for the Fitzroy Valley, which they called Jandu Yani U, a Bunuba term meaning 'for all families'. Triple P is proven effective but had previously been delivered in Aboriginal communities by other government organisations with limited engagement and success.

In consultation with local Aboriginal parents the Marulu Team found that the parents preferred Aboriginal people teaching them how to parent their children. So, in the Jandu Yani U project mostly local Aboriginal people were trained as parent coaches to deliver the program to families.

The project was a success: 36 (95%) of Parent Coaches (63% were Aboriginal) completed the full training and were accredited by Triple P International; 38 families completed the parenting course; and a further 80 families requested to be added to a waitlist to receive the course. At least one parenting strategy was also shared informally with over 530 adults (60% of the adult population). The training improved Parent Coach confidence, skills, and empowerment. The parenting course increased parenting confidence and efficacy and wellbeing, and reduced challenging child behaviour<sup>1</sup>.

### **Bigiswun Kid Project**

While there were many benefits to the Lililwan Project both for the Fitzroy Valley and nationally, most of the local benefits targeted younger or the next generation of children. Leaders at MWRC are concerned that the brave women and children from the Lililwan Project didn't receive the supports they needed after the project and that some of the children are struggling in adolescence with poor health and educational attainment, high rates of self-harm, suicidal ideation and contact with juvenile justice. So, MWRC decided to partner with researchers from The USYD to follow-up the Lililwan cohort in 2020-2021 at age 17-19 years.

The overarching aim of the Bigiswun Kid (Kimberley Kriol for adolescent) Project is to identify the needs of adolescents and build knowledge to improve services and the health and wellbeing of adolescents in remote Aboriginal communities. The specific aims are to:

1. Provide a voice to adolescents and their families to understand the health, mental health, and wellbeing status of the Lililwan cohort at age 17–19y, ten years after the Lililwan Project, and identify what is needed to promote adolescent health and wellbeing in the community.
2. Examine relationships between exposures during pregnancy, birth characteristics, and health and neurodevelopment at 7-9 years, and positive/adverse adolescent outcomes at 17-18 years. This information will



identify prenatal and early childhood factors that promote good health and wellbeing in adolescence.

3. Determine whether management plans provided in the Lililwan Project were followed and identify past and present gaps in service and support needs and barriers to service use. Such information will be used to inform future service planning.
4. Determine how key FASD facial features and other facial anomalies change from childhood (age 7-9) to adolescence (age 17-19), and how they differ to people who do not have the facial features<sup>50</sup>.

### **Marurra U Partnership**

Marurra U project, Marurra U means to 'embrace with love and care'. Over the past 5 years MWRC have partnered with Royal Far West, a specialist allied health, developmental paediatric and disability service. Royal Far West have been working with MWRC to build capacity of staff and families in supporting children affected by early life trauma, disability, or developmental delay. Royal Far West have also helped fill service gaps in the delivery of supports to children with complex needs and their families and brought expertise and allied health teams to the Fitzroy Valley to show the community, families, and support services 'what good looks like'. This work has involved delivering professional learning across a range of Fitzroy Valley programs and services, therapy to young people and their families, trialling telecare in a remote community school, intensive therapeutic camps and working with a range of organisations to make their environments more trauma informed.

## **COMMUNITY RESILIENCE**

Notwithstanding many of the issues identified in this report, Aboriginal people's inherent strengths, resiliencies and culture are a constant source of healing and recovery.

Since the 1960s all the language groups of the Fitzroy Valley have worked closely together to grow Fitzroy Crossing into a service township and establish their own self-determining ACCOs. These organisations, many of which still exist today, provided the mechanisms by which the community could develop their own, culturally grounded, social, and economic infrastructure for the Fitzroy Valley.

Despite these incredible community efforts, disadvantage persists, entrenched by ongoing structural marginalisation.

ACCO's in the Fitzroy Valley are recognised internationally for their forward-thinking initiatives to reduce harms from alcohol in their community and recognise and address FASD and early life trauma<sup>35</sup>.

More recently with the advent of the COVID-19 pandemic, Aboriginal people, families, and communities displayed great initiative and resilience in adapting quickly to the challenges – going out on country, keeping young people safe, and keeping COVID-19 out of communities. Similarly, local ACCO's adapted quickly to new styles of service provision including providing care packs, in community activities, food and other supports as needed.

## **HEALTH CARE DELIVERY: WHAT WORKS FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE?**

There is an increasing body of work articulating what works for program delivery and health and wellbeing for Aboriginal and Torres Strait Islander people.

Research undertaken by the Healing Foundation identified a number of common elements crucial to the success of healing initiatives in Canada, the United States, New Zealand, and Australia. These are:

- a clearly defined problem or issue to be addressed and/or goal to be achieved through the healing initiative
- being informed by and drawing from Indigenous culture and traditional Indigenous healing practices and supporting people on a healing journey towards 'a good life'
- a focus on collective family and/or group engagement (sometimes supplemented by individual support)
- supporting people to understand problems in the context of history, life experience and socio-cultural context

- considering increased self-esteem, cultural knowledge, identity, and connectedness as crucial to wellbeing
- being supported by appropriate and participatory evaluation methodologies<sup>56</sup>

Considering the research, The Healing Foundation has identified eight critical elements to inform the development and evaluation of quality Australian healing initiatives:

- developed to address issues in the local community
- driven by local leadership
- have a developed evidence and theoretical base
- combine Western methodologies and Indigenous healing
- understand the impact of colonisation and trans-generational trauma and grief
- build individual, family and community capacity
- be proactive rather than reactive
- incorporate strong evaluation frameworks.

In 2014 The Journal of Indigenous Policy reported on evidence gathered from a series of government program evaluations to describe the common elements of successful programs for Aboriginal and Torres Strait Islander people<sup>15</sup>.

- Community involvement and engagement
- Adequate resourcing for planned and comprehensive interventions
- Respect for language and culture
- Working together through partnerships, networks, and shared leadership
- Development of social capital
- Recognising underlying social determinants
- Commitment to doing projects with, not for, Indigenous people
- Creative collaboration that builds bridges between public agencies and the community and coordination between communities, non-government organisations and government to prevent duplication of effort
- Understanding that issues are complex and contextual



**Additionally, a number of observations about what doesn't work were made:**

- One size fit all' approaches
- Lack of collaboration and poor access to services
- External authorities imposing change and specifying reporting requirements
- Interventions without local Indigenous community control and culturally appropriate adaptation
- Short-term, one-off funding, piecemeal interventions, provision of services in isolation, and failure to develop Indigenous capacity to provide services.

These findings are supported by recommendations from the Wiyi Yani U Thangani report (p.387)<sup>7</sup> to address effective service delivery:

- Prioritising cultural determinants in relation to health and wellbeing outcomes
- Acknowledging the impact of racism and systemic discrimination in negative experiences of social and cultural determinants of health
- Ensuring Aboriginal and Torres Strait Islander communities are at the centre of design and delivery of health services
- Responding to the interconnectivity of social determinants

The value of building and maintaining respectful relationships and trust as a result of prioritising what works for Aboriginal people ensures positive outcomes for Aboriginal people. Additionally, acknowledging the impact of intergenerational and current trauma and implementing trauma responsive services contribute to more positive experiences for Aboriginal people.

The National Disability Services website provides some useful videos and other resources on trauma-informed support for people with disabilities. See <https://www.nds.org.au/zero-tolerance-framework/considering-additional-risk>



SECTION 2:  
DISABILITY SERVICES  
IN THE FITZROY  
VALLEY

## PRIOR TO 1993

Prior to the *Disability Service Act 1993*, there were no disability services and supports in the Fitzroy Valley. Many people with disability and high support needs were removed from their family, country and culture and placed in institutions or residential housing in Perth. A number of these individuals remain institutionalised, often with little or no ability to remain connected to their kinship system or culture.

## 1993-2017

The WA Disability Service Commission was established in December 1993 under the state's *Disability Service Act 1993*. The Commission was responsible "for advancing opportunities, community participation and quality of life for people with disability".<sup>6</sup>

The Disability Service Commission:

- helped connect people to services
- organised respite for families
- ran activities in the community, such as organising for carers and people with disability to get together for a day down by the river
- arranged for people with disability who lived in institutions in Perth to travel back to visit family and country
- helped family members understand their loved one's disability and how to support them.

In the Fitzroy Valley, there was one person employed by the Disability Service Commission. More often than not this was a local Aboriginal person. However, feedback from participants suggest that the non-Indigenous employees generally understood, and had regard for, cultural needs and the importance of kinship connections and responsibilities. This understanding came from living and working in the community.

The Disability Service Commission had an office in Fitzroy Crossing next to the local grocer and the office was open five days a week. The location was accessible not only for people in Fitzroy Crossing but for people in remote communities across the Valley. Given the limited access to phones, phone



reception and computers, face-to-face services (including the ability to drop in) are often the preferred option. Face-to-face also facilitates non-verbal communication where there are language or other communication barriers.

The above description of the Disability Service Commission was provided by senior representatives in the community. It is evident from the description that the old model, while limited, was well received because it was locally based.

## 2017-2021

### NDIS in WA

On the 31<sup>st</sup> of January 2017 the Commonwealth and WA State Government finalised a bilateral agreement for the state-wide roll-out of the NDIS. The state-NDIS scheme officially commenced on 1<sup>st</sup> July 2017. Only five months later, in December 2017, the WA government joined the national NDIS, in favour of the already agreed state-based version. This took effect on the 1<sup>st</sup> of July 2018. The NDIA was to continue to deliver the NDIS across WA in stages and finish the roll-out by 2020.

### NDIS in the Fitzroy Valley

Moving from the Disability Service Commission to a state based NDIS and then a national NDIS resulted in significant disruption to disability services in WA, especially in remote communities. When the Disability Service Commission rolled over to the state-NDIS the Fitzroy Valley officer was encouraged to move clients to NDIS plans, which took considerable time. These plans then had to be rewritten when the government moved to the national version.

As late as December 2020 we understand that the NDIA was still collecting client information from the Disability Service Commission.

**This indicates a significant time lag between the end of services offered by the Disability Services Commission (2017) and the time when clients were contacted, placed on NDIS plans and able to access disability services (in late 2020 and early 2021).**

At the time of writing this report (August 2021) there are still people in the Fitzroy Valley who have not had access to disability services since the old model ended in 2017. People who were not on plans under the Disability Service Commission but are eligible for disability services are also struggling to access services due to a lack of practical support to assist them to apply for the NDIS, difficulty navigating the process and a perceived reduction in services once on a plan.

To facilitate transition from the Disability Service Commission to the state based NDIS, an officer based in Fitzroy Crossing remained employed to assist people to transfer to the NDIS. Since the move to the national NDIS, this service has ceased.

The absence of a face-to-face service has left many people with disability and their families with nowhere to go to access disability services. There has been a lot of confusion for community people and an inability to access NDIS and connect to much needed services. Closing the office in Fitzroy Crossing also had a big impact on the ability of drive-in drive-out therapeutic services to connect to people with disability, especially those living in remote communities.

### **Remote Community Connector and Evidence, Access, and Coordination of Planning Programs**

In April 2019, the Minister for Families and Social Services, Paul Fletcher announced two new programs for regional WA: the Remote Community Connectors (RCC) Program and the Evidence, Access, and Coordination of Planning (EACP) program. According to the NDIA website, the RCC program would provide funds to ACCO's to employ local Aboriginal people to promote awareness and understanding of the NDIS. The EACP program was designed to help Aboriginal Medical Services to recruit "Evidence and Access Coordinators in remote clinics to facilitate the eligibility testing and access procedures of the NDIS".

This model was designed with input from the Aboriginal Medical Services specifically for regional and remote communities in WA. While some regions of WA were not able to adequately implement this model, it is working very successfully in parts of the Kimberley (Broome, Derby, Halls Creek, etc) through the Kimberley Aboriginal Medical Services with local Aboriginal Medical Services.



**However, the Fitzroy Valley does not have an Aboriginal Medical Service, so the EACP program has not been implemented in the region.**

Instead, the NDIA wanted ACCOs to take on the role of the RCC to explain the NDIS to community members. However, with no on-the-ground EACP program and only minimal (a few days a month) drive-in drive-out support from the NDIA, the RCCs would have to take on the role of raising awareness and understanding of the NDIS and the role of helping people determine their eligibility, apply for the NDIS, and navigate the health system to gather the necessary health data.

In late 2019, an ACCO in the Fitzroy Valley began discussions with the NDIA about taking on the RCC role. However, the role was only offered for a 12-month period and didn't include funds to cover a vehicle and fuel. Given the large distances between communities and that travel is the biggest part of a role like this, the position was not viable. After a protracted negotiation the ACCO did not continue discussions at the time because taking on the role would have meant running at a loss while delivering the work of a government service.

The ACCOs were also concerned about making promises to the community that they knew could not be kept. When explaining the NDIS to people with disability this must include a description of what the NDIS can provide (e.g., allied health services, day-to-day supports, equipment). This creates expectations that cannot be met in the absence of on-the-ground disability services. ACCOs need the communities' support and trust to exist, they are accountable to their families and communities. Given the severe lack of disability services in the region, ACCOs were reluctant to take on the RCC program knowing it would lead to disappointment, tarnishing their reputation with the community and reducing the uptake of their other services.

As a result, there is still no RCC based in the Fitzroy Valley and no drive-in drive out service offering the RCC program or the EACP program. Instead, people in the Valley are left without NDIS plans or with plans that are under spent and not understood. ACCOs and other locally based services are left with the added pressure of trying to support these individuals to navigate the complex NDIS system while conducting their own core business.

At the time of writing this report the NDIA was in discussions with a Fitzroy Crossing based ACCO about taking on the RCC role for 12 months. This time they were offering to cover some of the necessary costs, however, still without the support of the EACP.

A 12-month contract is a short time frame to cover employment of the RCC, training, building rapport with the families, understanding the landscape in terms of service providers, explaining the NDIS, helping people gather the necessary medical evidence, and signing them up to receive an NDIS plan. It is feasible to imagine that when the RCC funding finishes, families will be left to rely on the very scarce private drive-in drive-out disability services to understand and utilise their plan.

We understand that the RCC program is to be a short-term investment from the NDIS to introduce people to the NDIS and get them signed up on plans. However, this view reflects how little policymakers understand remote communities. A 12-month or even 24-month contract isn't sufficient for the following reasons:

- 1. Aboriginal and Torres Strait Islander communities have high numbers of people with disability or chronic complex health conditions.** In the Fitzroy Valley these individuals are spread over a large region (200km radius), with the majority not connected to any disability services. It is impossible to expect one or even two people to identify and support all these people in a 12-month period especially without the support of a locally based EACP Coordinator.
- 2. The high number of people with chronic complex health needs places a large demand on the short-staffed health service, which means accessing health records and services to confirm disability takes longer.** Like most locally based organisations, MWRC has been forced to unofficially take on the role of the RCC in addition to their own work. We have been helping people gather the necessary medical evidence to apply for the NDIS. On average it takes six weeks to receive this information from the health service. This takes substantially longer if the person doesn't have up-to-date evidence (or any evidence) confirming their disability and, therefore, needs to be assessed. People with cognitive disabilities are the most disadvantaged as there are no psychologists servicing the Fitzroy Valley to conduct the necessary validated cognitive assessments to confirm disability. A medical professional cannot and should not confirm an intellectual disability from talking to a person, rather formal assessment from a trained professional (e.g., neuropsychologist) is required.

3. **The NDIS is incredibly complex and places more onus on families to manage appointments and accounts than the previous disability service model.** For example, a person with disability or their carer is expected to review the costs set out in service agreements by providers to determine whether they are fair. This task involves having access to the internet to cross check the price against the complex price list provided by the NDIS and working out whether the time allocated by the service is reasonable. This task would be difficult for the most educated, let alone for someone with English as a second or third language, who may have poor literacy skills or little understanding of what the service is, let alone how long the service should take. The complexity of the NDIS means that people living in remote Aboriginal communities who do not have access to a computer or who have limited English, literacy or numeracy skills will likely need ongoing support that is based on-the-ground. Without locally based support coordinators this role is left to the RCCs.

### **Remote Early Childhood Support (RECS) program**

The RECS program was established to ensure children aged 0-7 years with developmental delay or disability were identified and provided with essential early intervention services. Like the RCC and EACP programs, the RECS program was implemented through Aboriginal Medical Services across the Kimberley. As there isn't an Aboriginal Medical Service in the Fitzroy Valley, MWRC partnered with Kimberley Aboriginal Medical Service (KAMS) to deliver this early childhood support program, given the Marulu Teams experience supporting families with complex needs such as FASD and early life trauma.

The program included two local Aboriginal people based in the Fitzroy Valley employed as family support workers who are supported by a drive-in drive-out allied health team from KAMS in Broome. The team consisted of a paediatric nurse, psychologist, physiotherapist, and speech therapist.

We commend the NDIA and KAMS for the establishment of the RECS program, which acknowledges the following:

1. the importance of the early intervention services for young children with developmental delay or disability
2. the difficulty diagnosing young children with a disability (e.g., the difficulty assessing and confirming intellectual disability before 4 years)
3. that getting a disability diagnosis can take months or even years (even longer in remote regions that have no diagnostic services)



4. the sensitivity of recognising that a child has some indicators of developmental concern, building understandings and acceptance and then supporting the families to see the need for supports, prior to connecting them to services. It takes time to build relationships and sensitively navigate processes.

The RECS program also helps address Target 4 of Closing the Gap Targets. Target 4 is that "children thrive in their early years" and this is measured by an increase in the proportion of Aboriginal and Torres Strait Islander children assessed as developmentally on track in all five domains of the Australian Early Development Census to 55 per cent by 2031.<sup>4</sup>

Having access to services through the crucial years of early childhood development can have a huge impact on a person's abilities and quality of life throughout their life. For example, one study found access to disability services for young children with FASD reduces the likelihood of secondary disabilities in adolescents, like mental health problems and reduces contact with the justice system. These services are particularly important in the Fitzroy Valley, given the Lirilwan Project found as many as 31% of children have at least one neurodevelopmental impairment<sup>27</sup>. Anecdotal evidence from the Lirilwan Project also suggested that the high prevalence of developmental delay means it is becoming 'normalised' and harder for families to identify.

We believe the RECS program is working well in the Fitzroy Valley. Having local Aboriginal people based on-the-ground building rapport with families means that the allied health team can easily locate and connect with families. This model also uses the two-way learning, two-way job model of Aboriginal people working alongside non-Aboriginal people (allied health staff) to effectively navigate between the two worlds (Aboriginal and Western). Much of the work of the family support workers to date is helping breakdown the stigma of disability and educating the community about the benefits of early interventions services.

This project started in the Valley in July 2020 and ongoing funding is still not confirmed. There are concerns over whether the model will continue to be funded as it was originally designed. This is outlined below in recommendation 2.

## Support Coordinators

Support coordinators are the gateway to accessing NDIS-funded disability services unless individuals have the capacity and time to manage the complexity of the NDIS independently. Currently, in the Fitzroy Valley, support coordinators employed by private drive-in drive-out companies are the only point of contact once a person has an NDIS plan. The support coordinator is expected to find individuals with disability and then successfully explain the complexity of the NDIS system without a community navigator or interpreter. Below are some of the challenges faced by support coordinators:

1. Difficulty in locating people due to transience, which is usually due to overcrowding, homelessness, seasonal movement, or travel for funerals and other cultural reasons.
2. Not all people have phones and even if they do the number can change frequently.
3. For various reasons related to history, culture, mental health and disability, some people do not feel comfortable opening their door to strangers. So, even if the support coordinator finds where the person lives there is a chance that that person won't open the door to them, especially if they are unknown and not expected.
4. Support coordinators are expected to explain complex NDIS processes to people who often have limited English (often their second or third language) and in some instances have an intellectual disability or cognitive decline.
5. People living in the Fitzroy Valley with disability often need help with issues beyond those provided by the NDIS, such as support to find housing, apply for Centrelink payments, access health or mental health services, or get birth certification. People may also be experiencing domestic violence or alcohol and/or other drug dependency and significant trauma histories. These issues will generally need to be addressed before a person has the capacity to consider things like occupational therapy. This can be difficult due to the absence of specialised support coordinators.

Currently service providers are struggling to employ and retain support coordinators due to these challenges. The lack of support coordinators means people are unable to access the disability supports and services listed in their plans resulting in under-utilisation of plans and significantly reduced outcomes.

## NDIS community support week

Despite strong advice from ACCOs against the idea of an NDIS community support week based on community concerns of lifting people's expectations without providing adequate resourcing and ongoing supports on-the-ground, the NDIA ran this event in October 2020.

While the event could be termed a success because around 30 people signed up for the NDIS, several concerns remain:

- The two existing disability services working in the Fitzroy Valley already have over 60 people on NDIS plans however less than half are accessing any service, due to a lack of both services and support coordinators.
- The event created expectations for people of getting supports once they signed up to the NDIS. When that support isn't forthcoming the onus falls onto ACCOs as there are no NDIS representatives on the ground.
- Although attempts were made to do so, the NDIA did not have local Aboriginal people available to act as community navigators and translators for the large team of non-Aboriginal people the NDIA brought to the event. This left people confused about what they had signed up to.
- Despite advice from ACCO staff to wait until the new year, the NDIA ran the event right before the wet season when drive-in drive out services stop for the Christmas break and cannot return until March-April due to flooding. This meant that when people's plans arrived in December, they had nowhere to turn to seek help. As a result, and as the ACCO services feared, people went to ACCOs to seek advice about what to do. This added to the workload of the already poorly funded ACCOs, who were expected to take on the responsibility of yet another government service.

## Service providers

There are four active NDIS-funded services in the Fitzroy Valley.

1. Service one has a footprint in the community with approximately three staff providing daily supports and transportation, mostly to adults with disability as well as drive-in drive-out support coordination and allied health services, mainly speech therapy and occupational therapy. This service always has at least one person based in Fitzroy Crossing but is limited by how many people they can support with daily services due to limited staffing and a lack of housing to employ more staff. The organisation has struggled to keep support coordinators for the region meaning the support coordination service has been severely limited.

2. Service two is a drive-in drive-out service that provides support coordination and therapeutic services, mainly speech therapy and occupational therapy. The people interviewed who use this service said they like the allied health service. However, due to limited occasions of travel to the Valley the support coordination is slow to assist with purchasing equipment and organising home modifications.
3. The third service is a community-initiated and led service. The Wangkatjungka community developed a partnership with a non-Aboriginal disability organisation in Broome to allow the community to establish themselves as a disability service provider. The community members run a sessional day program for people with disability and provide some in-home care.
4. The fourth service is a partnership between MWRC and the Kimberley Aboriginal Medical Services to provide the RECS 0-7 years early childhood service described above. The people we interviewed like that this service has a base in the community. However, a high turnover of the drive-in drive-out staff due to funding uncertainty has delayed some of the delivery of allied health therapy.

Data on the approximate caseloads of these services is outlined in Table 2.

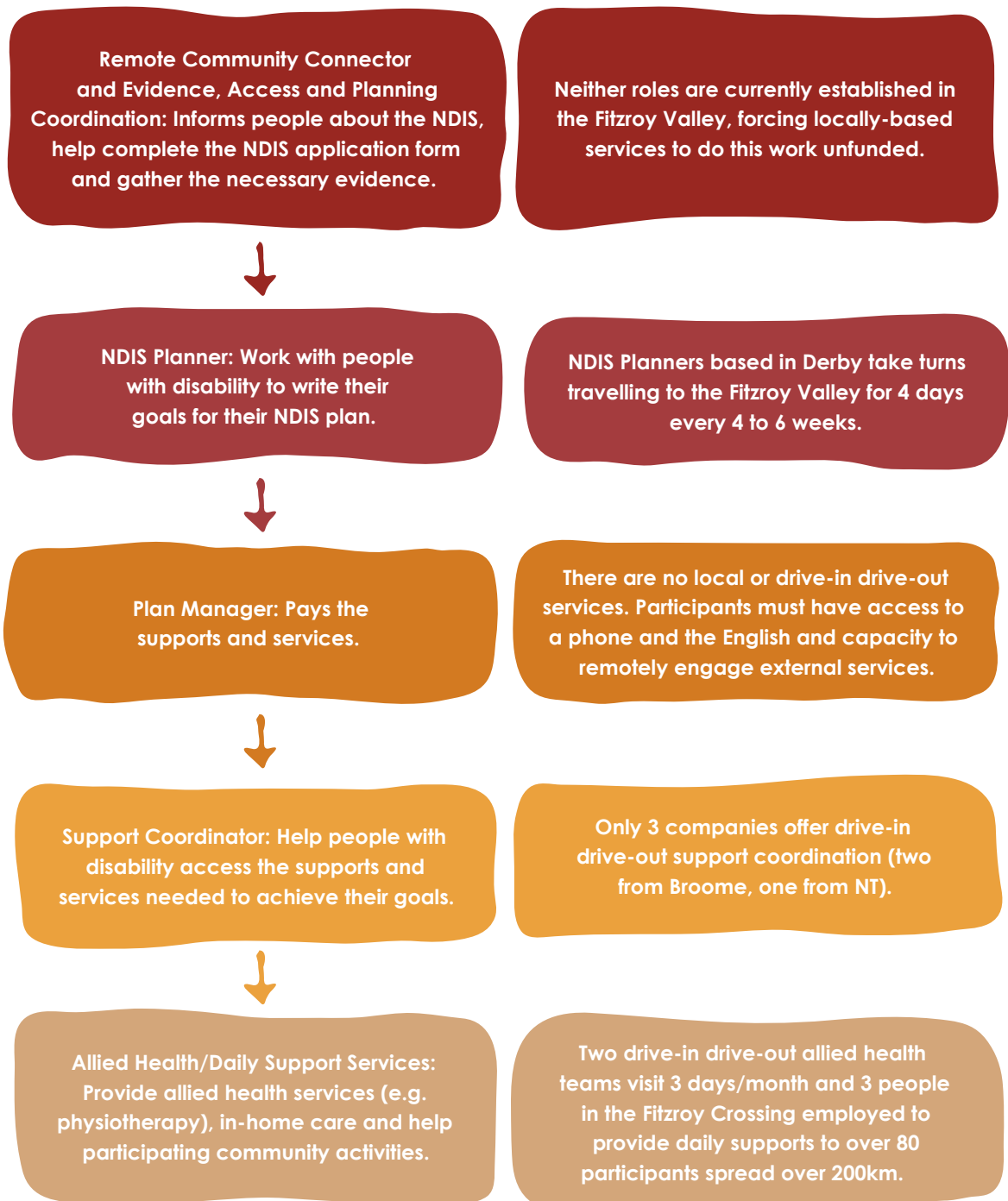
### **Extended family members as service providers**

Aboriginal communities in the Fitzroy Valley are made up of family groups so most in the community are related. Some communities are up to 200km away from town. Despite this, the NDIA has told several people that family members cannot be paid to provide care. As there are no disability support workers in remote communities and not enough in town, families are forced to take on the burden of providing full-time care for their loved one with disability while their NDIS plan goes unspent. Senior NDIA representatives told the authors that people can apply for exceptions to this rule, however, this has not been communicated to those people with disability who have previously asked whether extended family members can act as their official carers.

The Wangkatjungka community is the only community in the Valley that has been successful in obtaining approval for family members to act as carers. The Wangkatjungka CEO negotiated with NDIA representatives to allow extended family members to be paid to provide day-to-day supports to people with disability in their community. As a result, people in Wangkatjungka with disability are getting much more assistance with their daily activities than people living in other communities. However, people in Wangkatjungka are still having trouble accessing supports that community members cannot provide, such as therapy and home modification, equipment, and supplies.



**Figure 1. Participant Pathway:** This diagram illustrates the number of steps required to access disability services in the Fitzroy Valley (right) and the status of each of these steps (left).







SECTION 3: THE  
FITZROY VALLEY  
NDIS CO-DESIGN  
PROJECT

## PARTNERSHIP

This project builds on a longstanding, 12-year partnership between MWRC and The USYD and includes a new partnership with the NDIA. The project is being led by Emily Carter, CEO, and Sue Thomas, Strategic Priority Lead, from MWRC; Lauren Rice, Research Fellow, and Elizabeth Elliott, Paediatrician, from USYD; and Simone Kenmore, Previous Assistant Director and Greg Perrett, Previous Director of Planning and Approach at the Connectors Branch, NDIA.

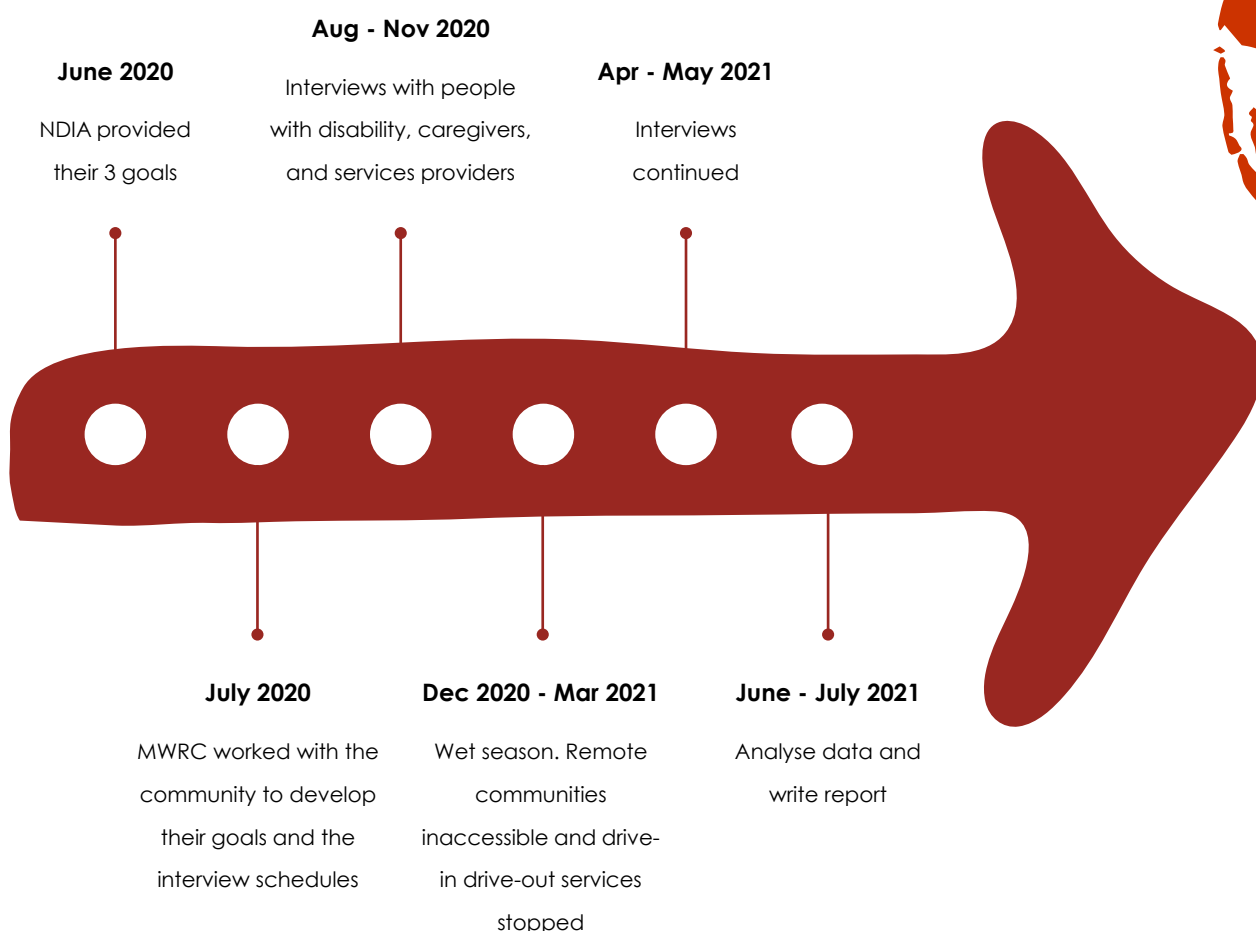
**The NDIS consultation began in July 2020 with funding from the NDIA. The NDIA proposed aims 1,5 and 6, outlined below in Table 1. The MWRC/USYD Team added aims 2, 3 and 4.**

**Table 1. Project Aims**

Aim*	Description
1. What does an 'ordinary life' look like for people with disability in the Fitzroy Valley?	The NDIS Support Catalogue does not necessarily describe the types of supports required to meet the needs of Aboriginal people living in remote towns and communities.  To identify relevant supports for these people the Agency and Local Co-Design Partner will work with community to define an 'ordinary life' in the context of their environment.
2. What are people's experiences with the NDIS and disability services in the Fitzroy Valley?	MWRC would like to capture people's experiences with disability services in the Fitzroy Valley, particularly since the roll-out of the NDIS began.
3. What are the facilitators and barriers to delivering disability services in the Fitzroy Valley?	MWRC would like to identify stakeholders' views on the key factors that help and hinder delivery of disability services in the Fitzroy Valley.
4. How could the NDIS roll-out be improved in the Fitzroy Valley?	MWRC wants to understand how the NDIS roll-out could be improved in the Fitzroy Valley.
5. What are the community's collective goals for people with disability?	The NDIA wants to better understand the collective disability goals of community. The NDIA, in partnership with the Local Co-Design Partner, will support participants and community members to define a set of collective disability goals to guide the NDIA and providers in identifying relevant supports for individual participants, including culturally appropriate supports.
6. What are the disability priorities for targeted action?	The NDIA would like to better understand how the NDIS can make a positive difference in the local community, and which actions should be prioritised in the short-term to build sustainable delivery models for disability supports.

*\*The NDIA proposed and wrote aims 1, 5 and 6 and the MWRC/USYD Team added aims 2, 3 and 4.*

**Figure 2. Project Timeline**



## METHOD

### Participants

We invited people with disability living in the Fitzroy Valley, their carers and key disability stakeholders to participate in semi-structured interviews. We focused on people with disability who have previously accessed disability services because two of our aims look at people's experience with the NDIS and disability services. It's possible that the people interviewed for this report are doing better than people with disability who have not had access to disability services.

## Interviews

The semi-structured interview was developed in consultation with local Aboriginal cultural advisors. Interviews with people with disability and their carers were conducted by a local Aboriginal person employed as a community navigator/interpreter and a non-Aboriginal researcher with disability experience working together. Participants were given a \$30 IGA gift card to thank them for their time completing the interview. To minimise the risk of coercion, participants were told that they would receive the voucher regardless of how many questions they answered.

## Walking alongside people with disability

In addition to the interviews, the authors helped support 20 people with disability apply and navigate the NDIS, e.g., applying for the NDIS, attending planning meetings, connecting with a support coordinator, attending support coordination visits, helping identify potential services, attending therapy sessions.



**Walking alongside people through these processes gave us further insight into the facilitators and barriers that people with disability experience.**

## Qualitative analysis

The responses in the semi-structured interviews were recorded verbatim and thematic analysis was used to identify key themes from each question. Two researchers independently read and re-read the responses to identify and code the themes. The two researchers then met to discuss the themes and when differences were identified they were discussed to see where themes could be combined into an overarching theme.

# RESULTS AND DISCUSSION

## Participants

### People with disability

We conducted semi-structured interviews with people with disability living in the Fitzroy Valley (n=15) and their carers (n=20). All the participants with disability and their family were Aboriginal and connected to one of the predominant five language groups in the Fitzroy Valley. All the people with disability interviewed were adolescents or adults and the carers were carers of adults and children with disability.

### Key stakeholders

We interviewed key disability stakeholders, including disability service providers (n=8), senior staff of ACCO's (n=3), a previous Fitzroy Valley Disability Service Commission Officer (N=1) and a state-NDIS Officer (N=1).

In addition to the formal interviews, we met with over 30 other stakeholders who helped inform this report. These included NDIA representatives, staff at the local hospital, private and government drive-in drive-out services, and senior staff from a range of disability services in the Kimberley and across Australia.

**Table 2. Disability Services in the Fitzroy Valley**

Services	Type of service delivery	Number of clients in the Fitzroy Valley*
Service 1	Support Coordination	40 to 50 people
	Service delivery	Therapy: ~ 15 people Daily support needs: ~20 people
Service 2	Support coordination	Unknown
	Service delivery	~20 people
Service 3	Support coordination	Not provided
	Service delivery	~12 people
Service 4	Support coordination	Not provided
	Service delivery	~25 people

\* These figures were provided during interviews conducted in November 2020

## Interviews with people with disability and their families

### Aim 1: What does an 'ordinary life' look like in the Fitzroy Valley?

Every person with disability interviewed/supported by MWRC staff to access services, wants to live in the Fitzroy Valley and reported many benefits to living in a regional town/community and being close to family, culture, and country. Some of these benefits include:

- they get to learn and continue to practice their language and culture,
- they stay connected to their country,
- everyone knows them and their needs and accepts them for who they are,
- being known by the community provides more opportunity for social interaction,
- the strong sense of community means everyone looks out for each other especially the most vulnerable,
- it is quiet and free from hustle and bustle making it easier for people with disability to navigate,
- having extended family near-by means they have more people to look out and care for them, which allows them more freedom around their community.

Martuwarra, The Fitzroy River, is the heart of the Fitzroy Valley. Spending time by the river is most people's favourite past-time. The people with disability that can access the river talked about the healing benefits of being near the water or out in the vastness of the country. For many people being 'on country' is their primary coping mechanism for managing negative emotions.

Parents of children with disability talk about taking their child to the river and letting them run around knowing they will be safe, as they have grown up to respect and understand the river.

People with mobility issues are unable to access the river due to the steep and unstable riverbeds.

**Everyone we interviewed who has limited mobility expressed the desire for at least one wheelchair accessible ramp to the river, so they do not have to stay home when their family goes fishing, swimming, or camping.**

However, they are unable to access a ramp through their NDIS plan as the plan is individualised and a ramp would be a community resource.

Ideally, the community would like more than one ramp as different family groups visit different areas along the river. Where they go depends on their language and family group.

People talked about needing more supports when they leave the Fitzroy Valley to go to the city (Perth) or even Broome. Being somewhere they do not understand, with fewer people that know them, means people with disability require more supervision and assistance to navigate daily life. Most people find the faster pace of urban life novel but stressful and not somewhere they wish to be permanently.

### **Home life**

Most people with disability live at home with their birth parent or relative (e.g., grandmother, aunty). Two of the people with disability that we interviewed live on their own with their children and one is homeless. This distribution seems representative of where most people with disability live in the Valley.

Most participants reported overcrowding in their home, with either too many people living there or extended family members staying for long periods. The latter was particularly common for people living in town as extended family stay with them while accessing services only available in town or during the wet season.

**Homelessness and overcrowding are well known to negatively impact physical and mental health<sup>17, 37, 51.</sup>**



There appears to be a higher prevalence of chronic mental health problems, like schizophrenia in the Fitzroy Valley, which is not surprising given the high rate of trauma and lack of access to psychological services. We spoke to some people living with schizophrenia in the Fitzroy Valley and they explained the impact their homelessness has on their mental health. One person noticed an obvious increase in his symptoms when he doesn't get enough sleep. He reported that this happens several times a week as he stays with family in a house with eight other people who prefer to stay up late at night.

**Some disability support workers described incidences of people with intellectual disability wandering around at night to escape the overcrowding at home.**

Support workers also reported needing to hoard food for their participants with disability, because if they take the food home, they will have to share it with family members then won't have enough food to get through the week.

Some people have had minor modifications made to their house to support their disability, but most are still waiting for these modifications. Few know how to access the support needed and those families that have tried (e.g., through the NDIS) have struggled to find a support coordinator who can organise the modification. The types of modifications needed include ramps, handrails, slip pads, and locked cupboards to keep children with disability away from chemicals.

Several primary carers of adults with disability talked about their fear of what will happen to their loved one as they age and when the parent passes away. They talk about their extended family members with disability who are forced to live on their own or with another family that doesn't have the capacity to look after them and of the unfortunate things that have happened to these individuals when they do not have the supervision and supports, they need to function.

There is no supported residential housing available for people with disability in the Fitzroy Valley. Two young men with disability are forced to live in the aged-care centre despite only being in their 20's and 30's. Others who do not have family that can look after them are forced to live in residential housing far away from their family and culture in Broome (397 km) and even Perth (2,374 km). Many of the people, including adults with disabilities and their carers we interviewed, said they would like supported living options for people with disability in the Fitzroy Valley.





## **Two young men with disability are forced to live in the aged-care centre despite only being in their 20's and 30's.**

### **Supports in the home**

All people with disability interviewed require some level of support in the home, most needing support for more than 50% of their daily home activities, e.g., showering, preparing meals, cleaning, etc. For most, this support is provided by a family member who lives with them. Only one of these family members are funded by the NDIS to provide in-home support. This family come from Wangkatjunga, the only community in the Fitzroy Valley where extended family members have been approved to be paid carers for people with disability. The community members we interviewed stated that this model is working well.

Two people that we interviewed receive some in-home support from a disability organisation. However, this organisation can only support a limited number of people as there is no housing to employ more staff.

### **Daily activities**

#### **Daily supports**

In town there is only one service that provides day-to-day supports to people with disability and this service has limited staffing (approximately 4 FTE) so can only support a small number of people with their day-to-day needs. We interviewed some of the staff and their greatest concern was not having anywhere to take adults with disability during the day. The adults with disability that we interviewed also expressed a desire to have more to do, as they spend most of their life sitting at home. Most of these individuals need a family member to stay home to care for them, meaning the family member cannot work.

Quite a few communities have limited or no phone access and internet access and families with two people unable to work (person with disability and carer) usually can't afford a car, which limits what a person with disability and their carer can do. It's also not uncommon for a person with disability to not be on a disability payment as their disorder has not been formally diagnosed due to a lack of diagnostic services.

It is very hot (above 30° C) most of the year in the Fitzroy Valley and can get up to mid 40's during the wet season. For people living in the community, power is provided through a power card and the power is cut off when the card needs to be topped up with credit.



**People living on a disability pension or other Centrelink payment cannot afford to have air conditioning on most of the time, so if the extended family members cannot afford to cover the cost, they are forced to sit at home in the dark and uncomfortable heat with little to do.**

The few people that are connected to the only service based in town are picked up to do their shopping and run errands, which they appreciate. However, one man reported that his paid NDIS carer picked him up for an hour each week and simply drove him around the town as there was nowhere for them to go. He found this degrading, like a child going for a drive, so declined the service and now remains at home every day, which impacts his wellbeing.

### Technical and Further Education (TAFE)

One disability service has developed a partnership with the TAFE to organise a training program for people with disability. This partnership has been a great success. Approximately, 25 people with disability are picked up every Tuesday by the disability service and driven to TAFE where they spend 6 hours doing a range of activities e.g., cooking, arts, etc. Several of the people with disability have learned to read and write as adults through this TAFE program.

All the people we interviewed who attend the TAFE program enjoy it and have requested something similar for the other days of the week. As it is run by TAFE it must have an educational component, which some people like. Others would rather there be a safe space where they can take part in the types of activities they enjoy, such as a day program, rather than having a structured school-like environment.

### Wangkatjungka day program

The Wangkatjungka community has found a space in their community to establish a day program for people on NDIS plans. The people with disability are picked up in the morning and given breakfast, are supported to shower if needed, and then spend the morning doing a range of activities. The participants are then dropped home around 12:00 pm with a packed lunch. The participants like having a reason to leave the house each day and a chance to get away and do something for themselves.

### Wangki Radio

Some people with disability work at the local radio station as DJ's. The people interviewed who do this role thoroughly enjoy having a paid job, contributing to the community, and having a reason to get out of bed. These individuals are supported by the only disability service that provides daily supports in Fitzroy Crossing town to get to and from the radio station. However, there are not enough staff to allow someone to stay at the station to support individuals with disability. This limits the number and type of people who can participate in these roles. The radio role is also limited to people who live near town, because disability support workers do not have the capacity to travel to communities to collect people for this activity. Having more housing for more disability support workers would increase the accessibility to this activity and other similar supported work environments.

### Weekend activities

Most people with disability stay home on the weekend as there is nowhere for them to go. They say this impacts their wellbeing as their life feels "hard and boring". People with disability who can get out because there is a car available or because they can walk down to the river to go fishing or swimming, which they love. However, as noted above this isn't an option for people in wheelchairs or with limited mobility.

All the adults with disability interviewed talked about wanting to go to Broome, Derby, or Kununurra for weekend trips. Some people have used their NDIS funding for respite in Broome and thoroughly enjoyed it. There are few services or shops available in the Fitzroy Valley. So, most people use their respite in Broome to go shopping, get a haircut, visit the bank, and access other services.

People with disability and their carers liked that they had options about how respite worked. For example, some people chose to take a family member as their support person to Broome while others preferred to go with a disability



support worker to give their family a break. The primary issue with the respite program was the long wait list. Most people can only go for one trip a year due to the high need and lack of respite houses.

A lack of support staff in the Valley was a commonly reported issue. People said they had no choice in who their support worker was so if they didn't get on with the support person there was nothing they could do about it which sometimes prevented them from wanting respite. These issues highlight the need for:

1. more respite houses across the Kimberley so people can not only go to Broome but also to Derby, Kununurra, Halls Creek, etc; and
2. more housing in the Valley for service providers to enable them to employ more disability support staff.

All the parents of children with disability that we interviewed said they would love the opportunity to take their child to Broome for the weekend to let them see the ocean and participate in normal activities not available in the Valley, like the cinema. However, none of the parents have been able to access respite service due to the long wait list and lack of support coordinators to arrange it.

#### After school, weekend, and school holiday activities for children

There are no after school, weekend or school holiday programs for children with disability in the Fitzroy Valley. There are no disability support workers available to care for children. As a result, parents of children with disability are unable to work outside of school hours, typically 8:30 am to 2:30 pm or during the school holidays.

The parents of all children that we interviewed have funding in their NDIS plan for someone to do things with their child after school, in the holidays or at the weekend. However, as there is no service available to provide this support, the money goes unspent and instead parents are left to incur this cost in addition to the limited capacity to work, reduced hours resulting in reduced income. Parents never get a break, which severely impacts their own wellbeing and the wellbeing of their other children.

## Aim 2: What is people's experience with the NDIS and disability services in the Fitzroy Valley?

Below are some common themes that arose from this question. Stakeholders reported that these are not teething issues for the NDIS that will improve over time, rather they are problems within the system that must be addressed.

### **Difficulty understanding the NDIS and NDIS plans**

Everyone with disability that we interviewed, and their carers said that they do not understand the NDIS or their NDIS plans. This finding is consistent with a similar consultation project on Palm Island<sup>44</sup>. They were frustrated that all the people that came to speak to them about the NDIS were non-Aboriginal people who didn't know how to explain the NDIS in a way that made sense to them. They wanted local Aboriginal people working alongside non-Aboriginal staff who could translate and help the non-Aboriginal person understand their needs.

### **Poor cultural awareness**

The interviewees were particularly frustrated by how little the non-Aboriginal staff knew about their culture, how they perceive disability and what certain genders can and cannot talk about. Many people that we interviewed said that the non-Aboriginal people working in the Fitzroy Valley, in the disability and other sectors needed more cultural training. One parent noted that by not understanding Aboriginal people and culture, services were forcing Aboriginal people to break their cultural protocol and beliefs to access essential services.

### **Barriers to support coordination**

All but one person we interviewed was dissatisfied with their support coordination. The most common issues were:

1. Not being able to contact their support coordinator, either because they didn't know who they were, the support coordinator had left an organisation and hadn't been replaced, the support coordinator was too busy, or they didn't know how to contact them.
2. Not understanding what the support coordinator said, because the information was too complex or made no sense or because English was a second or third language for the person with disability and their family and sometimes for the support coordinator too.

3. The support coordinator promised them things that they did not deliver. Those people who have had contact with their support coordinator often reported the coordinator telling them about supports or services they were entitled to but which they never received.
4. The support coordinators made them complete too much paperwork, which resulted in very little benefit.

### **No choice and control over disability services**

People felt they had little to no choice and control over their service provider due to the limited options. Most people recognised the difficulty the existing disability services faced in not having enough staff to cover the need, and the problem disability support workers faced in not having anywhere to take people, etc. Nevertheless, some people felt forced to accept sub satisfactory services as they were their only option. A few carers questioned who ensures the quality-of-service delivery in remote communities. These carers tended to be the parents of adult children who were worried that there would be no one looking out for their child other than them, and making sure that disability support workers were treating their child properly when they were no longer able to or they passed away.

A number of people didn't like the fact that the support coordinators and service providers were from the same organisation as they felt they had nowhere to turn if they had a problem. For example, they weren't comfortable complaining about the allied health professional to the support coordinator as the two always travelled out to the community together.

### **Too many people and too much paperwork for very little benefit**

Several people that we interviewed, and many more that we spoke to informally, said that they were reluctant to continue with or to bother signing up to the NDIS because it is a lot of work for very little benefit. The people who have plans said that access to NDIS involves a lot of strangers coming to your house, asking intrusive questions, and requiring lots of paperwork for little to no services. Those families who previously accessed WA Country Health Allied Health Services were no longer able to access those services once they had signed up to the NDIS, so some people perceived the access to supports ceased once they completed the burdensome process of getting an NDIS plan. People who had been on the national-NDIS since it began in late 2019 have not seen any improvements over the past 24 months, suggesting these issues are not simply teething problems with the scheme but rather systemic issues.



# CASE STUDY 1

Charlie's\* family had some concerns about his development from infancy. He was seen by a speech therapist at 2 years of age who suggested he be assessed for autism spectrum disorder (ASD). As there are no psychologists employed through the WA Country Health Service a private neuropsychologist was paid to conduct the assessments. Charlie was given an ASD diagnosis in 2017, which was the same year Disability Services Australia ended and the state-version of the NDIS began. This transition meant there were no services in the region that had the capacity to support the family.

The paediatrician contacted a service in Perth that at the time offered support to rural families. This service required a multidisciplinary report before services could be provided, the individually conducted speech and psychology assessment reports were insufficient. Continuously advocating for his support needs to be met, in 2019 Charlie's father worked intensively with MWRC who funded a multidisciplinary team to fly to the region to re-assess Charlie and write the report. In the same year the state-NDIS rolled-over to the national version and there was promise of disability services expanding in the Fitzroy Valley.

In November 2020, The Marulu Team at MWRC helped Charlie's father complete an NDIS application form. It took 10 months, 11 meetings, 20 emails and 10 forms for Charlie to receive 5 speech therapy sessions and an iPad. Barriers that have restricted service access have included the fact that Charlie's support coordinators are drive-in-drive-out, there are no disability services for children in the Fitzroy Valley, and the NDIS process is too complex and requires too many forms and meetings.

The severe lack of services does little to alleviate pressures on Charlie's father, who is restricted to working part-time to allow for the flexibility required to meet the needs of his son, who at eight years still has limited speech and requires 24/7 supervision and is obligated to take unpaid leave during the school holidays.

This equates to \$30,000 a year of lost earnings, income that could go towards 'growing up' his children.

While there are many benefits associated with living in the Fitzroy Valley for Charlie and his father, his father is increasingly concerned that they will be forced to leave family, country and culture, and the only life they know to access the supports Charlie requires.

*"Because we live in a remote community my boy gets a better lifestyle, for example, he has freedom down at the river and the whole community knows who he is, his needs and struggles and watches out for him. However, he is not getting the therapy supports he needs here. Do I have to move to a city to get supports for my son? Do my children have to leave their family, lose their cultural ways and freedom to get access to services? I am not a city person, have never lived in a city so don't understand it and have no family there. Is there support there to help me get by? Is this stolen generation all over again just to get disability supports?"*

Established to support the most vulnerable in our society, this experience highlights where NDIS is failing those it seeks to aid.



## Timeline of Charlie's diagnosis

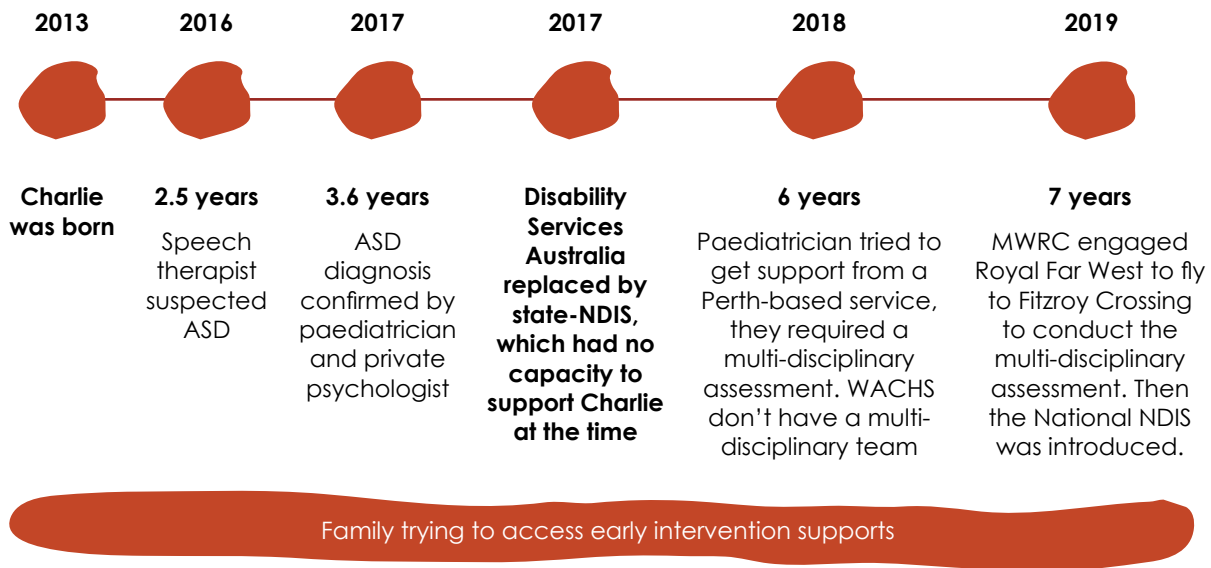


Figure 3. Timeline of Charlie's diagnosis and attempts for early intervention supports before the national NDIS roll-out

## Timeline of Charlie's NDIS-funded Supports

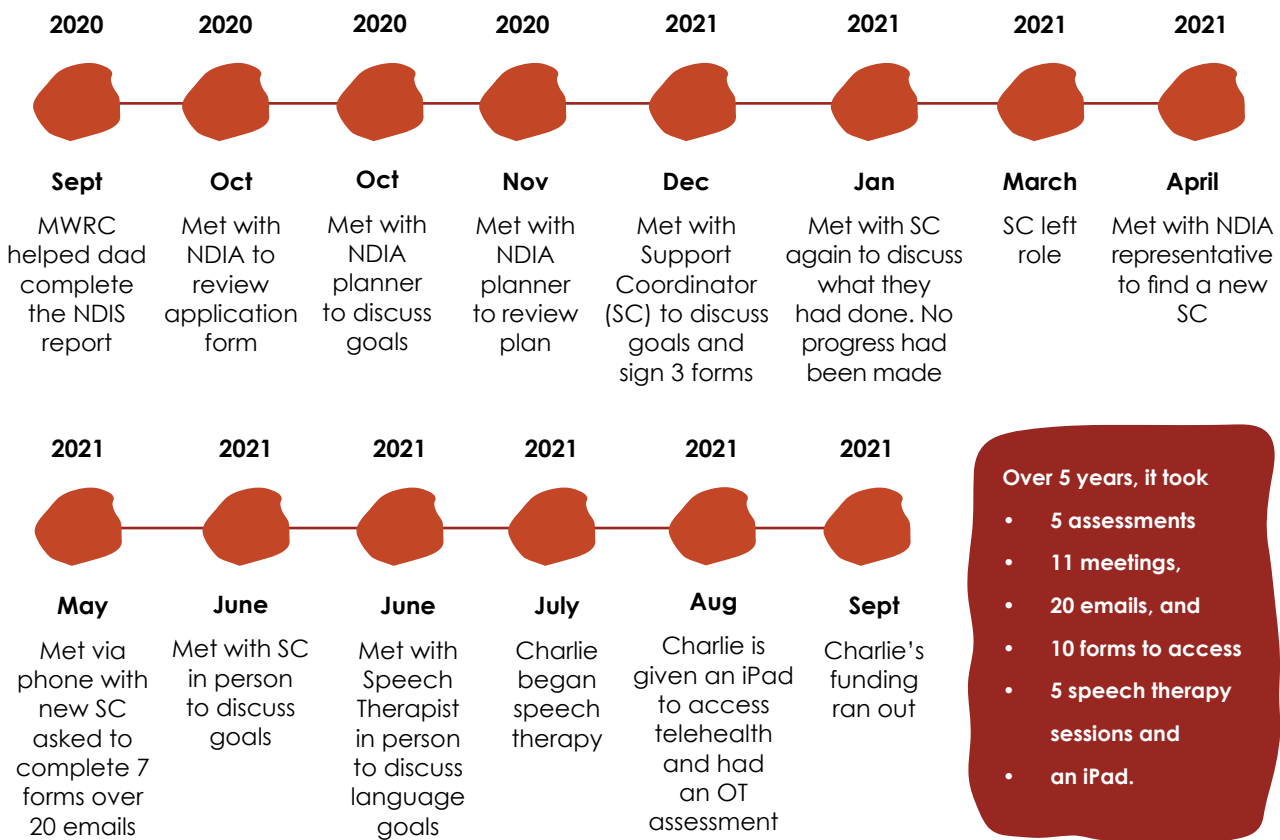


Figure 4. An outline of the steps required to access NDIS-funded early intervention supports for Charlie

# CASE STUDY 2

Molly\* is 5 years old living in a remote community with her mother and three siblings. Molly has a global developmental delay, is non-verbal and incontinent. Her mother has a range of health complications including a suspected cognitive impairment that cannot be diagnosed because there are no psychologists servicing the region apart from the school psychologist.

## **Support coordinator one**

The paediatrician helped sign Molly up to the NDIS in November 2019. Within the first 10 months of being allocated a drive-in-drive-out support coordinator, Molly didn't receive disability support. The few occasions the support coordinators came to the family home Molly's mother didn't appear to be home. However, Molly's mother confirmed that she fears she will be taken advantage of by strangers so is reluctant to open the door to people she doesn't know.

An ACCO assisting the family on another matter was concerned that the mother was struggling to independently manage her health as well as her child's support needs and Molly's high level care requirements. With the family's consent, the ACCO made multiple attempts to contact the support coordinator on Molly and her mothers' behalf but was unsuccessful. Lack of confidence in the system and having no relationship with this support coordinator culminated in the family's decision to sign up with a different support coordinator, and they were supported to do this by the ACCO.

## Support coordinator two

The ACCO arranged for the newly allocated support coordinator to meet Molly and her mother at their office and for a staff member to translate during the meeting. During the meeting, Molly's mother was made aware of the fact that she should have been receiving nappies and other supplies for her daughter's incontinence for the past 10 months in addition to receiving therapeutic supports. The costs of incontinence products are significant for people living in poverty. Although this meeting instilled some hope in the supports to come, the follow-through proved challenging.

After several months, the new support coordinator reported to the ACCO that although they had tried to visit the family home several times to complete forms that needed to be signed before service commencement, Molly's mother was never there. What was not known to the drive-in-drive-out service but was common knowledge across the community and to the local ACCO, was that Molly's mother was in hospital for several months and the children were being cared for by a relative.

## Support coordinator three and attempts at some therapeutic support

After 12 months, funding for Molly's care plan had solely been spent on the support coordinators travel into the community and their unsuccessful attempts to contact and locate the family. With the support of staff from the ACCO, including a translator, Molly's mother met with a NDIA Planner. Feeling supported by an Aboriginal person with experience in disability work at the ACCO, Molly's mother felt safer and more supported to express her concerns and needs, the result being that Molly's plan was doubled in value as her needs were made clearer and better understood.

Although the NDIA representative agreed that the complex needs of the family required a specialised support coordinator, there were no specialised support coordinators working in the Fitzroy Valley. A further barrier was that the family do not have access to a phone or reception to enable virtual connection.

With no specialist support coordinator in the area, Molly was then signed up to a third drive-in drive-out support coordinator. With the help of the ACCO staff, the third support coordinator was able to arrange for the completion of the necessary forms so that Molly could receive speech and occupational therapy. Although this appeared to be organised, Molly's mother later raised her frustrations that it had not been made clear to her that the therapy would



be provided in the school. She noted that Molly's primary support needs remained in the family home for multiple reasons, including the fact that school attendance was inconsistent and based on whether she had help getting Molly onto the school bus in the morning or not. The funding in Molly's plan to assist with getting her to and from school was ineffective because no in-home services are available in the area to help Molly get ready and on the bus.

### **Support coordinator four and still no nappies**

Support coordinator number three did not remain in their role long, and the external organisation struggled to find a replacement. The ACCO assisted Molly's mother to sign up to a fourth support coordinator, based interstate. Information received from the fourth support coordinator was that an incontinence assessment was required before nappies could be purchased for Molly. The incontinence specialist in Broome was contacted but was unavailable to travel the 4 hours to the remote community. As a result, the search for an alternative specialist is ongoing.

**It has been almost 2 years** since Molly received her first plan. Despite four incoming support coordinators, she has received only three early intervention sessions, and no in-home supports or assistance for the purchasing of nappies and other disability-related supplies. Molly's required learning support, physiotherapy and speech therapy have not been provided – a missed opportunity to maximise the benefits of early intervention. Meanwhile, her mother's cognitive capacity remains unknown, and she is receiving no supports for herself.

Life is already incredibly difficult for people living in remote Aboriginal communities. Molly's story is an example of bureaucracy being completely counterproductive. The NDIA has set Molly and her family up for failure, disappointment, and frustration. There is no way the NDIA would get away with this in the city, yet it appears to be the norm in remote Aboriginal communities.

## CASE STUDY 3

Jacinta\* is a 30-year-old woman with Cerebral Palsy and mild intellectual disability who lives with her grandmother, birth mother and nephews. Her ageing grandmother, Mary, is her primary caregiver as her birth mother suffers from severe mental illness. Jacinta only requires allied health support for her physical disability a few times a year. However, she requires assistance with all her daily activities, including showering, going to the bathroom, preparing, and eating meals, all housework, transport, and participation in community activities.

Mary provides all the in-home care and is finding it difficult to keep up with Jacinta's needs due to her own health issues. There is funding in Jacinta's plan for her to participate in community activities 4 days a week and to have someone provide some in-home support to reduce the burden on her grandmother. However, the lack of disability services locally means there is no one to provide the in-home care.

**Every Tuesday Jacinta is picked up by the locally based disability service and taken to TAFE where she is supported to take part in a range of activities, including learning how to prepare her own meals. Jacinta loves her TAFE program. Unfortunately, the rest of her week is spent sitting at home as there is nowhere for the support staff to take Jacinta.**

Mary reported that Jacinta has talked about wanting to commit suicide on several occasions and she believes Jacinta is depressed because she has little to look forward to in life. Mary has sought out counselling for Jacinta but has been unable to find a psychologist that travels to the Fitzroy Valley.

Jacinta's extended family get together every weekend by the river to fish, swim and share stories. Sadly, Jacinta and Mary can't spend this time with their family as there is no wheelchair access to the river.

Mary is worried about what will happen to Jacinta when Mary passes away. She fears that the only options are either for Jacinta to leave her community and country and live in a residential facility in the city or for her to live with extended family members who do not have the capacity to provide all the care Jacinta needs, putting her at risk of being neglected or taken advantage of.

Jacinta's birth mother also requires care because of her mental illness, but Mary has not bothered to apply for an NDIS plan due to the lack of services available and their lived experiences of the NDIS.



## CASE STUDY 4

Kent is a 25-year-old man who lives with nine family members in a three-bedroom house in a community near town. Kent shares a room with his uncle who is his primary caregiver. Kent's uncle has a chronic health condition that puts him in and out of hospital for lengthy periods of time. The other household members struggle to understand Kent's disability, which causes frustration for him and them.

Extended family from remote communities stay in the house when they need to come to town. At times, and particularly during the wet season, there can be up to 15 people camping in the house. Kent has an intellectual disability and requires 24-hour supervision. Overcrowded spaces and loud noises cause him great distress. So, when the house is overcrowded, particularly at night-time, he wanders around to look for peace and quiet. However, his lack of awareness of his surroundings and inability to perceive danger puts him at great risk of being runover or hurt. Staying up late at night is impacting Kent's health as he struggles to sleep during the day so is chronically sleep deprived, decreasing his functional capacity and increasing his support needs even more.

Kent's uncle puts off spending time in hospital for his own health as much as possible as he worries about Kent being out wandering around at night when he's not there. Kent's uncle has been on the housing waitlist for several years to get a two-bedroom place for him and Kent. However, even with this house, family obligations mean he will have to allow extended family members to stay there when they are in town. Kent's uncle would prefer that Kent have his own one-bedroom place with supported living as this would mean that the support staff could ensure only Kent lives there giving him the peace, quiet and routine he requires. Having Kent in a supported home would also mean Kent's uncle can focus on his own health, get the surgery he needs, and rest assured knowing Kent is being looked after.

# INTERVIEWS WITH NDIS SERVICE PROVIDERS AND OTHER KEY STAKEHOLDERS

**Aim 3: What are the facilitators and barriers to delivering disability services in the Fitzroy Valley.**

Question One: Are there any things that make providing services in the Fitzroy Valley easier, such as partnerships, location of staff, etc.

## **1. Being based in the Fitzroy Valley or having partnerships with Fitzroy Valley based services**

*“Having a staff member based in the community has helped connect us to families as well as ensuring people with disability have access to support when we are not there. The 15 people we have provided therapy to is because the person on-the-ground knows where they are, can build rapport over time and is able to connect us to them”*  
– A drive-in drive-out therapist with on-the-ground support.

All disability service staff interviewed stated that having a presence on-the-ground either within their own service or through a partnership with a Fitzroy Valley based service made it easier to identify, connect with and support people with disability. Only one drive-in drive-out service has created a presence in the Fitzroy Valley. This service notices many benefits to being based in the Fitzroy Valley but struggles to expand due to lack of staff housing.

While all service providers had positive experiences working with local services, this was not standard practice for drive-in drive-out disability services. Some drive-in drive-out services have tried to build partnerships with local services, but the external services do not allocate funding to pay the local service for their assistance. Also, local services are stretched with their own work and do not have capacity or responsibility to connect drive-in drive-out services with participants. This burden of expectations on ACCOs is growing and could be turned into a solution if adequate resources were provided.

## **Working alongside local Aboriginal people**

“Partnerships with local Aboriginal Community Controlled Organisations and



positive relationships with Aboriginal community members" – A drive-in drive-out therapist.

Staff who have had an opportunity to work alongside a local Aboriginal person said that this allowed them to understand the culture and improved two-way communication, which helps gain the trust and respect of people in the Fitzroy Valley. Having a local Aboriginal person who can translate and advocate, allowed service providers to better understand the needs of each person and ensured the person and their carers understood the NDIS and their plans.

Only two disability services allocate funding to employ local Aboriginal people. However, for one service the funding is not to enable the Aboriginal person to work alongside non-Aboriginal staff, but rather pays for the Aboriginal person to take on their own responsibilities. This disability service reported issues with local staff retention due to the many challenges experienced by local Aboriginal people (e.g., frequent loss of family members due to high mortality rates in the region, high demand of family carer responsibilities, lack of transport from remote communities to get into town to work, the burden of working with family, and family trauma).

The other service employs local Aboriginal people based in the Fitzroy Valley to work alongside drive-in drive-out non-Aboriginal staff. This service reported many benefits to this model, employing local Aboriginal people helps these services gain people's trust and ensures the person with disability is available and ready to receive the service when the drive-in drive-out team arrive. The local Aboriginal staff reported benefits to having the support of people with disability experience working alongside them through a drive-in drive-out model but felt that they would be able to achieve much more if they had someone with disability experience based in the Valley full-time working with them.

Question two: Are there any services that people have requested that you are not able to provide? If yes, why?

*"There are no neuro-related services for people with brain-based disabilities or people with mental health problems. So, their physical needs are getting met but psychological needs often have to happen before physio treatment can start and there is just nothing to help with this need" – A disability service provider.*

There were quite a few supports requested that disability services were not able to provide or connect people to, either because the service was not operating in the Fitzroy Valley or was operating at limited capacity. The most common of these requested services are listed below.

1. **Locally based support coordination** so that people with disability have a name and face that they can go to when needing help with their NDIS plans and who is able to follow-up with services to ensure supports are provided. This service is in high demand in the region as people have a preference for face-to-face services. There used to be a locally based person available under the disability services model, recognising the importance of respectful relationships, which people liked.
2. **Support workers based in the Fitzroy Valley** who provide daily supports, such as driving someone to work, assisting with in-home care, taking people to medical appointments, ensuring people can pick-up and are taking their medication, supporting people to participate in community events and activities.
3. **Repairs for wheelchairs.** The local mechanic has assisted with some repairs, but people often have to wait weeks for wheelchair parts or for the drive-in drive-out support coordinator to organise payment for the mechanic.
4. **Respite** is commonly requested by clients and their families. This is something that has only been accessible to a few participants due to the shortage of respite options in the Kimberley and the long waitlist. The lack of support workers on-the-ground means carers and families do not get a break from caring for their loved one and people with disability are forced to rely on their family 24/7.
5. **A psychologist to provide emotional, behavioural, and cognitive supports** for people with disability or chronic mental illness and allow their parents and family members to gain knowledge about the person's disability and learn how to support them. There is only one psychologist who can travel to the Fitzroy Valley to provide NDIS-funded supports. She is based in Broome and advised that most of her time is taken up with court order cases or her large caseload in Broome, so she has limited time to see people across the Fitzroy Valley. The lack of psychological support is particularly concerning given the known prevalence of early life trauma in the region<sup>27</sup>.
6. **Day programs and after school care programs** were also highly requested as there is nothing for people with disability to do and no place for them

to go in what is often extreme (>30 degree) heat. Having nothing to do and nowhere to go has played a role in the high turnover of local staff employed as disability support workers, as they feel at a loss with how to support the person. The lack of opportunity to participate in the community means people with disability spend most of their time at home, which is almost always overcrowded and impacts their quality of life and wellbeing. Having a day program would make it easier for drive-in drive-out disability services to locate people and have somewhere to provide therapeutic supports.

7. **Other supports** requested include a dietitian; therapy resources such as gym equipment for the physiotherapist; assistance with housing applications; more help from organisations such as Autism Australia and specialist supports; counselling services for mums and families; in town therapy support.



### Question three: Are there any things that make providing services in the Valley hard?

Based on the interviews with services there were four common themes that made providing service delivery in the Fitzroy Valley hard. These are outlined below.

#### **Issue 1: Not being based in the Fitzroy Valley**

As noted above, face-to-face is the preferred and often necessary model of service delivery in the region. Services based in the Fitzroy Valley say they find it relatively easy to gain trust and build rapport with people with disability and their family, which makes service delivery and being able to locate people much easier. The services that drive-in and -out talk about the difficulties they have building connections. Most drive-in and drive-out services cover a large area so can only spend two or three days a month in the Valley. These services struggle to connect to participants in that short timeframe, particularly if the person doesn't have a phone or lives in a community with no phone reception so doesn't know when the service is coming. The drive-in drive-out services also struggle to cover their full caseload for the region in only 2 or 3 days. Almost one day is consumed by the drive from Broome to Fitzroy Crossing. The return drive-in one day from Fitzroy Crossing to outlying communities leaves little time for contact with the person with disability. These issues mean participants often wait months between visits/therapy sessions, reducing the impact and likely efficacy of the services. The service providers note that they charge the individuals for their travel time even if they do not find them, which is often the case.

**The current drive-in drive-out model is, therefore, costing the NDIA a great deal in travel and accommodation costs with little return.**

**Issue two: Lack of housing to establish/expand disability services in the region**

A lack of housing is the main reason why disability services can't establish themselves in the community and why the existing services can't expand to meet the need. The housing shortage not only impacts non-Indigenous service providers but prevents services from being able to employ and house Aboriginal staff.

The severe overcrowding in houses in Aboriginal communities impacts all aspects of a person's life, including their work. It is a cultural expectation that Aboriginal people support the members of their kinship group where possible. Thus, someone in paid employment would be expected and want to help support the other family members living with them. However, having seven or eight other people living in a house means all their salary will need to go on food, electricity, and other basic living needs, which leaves no money for themselves. The high demand placed on the few who are employed reduces the reward and motivation to work.

Many Aboriginal people in the Fitzroy Valley want to find jobs that provide allocated housing to allow them to move out of the overcrowded living conditions. The younger generation also talk about wanting their own housing so they can gain independence from their parents/grandparents.

**Issue three: Low health and disability literacy**

*"People don't know what good looks like; they have no idea what an occupational therapist is let alone what they do and why their child would need one". – Senior Community Representative*

The disability stakeholders reported low health and disability literacy as a key barrier to providing disability services. A lot of people in the Fitzroy Valley have not heard of the NDIS or are aware that they are eligible to access funding. People on NDIS plans and their carers still do not understand what the NDIS is

or how to use their plans. Quite a few people we interviewed didn't even know whether they were on a plan. The few people who do know what the NDIS is usually have someone in their community who is assisting them to connect to services and ensuring they are making the most of their funding.



**This lack of understanding of the NDIS is not surprising given it is the responsibility of the remote community connectors to explain the NDIS and support coordinators to explain peoples plans and there is no active RCC and a no locally based support coordinators in the Fitzroy Valley.**

Service providers mentioned that some of the parents/primary caregivers of their participants didn't know the name of their child's disability or diagnosis and didn't remember anyone trying to explain it to them. The disability service providers felt that the lack of education about a person's disability means that people with disability and their families do not know the potential of what services can provide.

Services that work with children highlighted the need for more education for parents so they can understand child development and what affects a child's growth. These services believe that if parents were taught about their child's needs at an early age, especially those with disability, it would ensure parents invest their time in implementing early intervention strategies to ensure better outcomes later in life. It would also allow services to provide more supports that the parents could then implement in between sessions. More education across the Valley about disabilities in general would also allow for other carers and family members to understand and support people they know who have disability.

However, this education must be led by Aboriginal people to ensure the information shared fits with the beliefs and values of Aboriginal people and communicated in an accessible and appropriate way.

#### **Issue four: Silo record keeping**

A range of health services work in the Fitzroy Valley, and each has their own record keeping system. This means a patient's records can be spread over eight different databases that aren't all accessible to medical professionals. The large number of databases makes it difficult for the NDIA and NDIS-funded service providers to access a person's full medical records. Instead, they only get a snapshot of the medical history or current service provision. Inability to access a person's medical records can delay access to the scheme and service delivery as the medical information is often required to confirm the permanency and functional impact of a disability. Good record keeping is particularly important in remote communities where there is a high turnover of health staff and limited health literacy.



SECTION 4:  
RECOMMENDATIONS

#### **Aim 4: How could the NDIS roll-out be improved in the Fitzroy Valley?**

**Recommendation 1:** The NDIA should invest in 5-year funding for the Remote Community Connector program and implement the Evidence, Access, and Coordination of Planning program in the Fitzroy Valley to ensure access to the scheme is streamlined and efficient.

The RCC program appropriately acknowledges the barriers faced by Aboriginal and Torres Strait Islander people living in remote communities in accessing services. However, these barriers don't go away after 12 months, particularly with a service as complex as the NDIS.

We recommend that the RCC program be funded for five years to ensure there is sufficient time for staff to travel to each of the 36 remote communities to inform people about the NDIS. Extended funding will ensure the staff working on these programs are available to break down the barriers experienced by drive-in drive-out NDIA staff and service providers so they can locate and engage people with disability in a culturally appropriate way.

The RCC program was designed to align with the EACP program. We commend the NDIA and the National Aboriginal Community Controlled Health Organisations for working together to create what we call a two-way job, where the RCC and EACP staff work together to bridge the gap between the two worlds (Aboriginal and non-Aboriginal Australians). However, only the RCC program has been proposed for the Fitzroy Valley. Without the support of the EACP program the RCC's will be set up to fail. It is unrealistic to expect a person to have the necessary local cultural knowledge, language, and community ties required to successfully conduct the RCC role, as well as the knowledge of disability and disability service experience required to deliver the EACP program responsibilities. See Figure 5 for a breakdown of the roles and responsibilities required from the RCC and EACP programs. This table clearly shows that these roles can only be filled by a local Aboriginal person (RCC) and someone with experience living in the 'white-man's world (EACP).

We recommend that the NDIA provide funding for a person with disability experience to live in the Fitzroy Valley to implement the EACP program and walk alongside the RCC's to help inform and connect people to the NDIS. MWRC successfully use this model across all their services and has good evidence of its success. Goal five of the NDIA Rural and Remote Strategy is to "Harness Collaborative Partnerships", which includes understanding what already exists and what works and builds on that for success.



Having an Aboriginal person with local knowledge working alongside someone with disability knowledge will ensure a streamline process into the NDIS for people with disability while also help building up local people in the disability sector.

Similar models have been proposed by other first nation groups across the country including the Aboriginal and Torres Strait Islander Disability Network of Queensland, who in their consultation report for the new National Disability Strategy, proposed the need for community navigators to help people navigate complex government services<sup>57</sup>.

### **Two-Way Knowledge, Two-Way Jobs**

#### **Key knowledge required to implement the NDIS in the Fitzroy Valley**

#### **RCC - Local Aboriginal Person with strong connection to the community**

- Must be trauma-informed.
- Must speak Kriol, speak/understand some traditional language (e.g., Gooniyandi, Bunuba, Walmajarri, Wangkatjunka, Nyikana) and know how to break high English down and translate it into Kriol.
- Must understand cultural protocol (e.g., who can provide supports to who, family connections, what you can't ask certain genders, when is it ok to visit a person who has recently lost a family member, who can enter a remote community, how to approach someone's home).
- Due to the transient/homeless nature of the community, need to know where people are currently 'stopping'.
- Some understanding of people's circumstances, particularly when they have a disability and no primary caregiver (e.g., is there anyone in the extended family that can assist the person, are the NDIS goals being discussed in the planning meeting achievable given their living circumstance, is the person likely to own a fridge/basic cooking supplies or other items relevant to their daily support needs).

#### **EACP/Planner - Person with a good understanding of the western world**

- Must be trauma-informed.
- Must understand different disabilities (e.g., FASD, ASD, ID, GDD, epilepsy, cerebral palsy, Down syndrome, schizophrenia, psychosis, etc).
- Must know what functional impairments/ disabilities/health conditions/mental health conditions qualify for NDIS and what don't.
- Must know how these disabilities impact a person's life.
- Must know what type of supports exist for people with different disabilities as people may not know what they can ask for (e.g., what resources are available for someone with vision impairments?).
- Must know how to navigate the NDIS. What is an NDIS Planner, Plan Manager, Support Coordinator, Specialised Support Coordinator, Disability Support worker, Occupational Therapist, Speech Therapist Physiotherapist.
- Must understand how to navigate the complex health system. Is the person's health record with WA Country Health Service, Boab Health, KAMS, Royal Flying Doctors (RFD), Kimberley Population Health, KMHDS.
- Must have good numeracy and literacy skills and be proficient in Outlook, Word doc etc.

*Figure 5. This figure illustrates the knowledge required to successfully implement the NDIS, a western service, in the Fitzroy Valley, a collection of Aboriginal communities.*

**Recommendation 2: The NDIA must continue the Remote Early Childhood Services program to ensure children can thrive in their early years and reach their full potential, which may reduce reliance on the NDIS in the long-term.**

The RECS program provides crucial early intervention supports to help young children with disability or developmental delay reach their full potential. These services can help some children catch up their development to a point where they no longer require disability services. The RECS program also helps address Target 4 of the National Closing the Gap Targets, which aims to ensure children can thrive in their early years and is one of the few elements of the NDIS that is working well in the Fitzroy Valley. However, it is currently under threat as there is a push to remove the allied health team from the RECS model and for family support workers to sign up young children to NDIS plans to access private disability services. This change is problematic for the following reasons:

1. Getting an NDIS plan means confirming **permanent** disability, which often requires a diagnosis or assessment of function. The paediatric health service is severely stretched and doesn't have the time or resources (e.g., neuropsychologist) to assess and diagnose all children, for some children a formal diagnosis is not even possible before 4 years of age due to the nature of the assessments. Meaning children will miss out on crucial early intervention services waiting for a diagnosis.
2. Even if a child has a diagnosis and an NDIS plan, there aren't enough disability services working in the Fitzroy Valley to provide the crucial early intervention therapies. So, children will have plans but minimal to no therapeutic support.

The only justification for getting rid of or changing the RECS model is if a better model of support is provided. We recommend that the RECS model continue as it is currently designed across the whole Kimberley and that a minimum of 5-year funding be provided to ensure its protection. This will enable the opportunity to build the local workforce with appropriate allied health assistant qualifications.

**Recommendation 3: The NDIA should ensure locally based support coordination and specialised support coordination services are available to break down barriers to accessing disability services and reduce underspend and travel costs.**

Support coordinators are the gateway to disability services for people in the Fitzroy Valley. Their role is to help people identify the supports and services needed to achieve their goals. Support coordinators are particularly important



for people living in remote communities, where there are extra barriers to overcome to access services, such as distance, lack of services, high turnover of staff, and family complex life circumstances, traumatic events, and cultural commitments. The only way support coordinators can identify and address these barriers is if they are based locally and develop deep understandings and can observe and understand the issues people face.

As is mentioned throughout this report, people in the Fitzroy Valley rely on face-to-face services to overcome language and cultural barriers. Few people have access to a computer and phone numbers are constantly changing. The high turnover of support coordinators employed by the drive-in drive-out services and the extremely high underspend of NDIS funds shows that the current model of service delivery isn't working.

People in remote Aboriginal communities also experience high rates of adversity due to poverty, overcrowding, domestic violence, mental ill-health, complex trauma, and increased burden of disease etc. These adversities impact a person's basic needs, and these needs must be addressed to give that person the capacity to engage in disability services. The NDIA has allocated funding for specialised support coordinators to help people address these barriers, however, there are no specialised support coordinators servicing the Fitzroy Valley.

The NDIA needs to work with services in the Kimberley to establish support coordinators based in the Fitzroy Valley, including specialised support coordinators, to serve the large number of people with known complex needs. Having locally based support coordination will mean people have a face person they know they can go to for support, which is one of the features missed most about the old Disability Services Commission Model.

Locally based support coordination will:

- save the NDIA money as it takes away the travel costs of drive-in drive-out support coordination from Broome and Darwin
- save the NDIS money in support coordinators not being able to locate people
- decrease the time between receiving a plan and accessing supports and services as the support coordinators can see the participants more than once a month
- reduce the likelihood of underspend as the locally based support coordination will be better placed to address barriers to service delivery
- direct the participants' packages to the services they need, increasing impact.

**Recommendation 4: The NDIA should invest in disability services and/or local services to employ, train and support locally based allied health assistants to reduce the overreliance on expensive specialised drive-in drive-out services.**

Many people reported having to wait months to access NDIS-funded allied health supports, such as speech therapy, physiotherapy, or occupational therapy. These services are essential for assessment and treatment to enable people with disability, and particularly children with developmental delay, reach their full potential.

Intellectual disability costs Australia approximately \$14,720 billion annually<sup>19</sup> and this cost is directly associated with the severity of behaviour problems<sup>21</sup>. The longer a problem behaviour persists the harder it is to change, so early intervention is essential for reducing the impact and cost of behaviour problems. While early intervention is available through the RECS program, this is only for children under 7 years of age who do not have an NDIS plan. The RECS allied health therapy team also only have four days a month to provide effective allied health therapy to all children in the Fitzroy Valley with developmental delay.

Similarly, the two NDIS-funded drive-in drive-out allied health services available for people over 7 years can only come every 4-6 weeks during the dry season, severely restricted during the wet, and are expected to cover the full 200km radius in 2-3 days. These disability services have a high turnover of allied health professionals so long delays between appointments are common, further reducing the amount and efficacy of support available for people with disability.

If disability services had a footprint in the Fitzroy Valley, they could build capacity in allied health by training local Aboriginal staff to be *allied health assistants*<sup>36</sup>. Allied health assistants could ensure that essential therapy services were maintained between monthly drive-in drive-out allied health sessions and potentially fill service gaps by supporting people to access telehealth services when needed, reducing the need to pay expensive allied health professionals to travel as often from Broome/Darwin. **For this model to work there would need to be a full-time person with disability experience walking alongside the allied health assistants** to allow them time to build the knowledge and confidence needed to succeed in this role.

**Recommendation 5: As recommended in the NDIA's Rural and Remote Strategy, the NDIA should 'harness collaborative partnerships' by investing funds so disability services can engage ACCO's to successfully establish and integrate their disability service in the Fitzroy Valley.**

While some communities, like Palm Island, have a preference for ACCO's to take on the work of private disability services<sup>44</sup>. The ACCO's in the Fitzroy Valley feel stretched with their current workload and are instead happy to support an external service to create a base in the Fitzroy Valley.

ACCO's are borne out of Aboriginal communities to act as their collective voice. These organisations consist of local Aboriginal staff who have spent all their life in the Valley and know what does and doesn't work. Services new to the region, including drive-in drive-out services are constantly popping into ACCO's to seek guidance on how to engage the community and fit in with existing services. Although staff are usually happy to help, ACCO's rely on short-term funding to do specific tasks. Any work outside of those tasks is unfunded and adds extra burden on an already stretched team.

We recommend that the NDIA makes funding available so that services that want to establish themselves in remote Aboriginal communities can engage local ACCO's to introduce them to the community and advise how best to establish and integrate themselves. This funding could be like the Information, Linkages and Capacity Building (ILC) grants that were made available to services in other states at the start of the NDIS roll-out. The nature of these grants evolved as the roll-out in other states progressed. The delay in rolling out the national NDIA in WA meant the grants were two steps ahead of services in WA so these services missed out on some of the benefits of the ILC funding.

**Recommendation 6: The NDIA should implement strategies to ensure accountability of services in remote settings.**

One of the key features of the NDIS is the opportunity it provides for people to have 'choice and control' over the services they receive. If people aren't happy with a service, they can move to another one. While this process is true in urban communities it's not the case in remote communities where there are limited or no other options due to the small number of services.

The lack of choice and control in remote settings means it is vital the NDIA ensures that service providers are closely monitored and held accountable. The national NDIS has only been in place for 18 months in the Fitzroy Valley and people have already reported feeling vulnerable. They say they have nowhere to turn when they are unhappy with a service provider due to the

lack of choice, particularly when the support coordination service is offered by the same organisation as the other disability services.

We recommend that the NDIA invest in evaluation and monitoring strategies to ensure that private disability services working in remote regions are providing optimal care. Without this investment, the NDIA is putting people with disability at risk.

**Recommendation 7: The NDIA should provide a clear process for extended family members to become paid support workers of people with disability when no services are available and support coordinators and planners should inform families of this process.**

Aboriginal communities in the Fitzroy Valley are made up of family groups so most, if not everyone in a community, is related. Some communities are up to 200km away from town. Despite this, the NDIA has told a number of people in the Fitzroy Valley that family members cannot be paid to provide formal care. As there are no disability support workers in remote communities and not enough in town, families are forced to take on the burden of providing full-time care for their loved one with disability while their NDIS plan goes unspent. Senior NDIA representatives told the authors that people can apply for exceptions to this rule, however, this information has not passed down to NDIA staff on the ground.

We recommend that the NDIA create a clear process for extended family members to be considered for the role of disability support worker when there are no services available and that this process is clearly articulated to people with disability and family to ensure their plans can be used and they can receive the supports they require.

**Recommendation 8: The WA Country Health Service, Kimberley Aboriginal Medical Service, Primary Health Network and Private Health Services in the Kimberley should establish a single accessible medical record for people in the region.**

Staff from Aboriginal Community Controlled Organisations and disability and health services that have helped people with disability gather evidence to support their NDIS application all noted how difficult it is to locate a person's full medical records. As noted above, there are a range of different health services in the Fitzroy Valley with their own record system and sometimes multiple systems in one service, which means a person's medical history and current service provision can be spread over eight different databases. This silo recordkeeping increases the likelihood of people falling through the gaps or double up of service delivery.

Given the overlap in disability, health, and mental health, we recommend all disability and health services work toward a single accessible medical record system. The level of information shared between services can be limited to a need-to-know basis to protect privacy. The high staff turnover of health professionals makes a centralised system even more important. Given disability and health services are often provided in remote communities, this system should be accessible remotely, such as through a secure app.

**Recommendation 9:** The WA Country Health Service should establish a team of clinicians to identify and support people with neurodevelopmental impairments as the earlier these impairments are identified the better the outcome for the individual, meaning less reliance on government services in the long-term.

Almost everywhere else in Australia, a doctor who suspects a person has a cognitive impairment will refer them to a clinical psychologist or neuropsychologist for a cognitive assessment. This assessment will confirm the nature and extent of the impairment, which will inform the types of supports and services the person requires. In Alice Springs, the Central Australian Aboriginal Congress Child and Youth Assessment & Treatment Service was established to assess, diagnosis and manage children aged 0-18 years with suspected neurodevelopmental delay/disorders. The team of eight includes a team leader, two paediatric neuropsychologists, two speech pathologists, an occupational therapist, an Aboriginal family support worker and a clinical case coordinator who work closely with the paediatricians<sup>13</sup>. Having this service embedded within an Aboriginal Medical Service helps ensure the assessments are conducted with proper cultural knowledge and understanding.

In the Fitzroy Valley, and we believe possibly the whole Kimberley, there are no psychologists/neuropsychologists employed through the health service to conduct cognitive assessments or provide management for cognitive, emotional, and behavioural problems. As a result, people with cognitive impairments are left undiagnosed and unsupported. This is even though the Fitzroy Valley has the only known prevalence of FASD in Australia and one of the highest rates in the world.<sup>27</sup>

Our organisation has seen the impact that a lack of supports, and services have on the health and wellbeing of people with neurodevelopmental disabilities. People with FASD or intellectual disability are forced to fend for themselves, unable to make healthy choices and at risk of being taken advantage of. They often develop preventable health or mental health conditions, end up severely unwell or disabled and die at a young age. Our staff and community members watch this happen to their family members over and over.



In her 2019 report on the death of 13 young children in the Kimberley, Coroner Fogliani highlighted the need for increased child health services. While Coroner Fogliani focused on diagnostic capacity for FASD, we recommend increasing capacity for the identification of neurodevelopmental delay or impairment from all causes. The focus of the NDIA is on functional capacity not specific diagnoses, as are the criteria for NDIS support. We agree that focussing on identifying a participant's support needs rather than a diagnosis will better help direct their care plan and have a greater impact on their quality of life. The supports funded for participants must be informed by in-depth knowledge of the impact of impaired cognitive functioning on activities of daily living. Understanding the trajectory of the impact of cognitive impairment over the life span is also essential for the planning and implementation of supports for neuro-developmentally compromised participants. Access documents for NDIS must therefore be prepared by qualified staff (e.g., neuropsychologists) trained to understand the role of standardised assessments for cognitive function and the impacts of cognitive impairment on functional capacity. Neuropsychologists are trained to undertake and interpret cognitive assessments and their role in preparing access documents should be considered essential.

The authors of this report presented evidence to the Senate Inquiry into the NDIS Independent Assessments on the need for these assessments to be culturally appropriate and conducted by qualified staff<sup>11, 12</sup>.

We recommend that the WA Country Health Service establish a neurodevelopmental team to assess, diagnosis and manage people with suspected neurodevelopmental delay/disorders, like the service in Alice Springs. At minimum, neuropsychologists should be employed to work in the Fitzroy Valley with the existing health and allied health teams, particularly the paediatric team.

**Recommendation 10: Commonwealth and State Government need to invest in services to allow people to heal from and break the cycle of intergenerational trauma.**

Target 14 of the Closing the Gap Targets is that *people enjoy high levels of social and emotional wellbeing*.<sup>4</sup>

Data from the Lillivan Project found that 90% of children aged 7-8 years living in the Fitzroy Valley in 2010 had experienced significant early life trauma<sup>27</sup>. It is well known that early life trauma increases a person's risk of developing chronic health and mental health problems later in life<sup>18, 20, 22, 32, 34</sup>,



including increasing the likelihood of people with developmental illnesses like schizophrenia that can lead to permanent disability<sup>38, 48</sup>.

Trauma is the underlying thread to many of the social adversities experienced by people in remote Aboriginal settings, such as drug and alcohol dependence, mental health problems, domestic violence, and incarceration. Addressing trauma means addressing the root cause rather than the symptom.

Despite the high prevalence of early life trauma there is a severe lack of social and emotional wellbeing services to allow people in the Fitzroy Valley to heal. A list of the existing services as we know them is provided below.

1. The WA Country Health Service Kimberley Mental Health and Drug Service (KMHDS) only has the capacity to support people with severe mental health problems. While the team are hardworking and responsive, most of their time is taken up responding to crisis or people with chronic mental illness. There are no psychological services available from the KMHDS only a visiting psychiatrist.
2. MWRC family support and legal team have an art therapist/counsellor who provides support to women and families affected by domestic violence. Like the above service, the counsellor spends much of her time having to respond to crisis and struggles to meet the need of the whole community.
3. Two external private companies provide drive-in drive-out counselling three days a fortnight. Like the above services, these individuals struggle to meet the demand within their timeframe, particularly given the great distances they must travel. The long history of ever-changing drive-in drive-out services also makes it difficult for these services to build the rapport and trust required for people to feel comfortable to open up and benefit from the services.

Having to respond to the high level of crisis facing the Fitzroy Valley community leaves little time for these services to provide ongoing therapeutic support to allow people to heal from their trauma. The lack of support means the mental health problems in the region are widespread, persistent, and complex, which means they require intensive and experienced responses.

We recommend the Commonwealth and State Government provide funding to local services to implement evidence-based therapeutic services to allow each community to work together to acknowledge, address and respond to the intergenerational trauma that has plagued them because of policy failures and poor resourcing for decades. The types of therapeutic services required include:

1. Clinical psychologists/counsellors experienced in helping people recover from trauma. These must be male and female to meet cultural needs and based in the community working alongside local Aboriginal people.
2. Wrap-around supports for young parents to break the cycle of trauma (social worker, counsellor, Aboriginal family support workers working together with existing services).
3. Funding for community-wide on country healing camps as well as opportunities for people to go on country as part of their therapeutic supports.

*Recommendation 11: Staff from Commonwealth, State, Aboriginal Community Controlled and Private Organisations working in the Fitzroy Valley must understand how disability is perceived by Aboriginal people and adapt their perception of disability from impairment to strength focused.*

*“Disability doesn’t exist in our culture. You say, ‘this is Jimmy, and he has autism’, we say ‘this is Jimmy.’ This is an important distinction that is rarely understood by non-Aboriginal people, but it must be if people want to succeed in our community.”*

The term disability is a western construct imposed on first nation groups around the world<sup>60</sup>. It is how the western world identify and understand people in need and provide the necessary supports. However, it goes against an Aboriginal person's cultural beliefs to have to identify as having a disability. The families that we interviewed take a strength focused approach in how they perceive disability, they focus on how a person can contribute to their community rather than how they can't. If an impairment needs to be described, then they discuss what they do to support the person rather than what is wrong with that person.

For example, “You will need to speak up when you talk to Mary” rather than “Mary is deaf”. “It's best to write things down for Joey” rather than “Joey has a memory deficit”.

While the NDIA aims to focus on function rather than diagnosis, a diagnosis is often required to confirm the permanency of a functional impairment. In an NDIS planning meeting the better the functional difficulty is described and how it negatively affects the person's life the more funding they are likely to receive, which is deficit focused. We strongly urge the NDIA to change this process when working with Aboriginal people. To identify the support needs, NDIS Planners

should focus on how family members adapt their lives to accommodate their loved one. The planners should also focus on how funding can be provided to better enable a person to **contribute** rather than just **participate** in their community.

*As noted above, MWRC helped support 20 people with disability to access various aspects of the NDIS, which included going to a range of services to collect proof of identify or proof of disability. Through this experience we saw people with disability and their families openly discuss their support needs to some staff but close-up in front of others and say, "he fine". The primary difference between these interactions was the language used by the staff. Those that understood Aboriginal ways of thinking about disability knew how to ask questions that would make people feel safe to talk about their needs.*

Commonwealth and State Government as well as private services working in Aboriginal communities must understand and take Aboriginal people's perceptions of disability into consideration to ensure people feel comfortable talking about their and their family's health, social and emotional wellbeing needs.

**Recommendation 12: Commonwealth, State, Aboriginal Community Controlled and Private Organisations working in the Fitzroy Valley must ensure their staff have received formal cultural, early life trauma and neurodevelopmental disorder/FASD training.**

We know that:

1. 90% of people living in the Fitzroy Valley have experienced significant early life trauma by 7 years of age<sup>27</sup>;
2. 80% of people living in the Fitzroy Valley are Aboriginal and belong to one of five language groups<sup>40</sup>; and that
3. 20% of people in the community may be affected by a neurodevelopmental disorder, like FASD<sup>27</sup>.

Based on these statistics it is reasonable to assume that everyone working in the Fitzroy Valley will interact with Aboriginal people; people affected by trauma and people with neurodevelopmental disorder. Everyone working in the region, therefore, require cultural, trauma, and neurodevelopmental disorder training so they can successfully interact with and support people in the region.





**The argument that it is too expensive to train staff on three-month contracts places the needs of the service over the needs of some of our most vulnerable citizens.**

**Recommendation 13: Western Australian Government Services must work together to prioritise the housing shortage for disability workers in the Fitzroy Valley.**

The lack of available housing for Aboriginal and non-Aboriginal staff in the Fitzroy Valley is longstanding. It is the primary reason that disability services don't have a footprint in the region and that existing disability services can't employ enough staff to meet the needs of people with disability.

There are no houses available to rent or buy, which means anyone wanting to live and work in Fitzroy Crossing must secure housing through their place of employment. Housing in Aboriginal communities is provided to local Aboriginal people. However, a shortage means these houses are severely overcrowded, leaving people homeless and placing more demand for employment-based accommodation for local Aboriginal people.

Target 9 of the National Closing The Gap target's is "people can secure appropriate, affordable housing that is aligned with their priorities and need" and is assessed as closed if by 2031 there is an increase in the proportion of Aboriginal and Torres Strait Islander people living in appropriately sized (not overcrowded) housing to 88 per cent.<sup>4</sup>

The federal government promised to make the NDIS accessible to all Australians, but all levels of government agreed to improve the lives of people with disability, through the National Disability Strategy.

**It is, therefore, the responsibility of all of governments to ensure the housing shortage is addressed so that disability services can be provided and the lives of people with disability can be improved in the Fitzroy Valley.**

As we understand it, the Department of Communities (Housing) own land in Fitzroy Crossing that could be used to build more houses. Department of Communities with funding from the Australian Government are also responsible for building houses in Aboriginal communities to address the housing crisis.

**Aim 5: What are the community's collective goals for people with disability?**

Recommendation 14: Western Australian Government Services should work together to develop a residential facility in the Fitzroy Valley for adults with disability.

According to The International Covenant on Economic, Social and Cultural Rights, **adequate housing is a human right in Australia**. As noted above, a number of people with disability are homeless and many others live in inadequate overcrowded homes with up to five people sleeping in one bedroom. There are also two young people with disability (aged under 35 years) who are forced to live in an aged-care facility in Fitzroy Crossing.

The federal government has acknowledged how inappropriate it is for young adults with disability to live in aged-care and developed a strategy that aims to ensure "no people under the age of 45 living in residential aged-care by 2022" pg.5.<sup>5</sup>

The government cannot rely on, or assume that, private disability services will take on the responsibility of developing infrastructure required for services like a residential facility for people with disability in very remote communities like the Fitzroy Valley.

**As is evident from this report the NDIA's logic of "sign people up to the NDIS and the services will come" has clearly failed the people in the Fitzroy Valley.**

Infrastructure development is complex in very remote regions and requires all levels of government to work together. We, therefore, recommend that the government develop the necessary infrastructure so that disability services can provide housing and necessary in-home care for people with disability who do not have a home or are unable to receive necessary care at home.

Below are some of the potential benefits of having a residential facility for people with disability in the Fitzroy Valley.

1. The facility would increase the health and quality of life for people with disability in the Fitzroy Valley who don't have a stable home or lack a primary caregiver despite their high needs. The facility would provide a safe place to live and receive daily in-home care.
2. The facility would enable young adults (those under 50 years) to live in age-appropriate accommodation rather than in an aged-care facility and gain the dignity and independence they deserve.
3. If the facility could accommodate adults with disability whose parents are still alive, it would improve the quality of life for these parents and allow them to gain full-time employment.
4. The facility would mean that when parents pass away, the person with disability could remain in their community and continue to experience the many benefits of living in an Aboriginal community on Country and amongst family and culture enhancing wellbeing.
5. The facility could have a short-stay option to provide short-term accommodation for people with disability when the family need to travel, such as for a funeral, or for family respite. A short stay would also mean people with disability in remote communities have somewhere to stay in town when they need to access the hospital or other health services.

A residential aged-care facility is available in Fitzroy Crossing, so we know this type of service is feasible and sustainable to run if the infrastructure, resourcing, and ongoing funding is provided.

**Recommendation 15:** Disability services should establish and run day programs for adults with disability so they can participate in the community, service providers can locate people with disability and family members can return to work.

Two services that are working well for people with disability in the Fitzroy Valley are the TAFE program and the Wangkatjungka day program. The TAFE program provides adults with disability a place to go to get out of their house, socialise and learn but functions only one day a week and need exceeds capacity. The Wangkatjungka day program provides a place for people to get out, shower, have a meal and socialise or participate in activities of their choosing but is located 100km from Fitzroy Crossing town and is only appropriate for Wangkatjungka community members. A day program based on the TAFE program and Wangkatjungka model, run in Fitzroy Crossing town and surrounding larger communities would provide the following benefits:

- A safe place for people with disability to go each day
- A reason to get out of bed and opportunity to participate in activities of their choosing, which increases quality of life
- A space for local services to run workshops with people with disability, such as art therapy, creating meaningful community participation
- Respite for families, including allowing carers to re-enter the workforce
- A place where drive-in drive-out allied health professionals could easily locate people with disability and possibly provide allied health services.

These programs are challenging to establish and implement using funding from individual NDIS plans. We recommend the NDIA provide block funding to disability services to cover the additional costs required to establish and implement these valuable group programs. Funding could be allocated in a similar way to that provided to other states through the ILC grants. Adequate infrastructure is a barrier to establishing services, so an additional space could be built within the infrastructure of the residential facility.

**Recommendation 16:** State and Local Government should work together with communities to develop the infrastructure required for after school care and school holiday programs for children with disability.

The need to constantly supervise and entertain young children is physically and mentally exhausting. Thankfully, the level of supervision required declines as children get older. However, for children with disability this need for constant vigilance never ends.



Children with disability usually have funding in their NDIS plan for someone to help them participate in community activities after school and in school holidays and give **families much needed respite**. Sadly, none of the children with disability in the Fitzroy Valley or their families have been able to access community participation or respite because the services don't exist. The lack of disability literacy and high level of overcrowding means parents of children with disability usually can't ask extended family to help care for their child. Instead, parents are forced to provide this 24/7 care every day, leaving them drained.

The lack of after school or school holiday care has a ripple effect.

1. It impacts the child with disabilities wellbeing as they can't socialise or participate in community activities like their peers.
2. It impacts siblings as they never get a break from their sibling with disability and never get alone time or attention from their parent.
3. It impacts parents' ability to work or get a break, which impacts their financial situation quality of life and mental health which then impacts the child's mental health.
4. It impacts the economy as it means parents of a child with disability can't work outside of school hours. The need to have all school holidays off means they often can't even gain part-time employment.

Ensuring access to after school and school holiday programs would provide meaningful community participation for the child and have a big impact on the quality of life and wellbeing of the child and family.

Just as housing plays a large role in the lack of disability support workers, there is also no dedicated, accessible place to take people with disability across the Fitzroy Valley. Having safe and secure environments allows people with disability more freedom to wander around and explore and **reduces the need for one-on-one supports, which reduces cost**. Children with no sense of danger particularly require safe environments. The swimming pool and playground are the only places in town for people to take children, but the pool is only opened for half of the year and the playground is not securely fenced so children who have no concept of danger can easily abscond.

At present there is no location beyond the school that is accessible, safe, and secure to run these activities. We recommend the State and Local Government work together with communities to modify existing or establish new infrastructure for these programs. Without the infrastructure the NDIA is setting disability support workers up to fail and placing vulnerable children at risk.



**Recommendation 17:** The Commonwealth Government should provide funding to local services and organisations to enable them to offer supported work environments for people with disability to increase the number of people in the workforce.

In our interviews, people with disability who work at Wangki Yupurnanupurru radio in Fitzroy Crossing talked about the many benefits of having meaningful employment and purpose and being able to contribute to their community. Sadly, this opportunity is limited to a select few. The desire to contribute to community fits with how Aboriginal people perceive people with disability, as still being able to **contribute** rather than just **participate** in the community.

We recommend that funding be provided to local services to enable them to create supported work environments for people with disability. This recommendation fits with outcome three of the National Disabilities Strategy, which is to ensure economic security for people with disability. Consultations about the next National Disability Strategy have highlighted the need to focus on improving access to employment<sup>55</sup>.

Supported work environments are particularly important for people with disabilities like FASD, who might have normal intellectual ability but specific neurodevelopmental impairments (e.g., in executive function, attention or communication), that means they have the capacity to work if supervision and support is provided. Providing such support would significantly increase the employment rate in people with disability reducing their reliance on government supports and services.

### **Aim 6: What are the disability priorities for targeted action?**

All the above recommendations need to be implemented if we are to create equity and improve the lives of people with disability living in remote Aboriginal communities. However, some recommendations must occur before others. These are discussed below.

1. Disability services cannot establish themselves in the community without housing to employ staff. **Recommendation 13:** Addressing the housing crisis, therefore, must be a priority.
2. The NDIA have correctly identified and aimed to address the barriers Aboriginal people face accessing services with the Remote Community Connector (RCC), Remote Early Childhood Services (RECS) and Evidence, Access, and Coordination of Planning (EACP) programs

**(Recommendations 1 and 2).** These programs, along with support coordinators **(Recommendation 3)**, are crucial to the success of the NDIS in remote Aboriginal communities. However, the programs will only succeed if they are based locally and properly resourced. Locally based services will reduce cost in the long run as it eliminates the expensive travel costs and increases the service provision on-the-ground.

3. The first step in accessing the NDIS is to provide evidence of permanent and significant disability/functional impairment. It's not possible to understand or confirm neurodevelopmental impairments, like those associated with intellectual disability, dementia, or fetal alcohol spectrum disorder, without proper assessment by a psychologist/neuropsychologist. The WA Country Health Service are responsible for identifying and managing health and mental health conditions, including disability. The WA Country Health Service, therefore, must employ neuropsychologists to ensure the NDIS is accessible to everyone with disability **(Recommendation 9)**.



# SECTION 5: CONCLUSION

Remote Aboriginal communities are under-resourced and often carry high levels of burden of disease and need. Aboriginal people across the Fitzroy Valley continue to display high levels of connection to culture, language and country despite the disruption from colonisation. However, trauma, intergenerational trauma, poor health, and wellbeing including disabilities, limited access to economic opportunities and, less than satisfactory living conditions continue to impact on people's day-to-day lives. These contributing factors are in contrast to what a good life well lived looks like.

The systems and structures designed to support Aboriginal people are failing the people of the Fitzroy Valley and it is beholden on governments to do better.

The voices of Aboriginal people in the Fitzroy Valley tell a sad and all too familiar story of the failure of NDIS. People facing multiple barriers to accessing plans and subsequent supports. The issues identified in this report will not improve without systemic change.

The Fitzroy Valley has a long history of coming together to identify what they need and want and communicating this to governments and other stakeholders. MWRC and other local Aboriginal Community Controlled Organisations have been instrumental in forging services that reflect what works for local people. This is consistent with the body of research identifying what works for Aboriginal people when considering programs and services.

This report asks government to re-evaluate the way NDIA/NDIS works in remote communities. It provides evidence of what will work for Aboriginal people in the Fitzroy Valley.



**We urge governments to use evidence-based approaches to improve NDIS delivery for improved outcomes for Aboriginal people in the Fitzroy Valley.**

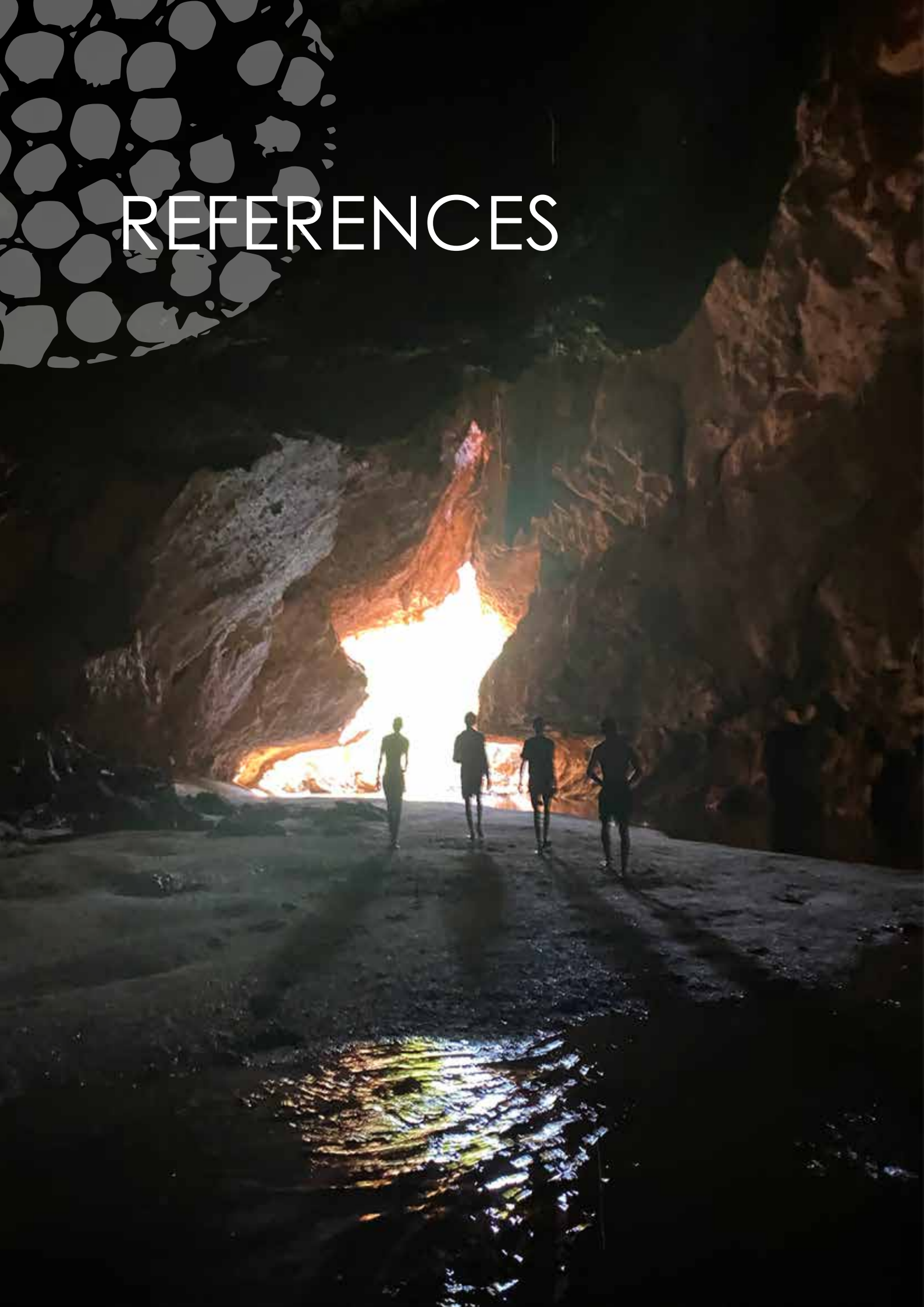
It demonstrates the commitment of MWRC and benefits of working closely with community and other strategic partners to identify needs and implement solutions.

The Fitzroy Valley is well positioned to become a pilot to trial approaches that reflect community need and community desires, delivered in a way that encourages participation and benefits to individuals and families. These findings will be transferable to other communities in consultation with and reflective of local services.

We commend the NDIA on the funding of this report and look forward to positive solutions to support Aboriginal people living with disabilities in the Fitzroy Valley.



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