

“PEOPLE DON'T KNOW WHAT GOOD LOOKS LIKE”

CREATING EQUITY FOR PEOPLE WITH
DISABILITY IN THE FITZROY VALLEY

SEPTEMBER 2021

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Acknowledgements

We would like to thank the many Fitzroy Valley families and carers as well as people with lived experience of disability, who provided their information and insights for this report.

We would also like to thank the wide range of stakeholders for their time, support, and valuable input. In particular, Donna Stephens, Greg Perrett, Robyn Bradbury, Simone Kenmore, Donna Butler, Linda McSherry, Sophie McCashin, and Jane Pederson.

Funding

This report was funded by the National Disability Insurance Agency and the National Indigenous Australians Agency. Lauren Rice was funded by The Ian Potter Foundation (#31110414) and a 2021 Westpac Research Fellowship; and Elizabeth Elliott was funded by the Australian National Health and Medical Research Council (GNT1021480).

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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?

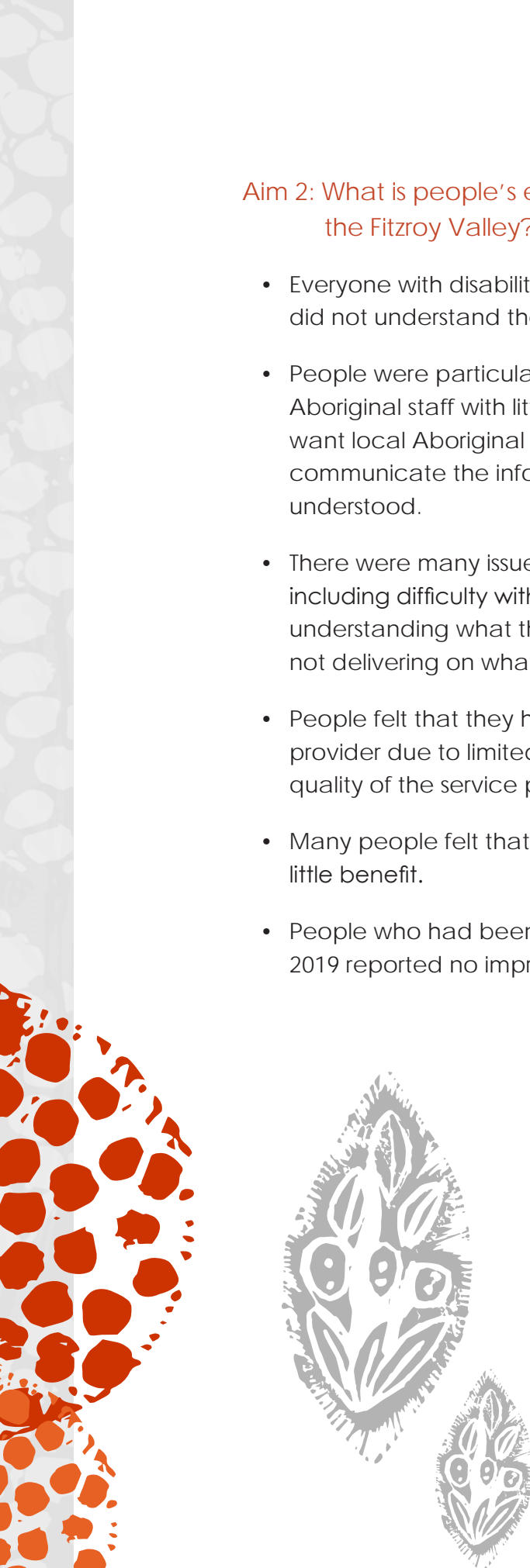
Aim 1: What does an ordinary life look like in the Fitzroy Valley?

- 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.

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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.



CASE STUDIES



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.

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 an 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 inter-state. 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.



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