

# NDIS participants experience in rural, regional and remote Australia. (Joint Standing Committee Inquiry) VicRAN Submission.



- > Barwon Resource Council
- > Colac Otway Region Advocacy Service
- > Gippsland Disability Advocacy Inc
- > Grampians Disability Advocacy
- > Regional Disability Advocacy Service
- > Rights Information Advocacy Centre
- > South West Advocacy Association



Image: Vicran logo with names of seven network members.

**Prepared for VicRAN by Karleen Plunkett.**

## **ABOUT VICRAN**

Victorian Rural Advocacy Network (VicRAN) is a network of seven disability advocacy agencies that operate across rural and regional Victoria. These agencies are in the Barwon, Colac/Otway, Gippsland, Grampians, South-West Victoria, Central and West Victoria, and North East Victoria.

### **VicRAN Mission Statement**

The Victorian Rural Advocacy Network aims to:

- Ensure that people with disabilities living in rural Victoria have access to resources & services to meet their needs;
- To work for the removal of all barriers preventing people with disabilities from participating fully in the life of the community;
- To promote community recognition of the rights of people with disabilities.

### **Statement of Purposes**

The primary purposes of the Victorian Rural Advocacy Network are as follows:

1. To act as a networking body for rural Victorian disability advocacy organisations.
2. To engage in systemic advocacy in regard to issues that affect people with disabilities in rural Victoria
3. To refer systemic issues affecting people with disabilities on a national or state-wide basis to appropriate advocacy organisations & authorities
4. To raise awareness of the rights, needs & issues facing people with disabilities
5. To advocate for & to provide opportunities for professional development to staff & volunteers belonging to the Network's member organisations

## **EXECUTIVE SUMMARY**

VicRAN members as organisations based in Victorian regional, rural and remote communities and working with clients in those communities have particular expertise and awareness of the issues NDIS participants living in regional, rural, or remote areas face.

VicRAN has long identified the significant disadvantages people in rural, regional and remote areas face in accessing the NDIS and engaging as participants in the Scheme.

The NDIS, as shown in the recent NDIS Review, has significant problems with how it operates, but these problems are magnified for people in rural, regional and remote areas due to distance, isolation, higher levels of poverty and significantly reduced options for services.

## **Recommendations**

NDIS needs to adapt its application/review process to better reflect the individual circumstances of rural, regional and remote applicant/participants by introducing a provisional application/review process. The provisional process would engage the experience and expertise of the applicant/participant, informal support, support coordinator as well as an advocate if required. The funding of this provisional process

should be granted on first application/review, based on applicant having a non-metro location.

VicRAN propose that the NDIS adapt its process to be user friendly for all levels of disability and include adaptable communication approaches using whatever form best suits the participant. Clarity is essential for participants to have full control during the application/review planning processes. The NDIS functions across the country applying the same criteria for all participants even though people living in rural, regional and remote face a radically different set of circumstances. If it were possible for the NDIS to manage rural and remote in a way that best serves Participants rather than disadvantages them. Having a separate rural and remote stream, not unlike other Government departments (Fire, Roads and Public Transport), would provide a service that would be more in-tune with Participants reality.

Vic RAN proposes that the NDIS allow for a more cost effective approach to the value gained by the participant by giving participants the ability to shop around when looking for service/support providers and equipment suppliers hopefully forcing those that are currently enjoying the bounty the closed market the NDIS provides them, to become more competitive.

The NDIS and Communities work together to deliver a system that is culturally appropriate and aligned with community expectations. NDIS should work to specifically increase the number of first nations LAC's, Support Coordinators and Support Workers [target?]

VicRAN propose that Local Area Coordinators (LAC's) require:

an in-depth understanding of family violence and are competent when supporting a person and/or family escaping violence.

Regular participation in trauma informed training, such as the guidelines provided by the Blue Knot Foundation.

VicRAN proposes the NDIS becomes more fluid on all levels to allow for unforeseen circumstances participants may find themselves in. Participants disability can change often not for the better, their circumstances can change too. These things are beyond their control, the NDIS has to be able to accommodate these changes as quickly as possible so that participants have the control over how they live their lives. A rapid response team should be set up to assist during these challenging times.



## **INTRODUCTION**

In late 2023, VicRAN members agreed to collaborate on a submission to the Australian Parliamentary Joint Standing Committee for the NDIS (JSC) inquiry into NDIS participant experience in rural, regional and remote Australia. In doing so, VicRAN members identified that that they covered all non-metro areas in Victoria for disability advocacy and NDIS Appeals and had significant expertise and knowledge of issues relevant to the inquiry deriving from their work supporting people attempting to access and/or participating in the NDIS.

## **APPROACH**

To obtain a true picture of the experiences people with disability who have applied or are participants of the NDIS Disability Advocates from VicRAN members have gathered experiences and case studies that were passed on to an external Consultant. These experiences and case studies were reviewed and the common threads / themes and problems soon became obvious. These themes were compressed to highlight the main issue/s always referring back to the Terms of Reference.

The extracts are from case studies and will reflect the five Terms of Reference. The full case studies are in the Appendix.

\* Please note all case studies are the real experience NDIS applicants and participants and de-identified to ensure confidentiality.

## **CONTEXT**

The people in these case studies are residents of rural and remote areas of Victoria. Areas include the Wimmera, Far East Gippsland, The High Country, South Gippsland and the Mallee. For many participants the nearest regional city is over a two-hour drive, longer if appropriate and accessible public transport is available.

Throughout the case studies several themes became evident. The following section of the submission will explore these themes in relation to the Terms of Reference.

## **TERMS OF REFERENCE**

### **A. The experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews.**

Many people cite that the NDIS not user friendly. It is quite often extremely draining and confusing. The constant plan reviews (even when not requested) instil a fear of losing funds or having support taken away as well as having to constantly justify the needs of their disability with professional assessments. These problems are compounded in rural, regional and remote areas by the burden of distance and the logistics of life while living outside the urban based services, where nothing is ever close at hand or easy to access.

NDIS applicants often need to submit specialist medical assessments with their applications that can't be obtained via the health professionals located in their local communities. For rural, regional and remote applicants, this often requires them to have to travel for several hours (with limited transport options), organise overnight accommodation and pay specialists thousands of dollars for their assessments. For a person with disability that can't drive, has limited public transport options, and possibly is unable to work, this is an extremely daunting and expensive process, with no guarantee of a successful outcome.

### **Case study 2**

The case study client lives in a remote part of East Gippsland. They live alone and do not have family support. The closest town to the person's home is small and has limited facilities. It does not have a general practitioner or professionals of the type the person needs. The closest large commercial hub is around two and half hours' drive from the person's home.

The person unsuccessfully applied to become a NDIS participant. Soon after applying our client received a confusing, poorly worded letter advising them that they had not provided sufficient evidence and that they should contact the NDIS call centre. The person contacted the call centre but found the experience so confusing and frustrating that they made no further calls and dropped their application.



## Case study 5

Dot and Harry access a range of professionals for Jake and Danielle's Social, health and well-being needs. This requires considerable coordination and planning. Dot and Harry drive both Jake and Danielle to their appointments which can be considerable distances away in other regional towns, this is not only time consuming, but it also provides no time for either Harry or Dot to manage their own health needs.

Following Jakes recent plan review that resulted in significant cuts to his existing funding, the assessments and reports sourced for Jakes review were from a myriad of health and allied professionals. The professional assessments were undermined when the LAC declined the funding for the additional services and supports. It was distressing that the LAC could and did override the knowledge of the specialised health professionals who had undertaken the assessments and drafted the reports.

**NDIS should adapt its application/review process to better address the needs and circumstances of rural, regional and remote applicant/participants by introducing a provisional application/review process. The provisional process should engage the experience and expertise of the applicant/participant, informal support, support coordinator as well as an advocate if required. The funding of this provisional process should be granted on first application/review, based on applicant having a non-metro location.**



## **B. The availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants.**

Participants of the NDIS are often not informed of the changes that are being made to their plan or have not had these changes made clear to them, changes can be made or denied without consideration of the challenges that rural and remote life can present. This can be compounded when the wait times for rural and remote services may be longer than six months.

### **Case study 4**

The children are unable to attend school, so they are home-schooled by their mother. Suitable schooling might be found in the capital cities but there are no schools of the required type where this family lives.

The mother is seeking additional support in the form of a support worker.

The NDIS maintains that the request is not reasonable and necessary and has denied the support.

The evidence the Agency requires to change its decision is onerous and expensive to obtain. It is made more difficult because of the distance between where the family lives and the children's specialists.

### **Case study 9**

Louise felt that due to her mental health and the issues around that, that her package should be Plan Managed. For some unknown reason Louise was informed her package had run out and had to put in a Change of Circumstances application. This has occurred twice. In the town that Louise lives in there are very few Support Workers. She is aware there is a worker living in the same block, but Louise made the decision to keep her as a neighbour rather than a Support Worker. Louise thought to increase the numbers of Support Workers the curriculum in High schools could include Certificate three and four in Aged and Disability.

**VicRAN propose that the NDIS adapt its process to be user friendly for all levels of disability and include adaptable communication approaches using whatever form best suits the participant. Clarity is essential for participants to have full control during the application/review planning processes. The NDIS functions across the country applying the same criteria for all participants even though people living in rural, regional and remote face a radically different set of circumstances. If it were possible for the NDIS to manage rural and remote in a way that best serves Participants rather than disadvantages them. Having a separate rural and remote stream, not unlike other Government departments (Fire, Roads and public transport), would provide a service that would be more in-tune with Participants reality.**

### **C. Participants choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services.**

The case studies show that requests for services and supports are not made flippantly. The participants should not be given the one size fits all solution but be able to source independent providers as well as registered providers to allow for a tailored and economic approach to meeting their needs.

#### **Case study 1**

Sharon is the mother of three children with disabilities, Sharon contacted Gippsland Disability Advocacy Inc (GDAI) for assistance with her children's upcoming NDIS plan reviews. A report was provided from Melbourne University Audiology and Speech Pathology Department and a functional assessment from an Occupational Therapist for funding of Phonak Listening System, which, was denied and deemed not necessary as part of the needs of both girls' autism.

It was pointed out to the LAC that the auditory hearing aids were deemed by both the assessing professionals to be extremely necessary for Sandra and Belle to be able to effectively function and participate fully in school, social settings and within the community. It was also pointed out to the LAC that the NDIS had approved goals and funded other activities that would be undermined if the girls did have the auditory hearing aids. It was very disturbing to be told by the LAC that auditory hearing aids could not be funded as deafness was not either of the two girl's primary disability.

This attitude and decision again demonstrated that the LAC was oppositional to the information and the assessments provided within the Professional reports.

#### **Case study 7**

I self-manage my NDIS Package to ensure I get value for money, but I cannot believe the costings of services such as Allied Health, equipment and being charged if a shift isn't cancelled seven days before that particular shift.

#### **Case study 8**

Our Son's electric wheelchair required new batteries, so contact was made with a manufacturer to order these batteries and we got a verbal quote which seemed quite reasonable. However, when we mentioned payment for the batteries would be coming from our Son's NDIS Package up went the price by \$400. We had no choice but to accept this price hike as there are very few companies / suppliers that have the batteries in stock. Our Son solely relies on his electric wheelchair as he is unable to walk. It felt we were being held over a barrel.



**The NDIS could adopt a more cost-effective approach to the value gained by the participant by giving participants the ability to shop around when looking for service/support providers, and equipment suppliers hopefully forcing those that are currently enjoying the bounty of the closed market the NDIS provides them, to become more competitive. Living in rural remote areas does not exclude participants from accessing equipment it does restrict the choice of suppliers.**

**D. The particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS:**

Navigating the NDIS is not easy for anyone, compounding this with living rural and remote and then being from a culturally and linguistically diverse background has to be one of the most important challenges for the NDIS to overcome.

For this reason, all levels of support must be culturally appropriate and seen without bias or judgement.

#### **Case study 4**

The mother has no family support. She is divorced from the father of the children. He is the subject of a court order prohibiting him from visiting the children without being under supervision. The father does not provide financial support for the children. The family's expenses are high, their income is low, and their NDIS plan is not generous.

#### **Study 10 Aboriginal and Torres Strait Islander Advocate with Lived Experience**

Aboriginal and Torres Strait Islander people are disadvantaged in so many ways when becoming a NDIS Participant and getting the support / services that are needed. Due to previous experiences with government services, there may be the lack of trust with service providers. Not being spoken to in language and resources being created that cannot be understood is disrespectful and humiliating. In remote areas supports and services are 'thin on the ground' and that has a huge impact on the person receiving the NDIS. When natural disasters occur such as floods and fires, this puts a whole new layer for the Participant continuing to receive the NDIS.

Also, if there's only one Support Worker supporting that person it can place a huge strain on the worker. It is very concerning that staff turn-over is high so there's no building of relationships that is a must.

The culture of Aboriginal and Torres Strait Islander people is one of community not so much on the individual. When a Support Worker, a LAC or Service provider isn't an Aboriginal and Torres Strait Islander this may be traumatising for the Participant, the family and the community.

At present the way the NDIS plans are done is the 'Western Way' - looking solely at the individual. However, it's a collective approach for Aboriginal and Torres Strait Islander

people that some live by. This collective approach feeds into the extended family members becoming part of the support team for the Participant but they may not have the Western Societies qualifications. Having equipment available such as phones, computers and mobility aids may be shared between members of the community.

**The NDIS and Communities must work together to deliver a system that is culturally appropriate and aligned with community expectations. The NDIS needs to specifically increase the number of culturally appropriate LAC's, Support Coordinators and Support Workers who have lived experience within the communities they support.**



#### **E. And other related matters.**

The following case studies highlight the individual and unique set of circumstances that need to be taken into consideration to have a plan that delivers the best and most needed supports with the least amount of distress.

Plans that have an in-built flexibility to sustain participants through the times when unforeseen circumstances have forced rapid changes, would be valued more than dollars and give participants the confidence and faith to respect the NDIS.

#### **Case study 1**

Sharon had to leave her home quickly to ensure her safety and that of her children's, this necessitated that she had to leave behind most of hers and the children's belongings including body socks, iPad and sensory comforters which have been essential items for the children. Additionally, Sharon had been supported with the children's day to day needs and activities, by her parents, who lived close by before having to leave her home.

### **Case study 2**

For whatever reason this person has fallen through the cracks and does not have a treatment history nor treating practitioners. Getting the evidence will be an expensive, lengthy, frustrating and possibly unsuccessful experience that the person likely cannot negotiate alone. There is a high likelihood that the person will give up on their application.

### **Case study 3**

While working with our client they told us they were dissatisfied with their service provider and support coordinator but believed the particular service provider was the only choice. The NDIS claims: 'Choice and control is a key principle to how the National Disability Insurance Scheme (NDIS) should work for participants. Self-evidentially, it is difficult to achieve that if there is no choice.

### **Case study 11**

Shannon loved the lifestyle the High Country gave her and her NDIS Plan supported her to remain living fairly independently at home as well as receiving the supports that were required. But this chosen lifestyle changed due to being caught in recent floods.

Unfortunately, Shannon had to quickly leave her home due to unbelievable rain and to get to somewhere safe. Shannon did return home but found it was uninhabitable. Shannon's home had previously been renovated to accommodate her physical needs and she found that there were very few options for her to live while her home was being repaired. Because of this Shannon became homeless, had no fixed address and became disconnected from her community.

### **Case study 12**

Any attempt to select quotes from Case study 12 would fracture the full story and it must be read in its entirety to fully understand the challenges faced by participants in some rural, regional and remote areas.

It highlights the multiple forms of abuse and social isolation that can result when a participant has very little or no choice.

### **Addressing the need for Change**

The following will also focus on 'other related issues'. The topics include Family Violence, Costings, Unhelpful or Obstructive Local Area Coordinator's (LAC's), Culturally Appropriate Services and Workers, Worker shortage and natural disasters.

### **Escaping Family Violence.**

- Having regular running Public and Community Transport options that is accessible and affordable to all.
- Work with the Building Industry to legislate that all housing must be built with six accessible features. This will also include renovations of refuges, houses, units, apartments, flats and boarding houses and the building cannot be signed off until the features are completed.
- Family Violence organisations need to have trained Support Workers who can be called upon and are able to travel to a location when a family is fleeing from the perpetrator.

**VicRAN propose that Local Area Coordinators (LAC's) require: An in-depth understanding of family violence and are competent when supporting a person and/or family escaping violence.**

**Regular participation in trauma informed training, such as the guidelines provided by the Blue Knot Foundation.**

### **High Costs for NDIS Funded Services/Costings.**

1. All services from Allied Health, equipment suppliers and organisations must be costed at the same rate as the community pays rather than the current NDIS costings. This should eliminate the higher costs for services some organisations and suppliers currently charge.
2. Reduce cancellation notices of shifts to 24 hours.
3. Having access to Allied Health services, a mobile bus, with a hoist, that can travel regularly to rural and remote townships with Allied Health services operating from them. This will eliminate the travel times and cost for Participants and long waiting lists.
4. Freedom from only having NDIS registered suppliers.

### **Unhelpful or Obstructive LAC's**

The role of LAC's must be very clear and concise with ongoing supervision by managers with yearly work appraisals. These appraisals should include anonymous feedback from participants back to the manager. People receiving the NDIS should be able to request a new LAC when there is a clash of personalities and not having to justify the request.

Where possible LAC's to be paired with a NDIS Participant from the same diverse background.

### **Culturally Appropriateness.**

The culture and identity of all Aboriginal and Torres Strait Islander people and all CALD Communities must be respected and celebrated. Communication in language is one key for each NDIS plan to be designed and implemented in a way that embraces culture and community. All LAC's and Planners must have an in-depth knowledge and be Culturally informed. Every discussion must be done with the person, their family and other informal and formal supports. Everyone must be aware, and in agreement, of the person's goals now and into the future.

### **Worker Shortage.**

To increase the number of available Support Workers, work with the Education Department to include Certificate Three and Four in Aged and Disability into the curriculum in Secondary Schools.

### **Natural Disasters.**

Natural disasters are occurring regularly, especially in regional, rural and remote areas and are having a significant impact on those receiving the NDIS. When Participants flee their homes due to fires or floods the role of the NDIS should be to continue having supports in place for Participants even for those who find themselves staying in motels, with family who are unskilled, couch-surfing or are actually homeless with no fixed address.

It would be ideal if each Local Government create a list of accessible available places where Participants can stay including Air B&B's while Participants homes are being repaired.



### **Distance.**

In almost half of the case studies distance was a factor that was raised as a physical, mental and financial strain on participants. It must be recognised that travel for rural and remote people often means a full day can be consumed just getting to the destination and it is not a holiday or a chance to do some shopping. Rural roads are often very poor and fuel costs



are often higher than the major towns. When a participant must travel all day for no other reason than to tick a box on a NDIS form only to have it rejected with little explanation is crushing. Rural and remote people make the effort, and it is an 'effort', and this should be recognised and taken into consideration when applications are made.

In rural and remote areas distance is exactly that and it's not easy.



**VicRAN proposes the NDIS becomes more fluid on all levels to allow for unforeseen circumstances participants may find themselves in. Participants disability can change often not for the better, their circumstances can change too. These things are beyond their control, the NDIS has to be able to accommodate these changes as quickly as possible so that participants have the control over how they live their lives. A rapid response team should be set up to assist during these challenging times.**

## **Conclusion.**

There are many unseen and unconsidered issues that rural, regional and remote participants face in their day to day lives. Having the NDIS as a willing and understanding partner would most certainly help give participants the confidence to live their lives to the fullest, not in constant fear of losing vital supports and not having to justify their disability continually.

If the NDIS was able to serve the needs of rural and remote participants the demand for advocates would reduce, however it is not, and our case studies prove that people with disability need the NDIS to hear them and partner with them to deliver a truly effective positive outcome. For rural and remote participants it often feels like they are being disadvantaged for living where they do.

One participant's final paragraph is one of sense and sensibility:

“I would like to imagine a future where the NDIS is less bureaucratic having a common-sense approach and transparent pathways to obtaining the right forms, documentation, assessments and reports and a less emotional strain on Participants, Families and informal community supports. “

The aim of this submission was to capture words and experiences from participants of the NDIS . It's been widely acknowledged, for many, the scheme isn't working and causes much

stress and anxiety but there are also positive stories about how the NDIS has made a huge difference in many people's lives.

“To finish on a positive note – we as a family have been able to have a holiday away with our Son and one of his Support Workers and we have all loved it.”

### **Acknowledgements.**

A huge thank you to the people receiving the NDIS for taking their time out of their busy days to share their experiences and their NDIS journeys. For many it can be traumatising as they tell their stories once more. This submission would not have been possible without the ongoing commitment from VicRAN staff and Advocates. They work tirelessly with People who are applying or are participants of the NDIS and have that “can do” work ethic.



## **APPENDIX Full case studies – 1 - 12**

### **Case Study 1**

Sharon is the mother of three children with disabilities, Sharon contacted Gippsland Disability Advocacy Inc (GDAI) for assistance with her children's upcoming NDIS plan reviews.

Sharon explained that she manages all three of her children's NDIS plans and that she had recently become a single parent after fleeing her home with her children to escape family violence.

Sharon's children are Sandra and Belle who are twins and 13 years old and son Toby who is 9 years old. Sandra has been diagnosed with autism, ADHD, OCD, anxiety, and selective mutism and Belle and Toby both have autism.

Sharon requested a NDIS plan review due to the change of circumstances for each of her children. The review request was made in February 2023 after Sharon had to leave her home quickly to ensure her safety and that of her children's, this necessitated that she had to leave behind most of hers and the children's belongings including body socks, iPad and sensory comforters which have been essential items for the children. Additionally, Sharon had been supported with the children's day to day needs and activities, by her parents, who lived close by before having to leave her home.

Sharon was receiving support from Orange Door and Quantum Support. Sharon stated that she was requesting advocacy from Gippsland Disability Advocacy Inc (GDAI) as she had a terribly negative experience with her previous LAC, this made managing her children's plans exceedingly difficult as the LAC was her only point of contact for all things relating to her children's plans. Sharon notes that during several interactions the LAC stated that if Sharon wanted to find another LAC "she wouldn't find anyone better." Sharon stated the LAC would yell at her and tell her off for using or asking to use NDIS funds for certain things. Sharon stated that she felt she was not respected or listened to; one example Sharon provided was that it took six phone calls to the LAC to get her to update Sharon's bank account details. Sharon was told by the LAC that she must pay for her children's attendance at the ASD clinic. Sharon stated that she raised with the LAC that she had been informed that she is the only person with children that have NDIS plans attending the clinic that was paying for this out of her own pocket. Sharon was told by the LAC that she would not get this covered in their NDIS plans and that was that.

The plan review that was requested in February 2023 by Sharon was not conducted until June 15<sup>th</sup>, 2023, the delay placed upon Sharon and her children's elevated levels of difficulty, stress, and financial hardship.

Sharon and the children lived in a refuge for an interim period until securing a private rental flat in a town where neither Sharon or the children had support, The three children had to be relocated to new schools and adjust to new people, new environments, and new routines. Sharon continued to also organise and transport them for their day-to-day activities. Sharon worked hard to try to create some semblance of routine for her three



children who were traumatised and had their worlds turned upside down.

At the time of the June 2023 review the LAC that Sharon been engaging with had resigned and left her role.

Sharon stated that she hoped that the June 2023 review would prove to be a different response and experience as she is sick and tired of the NDIS working against her and just wants to utilise appropriate supports for her children.

Sharon was fully prepared for the June 2023 review; Sharon had the necessary assessments reports completed that clearly identified the needs of each of the children and the services and supports that they need. Sharon was supported by GDAI advocate and in attendance was the LAC and a person who was observing as part of their orientation into their new role as a LAC.

Sharon's experience with the new LAC did not prove to be any better than the previous one. As her advocate, I was concerned with the adversarial approach that was taken by the LAC to the requests for funding of important aids and technology, psychology support and 1.1 Support.

An example of this was, a report was provided from Melbourne University Audiology and Speech pathology department and a functional assessment from an occupational therapist for funding of Phonak Listening System, which, was denied and deemed not necessary as part of the needs of both girls' autism.

It was pointed out to the LAC that the auditory hearing aids were deemed by both the assessing professionals to be extremely necessary for Sandra and Belle to be able to effectively function and participate fully in school, social settings and within the community. It was also pointed out to the LAC that the NDIS had approved goals and funded other activities that would be undermined if the girls did have the auditory hearing aids. It was very disturbing to be told by the LAC that auditory hearing aids could not be funded as deafness was not either of the two girl's primary disability. The lack of knowledge of autism by the LAC and the unwillingness to listening to Sharon made this an incredibly stressful and devaluing experience for Sharon and left her daughters without the necessary technology that would support their development and inclusion.

Additionally, the request for Sandra to have 1.1 support for 2 hours per morning prior to school was also determined by the LAC as "what would be expected of any parent to provide" and was denied.

This attitude and decision again demonstrated by the LAC was oppositional to the information and the assessments provided within the Professional reports. Sandra's disabilities, the recent traumas and life upheaval has escalated Sandra's behaviours, and she requires one to one support to ensure her and her sibling's safety, well-being and that she is ready for school.

Sandra's behaviours were identified both by Sharon and the reports as disruptive and stressful for the other children, who also need support to get ready for school and whom have also experienced trauma and changes. Sharon stated the mornings are distressing and exhausting.

Sandra had also been assessed by the professionals that provided reports as needing

psychological and behavioural therapies, this in the face of evidence with the reports was also denied and Sharon was told that she should access these services within the public health system.

It is extremely concerning that there does not seem to be insight or understanding within the concept of measuring “what is expected that a parent should provide” and how the decisions result in an increased social disadvantage and increased social inequality for Sharon and her each of her children.

When a sole parent and additionally a sole parent escaping family violence is measured against the “what a parent would provide” it puts the same expectation upon them that they have the same financial, support and time resources as two parent families.....it is not only ridiculous, but also unjust and unfair.

## **Case Study 2**

### **Preamble**

The difficulty of meeting the evidentiary requirements for NDIS participation is similar for people with limited finances, resources and knowledge whether they live in the capital cities or rural/remote Victoria. However, living in the more remote parts of Victoria imposes additional obstacles, primarily limited or no choice and significant distances to travel to access still limited services. Living in rural/remote locations often means limited access to extended family if they exist.

The issue of not having access to extended family is important because the NDIS routinely denies access to certain support by claiming that support is the responsibility of parents and extended family to provide. Our experience has been that NDIS decision-makers have a fixed and often incorrect idea of what extended family provides, have no idea of the family support available to individuals and have no interest in finding out.

For the reasons detailed above, people with disability living in the area in which Gippsland Disability Advocacy Inc. operates often do not have a medical history. Not being able to provide evidence from treatment practitioners often means people cannot satisfy the NDIS rigorous participant eligibility requirements.

The case studies below are or have been Gippsland Disability Advocacy Incorporated (GDAI) clients. Their AAT appeals took or will take around a year to resolve. We came to know something about the difficulties people with disability and living in Gippsland East as a regional area in the south-east of Victoria face.

The case study client lives in a remote part of East Gippsland. They live alone and do not have family support. The closest town to the person's home is small and has limited facilities. It does not have a general practitioner or professionals of the type the person needs. The closest large commercial hub is around two and half hours' drive from the person's home.

The person unsuccessfully applied to become a NDIS participant. Soon after applying our client received a confusing, poorly worded letter advising them that they had not provided sufficient evidence and that they should contact the NDIS call centre. The person contacted



the call centre but found the experience so confusing and frustrating that they made no further calls and dropped their application.

A year after receiving the NDIS correspondence, the person contacted Gippsland Disability Advocacy Inc. Communicating with the person has been difficult and, so far, unsuccessful because the person's intellectual disability impacts their ability to use email, use the telephone and travel.

For whatever reason this person has fallen through the cracks and does not have a treatment history nor treating practitioners. Getting the evidence will be an expensive, lengthy, frustrating and possibly unsuccessful experience that the person likely cannot negotiate alone. There is a high likelihood that the person will give up on their application.

### **Case Study 3**

The case study is a person who is a NDIS participant. They live alone in a small rural community in southwest Gippsland and do not have close family support. The town does not have professionals of the type the person needs. The person is required to travel considerable distances for appointments but cannot drive.

The person believed their plan was inadequate. The internal review was unsuccessful.

The person contacted Gippsland Disability Advocacy Inc. seeking help with their AAT appeal. At that time, the person had not received correspondence from the AAT but claimed their support coordinator told them that they (the support coordinator) had submitted an AAT appeal application. The support coordinator had not submitted an appeal application.

We found that the time in which to appeal had expired. We requested and were granted an extension of time. The matter was satisfactorily resolved.

While working with our client they told us they were dissatisfied with their service provider and support coordinator but believed the particular service provider was the only choice. The NDIS claims: 'Choice and control is a key principle to how the National Disability Insurance Scheme (NDIS) should work for participants. Self-evidentially, it is difficult to achieve that if there is no choice.

### **Case Study 4**

The example involves a single mother with two children with disability living in Gippsland East.

The mother has no family support. She is divorced from the father of the children. He is the subject of a court order prohibiting him from visiting the children without being under supervision. The father does not provide financial support for the children. The family's expenses are high, their income is low, and their NDIS plan is not generous.

The mother advises the children are difficult to manage. One child expresses suicidal ideation and self-harms. The children cannot be left alone together or individually and therefore must attend each other's, and their mother's, appointments. Both children are

easily distressed so appointments are often abandoned.

The children are unable to attend school, so they are home-schooled by their mother. Suitable schooling might be found in the capital cities but there are no schools of the required type where this family lives.

The mother is seeking additional support in the form of a support worker.

The NDIS maintains that the request is not reasonable and necessary and has denied the support.

The evidence the Agency requires to change its decision is onerous and expensive to obtain. It is made more difficult because of the distance between where the family lives and the children's specialists.

The mother drives fifteen thousand kilometres per quarter to take her children to appointments. Considerable time is spent driving to appointments, more time than a person living in a larger city might expect. Public transport to the various treating practitioners' rooms is not available.

Having a car is a necessity for this family because of where they live.

This situation has been made more difficult because face-to-face meetings have not been held. Discussions between the mother and the NDIS have been by telephone and have been when the mother has been attending to two children who require considerable attention. A NDIS decision-maker has determined that the requested additional support is not reasonable and necessary without having seen where and how the family live. This matter is ongoing.

**\*GDAI can provide many similar case studies but the lack of services and the difficulty of accessing the available services negatively impacts the quality of the NDIS support our clients receive.**

## **Case Study 5**

Jake is 7 years of age and lives with autism (level 3) ADHD, anxiety, intellectual disability, and sensory processing disorder.

Dot and Harry Abbott (Jakes maternal grandparents) made the decision to take on the responsibility of raising their grandson Jake after child protection removed him from his mother's care as an infant. Jakes mother was experiencing a decline in her mental health and had developed addictions that affected her ability to care for Jake. Additionally, Jake has also experienced the trauma of in recent times losing his father after he passed away.

Dot and Harry stepped in so that Jake would remain connected to his immediate family. Dot and Harry also have a daughter Dannielle who is 15 years old and lives with them. Danielle has autism, anxiety, depression, and she requires a great deal of support and supervision from her parents also.

Dot is sixty-two and Harry is sixty-five years of age, and it is at this time of their lives they should be looking forward to being able to take holidays, attending social events and activities and spend unlimited time with their daughter. They do not regret in any way

taking Jake into their lives but their health and relationships with each other have suffered and they have become socially isolated.

Jake requires 1:1 support and supervision at home with showering, dressing, continence management, eating and cannot be left unsupervised to play as his behaviours are highly destructive and he seeks out activities that present a substantial risk of harm to himself. Jake has many challenging behaviours and can become violent, regularly removes his pull up pants and smears faecal matter throughout his room, impacting the carpets, walls, mattress furniture, objects, and surfaces within the room.

Jake's disabilities require a high level of support and a range of services to assist him to continue to grow and develop.

Harry's health has deteriorated, he has congestive cardiac failure (CCF) which limits his mobility, Harry experiences breathlessness upon exertion. Additionally, Harry's mobility is also impacted by overly oedematous legs and the impacts of Polymyalgia, Harry also experiences chronic pain. Dot has been experiencing depression and she feels that this has also impacted upon her relationships with Harry and Danielle.

The Abbott family have no other family to rely on and their social activities and interactions with friends has become limited to deal with the demands of Jake's care and needs.

Jake's carer/ grandmother, Dot contacted GDAI seeking advocacy support following Jake's recent plan review that had resulted in significant cuts to Jake's existing funding. The assessments and reports Dot sourced for Jake's review were from a myriad of health and allied professionals. The professional assessments were undermined when the LAC declined the funding for the additional services and supports. It was distressing to Dot and Harry that the LAC could and did override the knowledge of the specialised health professionals who had undertaken the assessments and drafted the reports? Additionally, it was also upsetting to Dot that the large amount of time and money that she had invested in getting the reports appeared to have been in vain and meaningless.

Impact statements were provided by Dot, Harry and Danielle and conveyed the impacts of Jake's high level of need for support has had upon their individual health and well-being.

Included within Dot's and Harry's carer impact statements provided to the NDIS review were other numerous examples of Jake's destructive behaviours. The Abbott family have withdrawn from all social and community activities. Previously when the family have been out in the community Jake's behaviours included not understanding personal space, running away, and approaching strangers.

Danielle Abbott identified within her impact statement that Jake takes up all of Dot and Harry's time and that she does not get to go out in the community with her parents. Dot and Harry are also trying to support Danielle with a range of issues that she is experiencing and require their patience and understanding.

Dot and Harry access a range of professionals for Jake and Danielle's Social, health and well-being needs. This requires considerable coordination and planning. Dot and Harry drive both Jake and Danielle to their appointments which can be considerable distances away in other regional towns, this is not only time consuming, but it also provides no time for either Harry or Dot to manage their own health needs nor does it allow the couple to

nurture their own relationship. Harry has expressed concerns that he and Dot have many more arguments now than had across the whole life span.

The pressure on each member of the household and their relationships with each other is significant. To have with regular short-term respite, and an increase of 1.1 support hours which were determined as essential by the allied and health professionals accessed, would ensure adequate support for Jake and opportunities for further individual development, and for the family to continue to function as a family.

Within the review, funding was not granted above 5 hours per week for 1.1 support, this had been a reduction from within Jakes previous NDIS plan. The LAC informed Dot and Harry that the support funded at the review was accurate for Jakes disabilities and with consideration that they should meet his other needs.

The LAC explained that this is what is expected of all parents to provide to their children. Using this as a measure suggests that all families come from an even playing field, having the same health, social, economic status, and resources. In context it serves only to broaden the gap of disadvantage to Jake and the Abbott family. It is not only unfair, but it is also inequitable and socially unjust.

The supports that were not granted funding ranged from 1.1 support hours for Jake for social engagement and his capacity building, behavioural and psychological support, respite, continence management, Specialist physiotherapy, Occupational therapy assessments and play therapy.

**After the completion of the Review, Dot and Harry decided that they would lodge a request for a Review of a Reviewable decision supported by GDAI advocate. Once again Dot and Harry pursued more evidence in the form of reports and assessments. More time and money which they could not really afford doing this. The outcome was some increases support funding areas whilst others were continued to be refused. Dot and Harry then requested that GDAI support them in lodging an appeal the AAT which led to conciliation and negotiation and finally the level of supports that Jake needs were met within his NDIS funding!**

## **Case Study 6**

The NDIS can offer wonderful support to individuals with disability and families. The NDIS can, as it is intended, offer independence, choice and control over a person's life and the connection with their community. In my experience however, even in these good news stories the wins never come easy, they are hard fought and always precarious.

I would like to highlight the hidden stress and burden of being part of the NDIS system. The constant fear that what supports you have been able to access are never secure.

In my work with families with young children with disability, the fear of losing funds and subsequently losing support is ever present. This has a constant and wearing affect. In conversations with parents and caregivers, they can be extremely well versed in the language of the NDIS, the complicated process and even the names of forms. From a

bureaucratic perspective this may seem a positive thing, however if you reflect and listen why parents and caregivers feel the urgency to be “fluent in the language of the NDIS”, it is to survive. Families report that, unless you understand what the letters mean, there is no way you can meet their requirements, unless you complete the right form, unless you have the right report, they will take away the funding. Parents report it being a constant strain and concern that a review will be called without notice - do I have current diagnostic assessments, do I have evidence of outcomes achieved, can I afford functional assessments?

This type of relentless threat and burden on families and caregivers is not present, or would it be tolerated, in any other support system. It offers no sense of security for individuals or families beyond the life of their current plan, and even then, there are more and more reports of existing plans being cut. Imagine having to pay for an independent assessment before being able to be treated by a health professional in hospital, to provide evidence of what is “wrong with you”. To hope that the assessment report will meet the requirements for the funding for treatment.

**The financial and mental health burden perpetuated by the systems of the NDIS are cruel and must be addressed.**

### **Case Study 7**

I am a person with a life-long disability and been receiving the NDIS a year after moving to North-Western Victoria six years ago. Prior to the implementation of the NDIS I was receiving the Individual Support Package (ISP) so knew the benefits of having Control and Choice. The ISP was like the prelude to the NDIS in Victoria. When I heard the NDIS had the support of the Federal Government, I was so pleased as it was going to support people with disability, like myself, to live a life that was fulfilling and with dignity. I was both a little sceptical and looking forward to putting in an application.

I assumed applying for the NDIS would be straight forward. 'Boy' was I wrong! The amount of forms, organising assessments and reports needed nearly did my head in. To obtain to required documentation meant making appointments with appropriate people and putting time aside. The stress I was under was unbelievable and this went on for a few months. Then to add fuel to the fire I found out that if my application was approved I would need to do this same process again in one, two or three years. It left me feeling extremely insecure.

The good news was that my application was approved but the stress was still dragging me down. However, finding Support Workers who lived in town proved to be challenging. A Service Provider and I held several interviews and thankfully found two people who turned out to be excellent workers.

Not long after the first plan was implemented another LAC came on board and she was hopeless and disrespectful. Couldn't get my name right and would call support workers 'Social Workers'. Not one of my emails to this LAC were replied to. When it was time to reapply for my second plan I only received a phone call from the LAC telling me that the application would be the same as the first one. The end result was the package was halved and it was a two year plan. I did contact the NDIS to request for a different LAC and my new LAC is terrific. Since then we were successful in putting in a Change of Circumstances



application.

I self-manage my NDIS Package to ensure I get value for money but this is not easy the costings of services such as Allied Health are well above normal charges also being charged for a support shift if it isn't cancelled seven days in advance and the ridiculous over pricing of equipment.

One goal in my first plan was to have a hoist installed into my Van and the hurdles were shocking. Firstly an Occupational Therapist travelled 300km round trip to do an assessment of my physical capabilities, when it was approved the hoist could only be installed by an NDIS registered company 380 km away, even though there is a local engineering company in our town. The van had to be driven to the company for the installation and the driver had to return using public transport, a 14 hour day, the same to collect it, the fit out was only going to take 3 days but ended up taking 30 days. I was without transport during that time.

While the total cost may not have differed that much had our local firm been allowed to do the modifications it would have meant that my support package was being spent locally. Now when the hoist needs repairs I have it repaired locally rather than the almost 800km round trip to where it was installed. I know that having it repaired by an unauthorised repairer is in breach of NDIS rules but the rule is a silly one and unless someone from the NDIS wants to come and do the driving I will continue to have repairs done this way. Hopefully when the hoist needs to be replaced the NDIS will allow me to use a local company to do the fit out.

I would like to imagine a future where the NDIS is less bureaucratic having a common sense approach and transparent pathways to obtaining the right forms, documentation , assessments and reports and a less emotional strain on Participants, Families and informal community supports.

### **Case Study 8**

Our Son's electric wheelchair required new batteries, so contact was made with a manufacturer to order these batteries and we got a verbal quote which seemed quite reasonable. However when we mentioned payment for the batteries would be coming from our Son's NDIS Package up went the price by \$400. We had no choice but to accept this price hike as there are very few companies / suppliers that have the batteries in stock. Our Son solely relies on his electric wheelchair as he is unable to walk. It felt we were being held over a barrel.

Our Son attends a Special School and the need for more qualified staff is incredible.

To finish on a positive note – we as a family have been able to have a holiday away with our Son and one of his Support Workers and we have all loved it.

## **Case Study 9**

Louise moved from Melbourne a few years ago where she was receiving a NDIS Package. Louise found the application process brutal but was supported by an Occupational Therapist and her Support Coordinator.

Louise felt that due to her mental health and the issues around that, that her package should be Plan Managed. For some unknown reason Louise was informed her package had run out and had to put in A Change of Circumstances application. This has occurred twice.

Even though Louise's Support Coordinator was overloaded with other NDIS Participants she had real trust in her.

For Louise to maintain her mental health she has had to pay from her savings to see a private Doctor while waiting to hear back from the NDIS regarding her applications. Louise is a resourceful person and has developed her own strategies to deal with stress. Louise is concerned that due to there being only two OT's , one has a six months waiting list, in her region, people will fall between the gaps.

In the town that Louise lives in there are very few Support Workers. She is aware there is a worker living in the same block but Louise made the decision to keep her as a neighbour rather than a Support Worker. Louise thought to increase the numbers of Support Workers the curriculum in High schools could include Certificate three and four in Aged and Disability.

## **Study 10 Aboriginal and Torres Strait Islander Advocate with Lived Experience**

Aboriginal and Torres Strait Islander people are disadvantage in so many ways when becoming a NDIS Participant and getting the support / services that are needed. Due to previous experiences with government services there may be the lack of trust with service providers. Not being spoken to in language and resources being created that cannot be understood is disrespectful and humiliating.

In remote areas supports and services are 'thin on the ground' and that has a huge impact on the person receiving the NDIS. When natural disasters occur such as floods and fires, this puts a whole new layer for the Participant continuing to receive the NDIS.

Also, if there's only one Support Worker supporting that person it can place a huge strain on the worker. It is very concerning that staff turn-over is high so there's no building of relationships that is a must.

The culture of Aboriginal and Torres Strait Islander people is one of community not so much on the individual. When a Support Worker, a LAC or Service provider isn't an Aboriginal and Torres Strait Islander this may be traumatising for the Participant, the family and the community.

At present the way the NDIS plans are done is the 'Western Way' - looking solely at the individual. However, it's a collective approach for Aboriginal and Torres Strait Islander people that some live by. This collective approach feeds into the Extended Family members becoming part of the support team for the Participant but they may not have the Western Societies qualifications. Having equipment available such as phones, computers and

mobility aids may be shared between members of the community.

### **Case Study 11**

Shannon loved the lifestyle the High Country gave her and her NDIS Plan supported her to remain living fairly independently at home as well as receiving the supports that were required. But this chosen lifestyle changed due to being caught in recent floods.

Unfortunately, Shannon had to quickly leave her home due to unbelievable rain and to get to somewhere safe. Shannon did return home but found it was uninhabitable. Shannon's home had previously been renovated to accommodate her physical needs and she found that there were very few options for her to live while her home was being repaired.

Because of this Shannon became homeless, had no fixed address, and become disconnected from her community.

### **Case Study 12**

Carmen has an intellectual disability, mobility challenges and mental health challenges (notably, anxiety, depression, and self-esteem). Her NDIS package includes personal support through an occasional carer and social support through a NDIS provider that runs group socialisation programs. That NDIS provider is owned and managed by two people, one of whom (Barb) is also Carmen's landlord. Carmen rents a room in a 3BR house. One of her housemates, Lucy, also attends the group socialisation program. Lucy and Carmen had a falling out in the program over Carmen not wanting to do the activity Barb had set for the group and Carmen and Barb then having an argument about that. Lucy took Barb's side and Carmen took objection to that. At home, the falling-out between Lucy and Carmen continued for over two weeks. Barb did nothing to address that or the ongoing tension between her and Carmen and Carmen and Lucy in the group socialisation program. In fact, Barb told Carmen 'If you don't like it, you can leave' and made it clear that she meant both the program and the rental house. She also told Carmen that she couldn't use the lounge room at the house because 'Lucy and I bought all the furniture including the TV' and, later, that Carmen (who had – with our assistance – found somewhere else to live) could not take the bedroom furniture with her which Carmen had brought into the rental. She told Carmen that she would also have to pay a \$720 cancellation fee for ending her involvement in the group socialisation program early. There is no other provider of supported socialisation in the town or in the nearby region. Barb also contacted the real estate agent for the new flat we had arranged for Carmen and gave Carmen a bad reference, despite not being asked for one. Barb and the real estate agent know each other from a local community group and a local business women's association. We have now found Carmen more accommodation but in Melbourne. The thin market of NDIS providers in the area combined with the multiple roles played by Barb (NDIS provider, landlord, local business woman connected to others) also combined with her willingness to use her power over Carmen in this situation (by proactively offering a bad reference to someone with whom she has an existing business relationship) to create layers of discrimination and abuse. In our view, it was the thin market that made this possible and that inflated this abuser's power.

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