Submission to the NDIS Provider and Worker Registration Taskforce





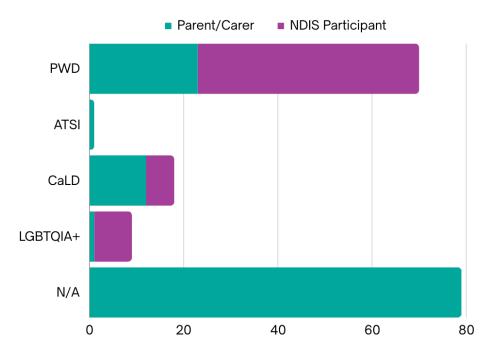
Acknowledgements

SWAN acknowledges the traditional owners of the land on which this submission was produced, the Wardandi Noongar people. We acknowledge the deep spiritual connection to this land and extend our respects to community members and Elders past and present.

Submission preparation

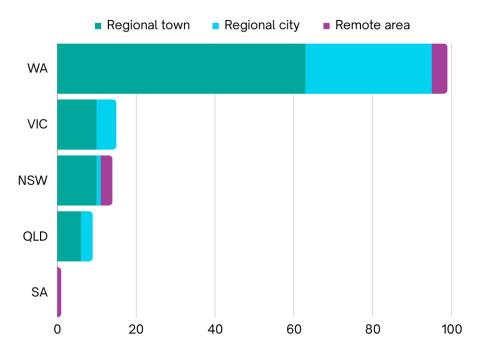
This submission was prepared by South West Autism Network Inc (SWAN). In order to write this submission, we listened to the views and concerns of people with disability, their families and advocates living in regional Australia. To aid in gathering quantitative and qualitative data, SWAN created a survey and invited people nationally to participate. SWAN received 156 responses and 114 completed surveys (73%).

Survey Respondent Demographics



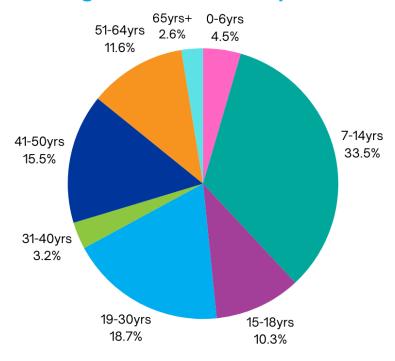
SWAN received responses from people living in regional cities, towns, and remote areas as can be seen in the chart on the following page.

Location of Survey Respondents



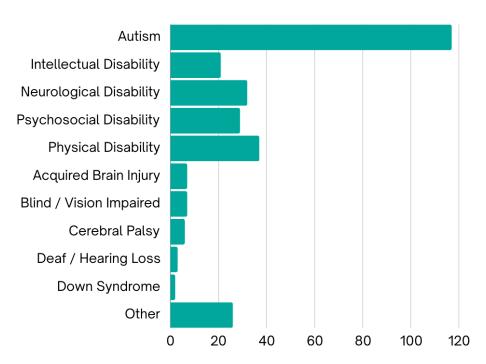
We sought details of the age of NDIS participants and as can be seen below, we received responses about the experience of people with disability across the lifespan.

Age of NDIS Participant:

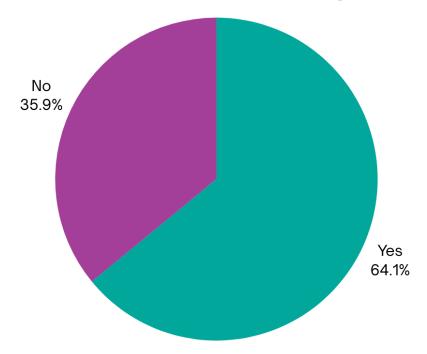


We also asked survey respondents about what type of disability the NDIS participant has, and whether they have more than one type of disability. Of note, 64.1% of NDIS participants in our survey have more than one disability.

Disability Type



More than One Disability?



As a regional not-for-profit Disabled Persons and Families Organisation (DPFO) providing information, peer support and advocacy, we are able to draw on fifteen years' experience supporting autistic individuals and their families, carers, therapists and the wider community. Our submission aims to include the voices of people who are NDIS participants, and families throughout rural, regional and remote Australia.

Introduction - About SWAN

The South West Autism Network (SWAN) is grateful to the Taskforce for making available this opportunity to provide feedback on NDIS provider and worker registration and regulation model proposed in the NDIS Review final report.

SWAN is a not for profit, charitable organisation supporting autistic individuals and their families living in the south west region of Western Australia for the past 15 years. We are a Disabled Persons and Families Organisation (DPFO) who are currently delivering two Commonwealth funded Information Linkages and Capacity Building (ILC) projects. We have almost 2000 registered members, with hundreds more people with disability and their families accessing free support from SWAN. All staff, volunteers and Board members either have a disability, or are the family member of someone with disability.

Our primary role in the community is to provide information, peer support, advocacy, and connection to mainstream and disability services. We build the capacity of people with disability and their families to navigate Government and non-government systems in order to meet their needs and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across the lifespan, and provide autistic safe space group programs for autistic children, teens and young adults through our AutStars and YES Program, in addition to delivering Youth Mental Health First Aid training to the wider community.



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NDIS Review Recommendation 17: A Step Back for Regional Australia?

The NDIS Review has sparked much debate, with numerous recommendations poised to reshape the future of disability support in Australia. While these changes aim to improve the system nationwide, their implications for NDIS participants, especially those in often overlooked regional and remote areas demand urgent attention. We have significant concerns that recommendation 17 breaches the human rights of people with disability to have full choice and control over who provides their supports.

The Risks of Mandatory Provider Registration and Enrolment

One of the most controversial recommendations is the mandatory registration or enrolment of all NDIS providers. While the recommendation aims to improve oversight of where NDIS funds are spent and improve quality and safeguarding of participants, the reality for people in regional and remote Australia is starkly different. In these areas, the scarcity of registered providers means that the majority of participants rely heavily on non-registered providers for essential supports. About 16,000 providers are NDIS registered, while more than 150,000 are non-registered.

In regional and remote Australia, far more towns have no registered providers than towns with registered providers. Thin markets are often mentioned when discussing problems with accessing NDIS supports. In geographically isolated areas, there is often no market – no providers at all. On paper, it looks different. There are large providers who have registered to provide services throughout Western Australia, for example, but actually have no 'boots on the ground' in regional WA.

The independent NDIS Review held one consultation forum with providers and a couple of advocacy organisations in WA. Our CEO had to contact the NDIS Review five times in order to be included in the WA online consultation forum, where she asked Professor Bonyhady to explain why WA providers were being consulted for the Review, but people with disability and families were not. He assured her that the Panel would return to consult people with disability and families, and that they would prioritise hearing from regional WA people. **The NDIS Review panel held no further consultations with people in WA.** In failing to consult people with disability in Western Australia, the NDIS Review Panel failed to consider the impact on people in geographically isolated areas in making their recommendation for mandatory provider registration or enrolment. This underlines how the input of providers were prioritised by the NDIS Review panel in developing their recommendations.

WA based people with disability and families living outside the metropolitan areas experience the greatest geographic isolation in the country, and the unique barriers and difficulties experienced by people with disability in WA were not considered by the independent NDIS Review panel and were ignored in the final report.

~ Disability Advocate

In geographically isolated areas, there are far fewer NDIS participants in the community. Due to the low demand for NDIS support services, it simply isn't cost effective to set up business solely for NDIS service provision. In such communities people with disability rely heavily on non-registered providers which provide other services to community members. The town physiotherapist, the cleaner or gardener recommended by word of mouth in the local Facebook community group, the builder who did great work on the neighbour's bathroom. These businesses support dozens or hundreds of non-NDIS clients. They are busy, hard-working and time-poor people, who simply cannot justify the unpaid time and cost required to go through the process of NDIS registration or enrolment, as well as the NDIS Code of Conduct training and NDIS Worker Screening Check in order for one person to continue accessing their services. Many are already regulated by mainstream registration systems, such as AHPRA or the Master Builder's Association. The ACCC applies to all Australian businesses. Under Australian Consumer Law, when people buy goods and services that have not been provided to an appropriate standard, the consumer is protected by consumer guarantees - including those purchased with NDIS funding. Most workers already have National Police Clearances and Working With Children / Vulnerable Persons Checks, and people with disability and families can be educated to demand these checks when engaging supports.

The only incentive for providers to undergo registration or enrolment is if NDIS participants comprise the majority of their clientele, not a tiny fraction that won't impact their income if lost.

~ NDIS Participant

Mandatory Provider Registration or Enrolment would be catastrophic in regional and remote Australia. Existing thin markets would evaporate entirely. In the pre-NDIS days, people with disability living in regional WA very often uprooted and moved to Perth to access disability support services. In 2024 this is no longer an option – the extreme housing crisis means that people cannot relocate – there is no available accommodation to relocate to.

The challenges faced by NDIS participants in regional Australia are compounded by geographic isolation, as highlighted in the case study below. The cost and availability of services are already pressing issues. By further shrinking the pool of providers that regional NDIS participants can access, costs dramatically increase. The limitation to registered or enrolled providers mean that travel costs would be charged for all services provided to participants with no local registered providers in their town. Will NDIA factor these additional travel costs into the NDIS budgets for participants in such areas? Currently this consideration is rarely given.

Thomas (name changed to protect privacy) lives in small town 92km away from the nearest therapy provider. His NDIS plan is charged almost \$700 for one hour of therapy by a NDIS registered provider. Thomas' NDIS plan does not include funding for the therapist's travel costs, so Thomas receives only one hour of therapy instead of the almost three hours of therapy he would receive if he lived in the same town as the provider. Thomas' family have been trying to move closer to providers in order to increase his access to services since 2021, but have been unable to secure accommodation due to the housing crisis.

There are many, many towns with no registered providers, and people in WA living more than 2000kms away from the nearest registered provider. In the Pilbara, for example, there are extremely limited allied health providers, registered or non-registered. A peer support group in the region approached Rio Tinto a few years ago, and the company started paying to fly in a number of therapists once a month to work with kids in the area, however this is not a sustainable option, and is not the responsibility of Rio Tinto to maintain.

As per the map on the next page, Western Australia has the largest land area classified as remote or very remote in the country.



Source: Australian Government Department of Health and Aged Care

The important thing to note here, is that a great many non-registered providers in regional and remote Australia are providing support to as little as 1-3 NDIS participants out of one hundred clients or more. SWAN have been canvasing non-registered providers in the south west region of WA, explaining the recommendations in the NDIS Review Report, and asking if they would register / or enrol. Every single one has said that they would not. We also asked if they would register or enrol if the process was simplified further, and again, the answer was 'No' from all but one provider – an Occupational Therapist solely working with NDIS participants as a sole trader. However, that Occupational Therapist believed that mandatory provider registration would end their business and they would have no option but to work for a larger provider. The high costs of registration and audit fees, and the extensive time required to prepare for and apply make the process unfeasible.

To become an NDIS registered or enrolled provider requires significant input of time and work, including:

- source information
- research and understand what is required
- educate staff
- complete application paperwork
- familiarise self and staff with NDIS policies, processes, operational guidelines and reporting requirements (all of which change frequently without notice)
- ensure all staff undertake and maintain currency of NDIS Worker Screening Checks
- ensure all staff complete the NDIS Code of Conduct training
- source and maintain National Police Clearances
- apply for and maintain currency of Working With Children Checks (WWCC)
- Maintain professional registrations (i.e., AHPRA)
- undertake professional development
- prepare for and pay for audit costs

As detailed above, the workload and costs act as significant deterrents from undergoing the NDIS registration or enrolment process, and further, deter providers from working with NDIS participants. Below are comments from non-registered providers responding to the recommended requirements of the four levels of provider registration or enrolment:

"We will never register or enrol. It's not worth the time, energy or cost. We have more than enough business outside of NDIS." ~ Builder

"It's hard enough trying to get staff in this area. I can't expect them to do all these extra forms and fees. They already have police clearances, that should be enough. We'd just have to refuse people on the NDIS." ~ Cleaner

"I only get paid for claimable hours. To register as a provider would mean a lot of unpaid work and extra costs. I'd just go work in hospitality instead." ~ Support worker (sole trader)

"It's not worth it. I only have two NDIS clients out of around 150." ~ Physiotherapist

Non-registered providers in regional Western Australia are concerned about the costs and bureaucracy involved in NDIS compliance, including audit fees, worker screening checks, and code of conduct training. These concerns are heightened as NDIS participants often represent only 1-3% of their client base. High staff turnover further increases the costs of

continuous compliance. Professionals in fields like allied health, cleaning, gardening, and building find these costs burdensome amid existing workforce shortages.

One allied health provider who was initially NDIS registered when the scheme rolled out in WA in 2018, de-registered in late 2020. They initially pursued NDIS registration thinking that it was in the best interest of their clients.

The time that it was taking to prepare for audit took both myself and two admin away from focusing on staff and service delivery (ie. their jobs). The stress this process caused, plus the cost of audits (initial and ongoing), led me to reconsider NDIS registration.

~ Director of multidisciplinary allied health business

Non-registered providers like allied health professionals, cleaners, gardeners, and builders in regional areas only have an incentive to undergo NDIS registration if a significant portion of their clients are NDIS participants, which is often not the case. These professionals are already subject to extensive regulatory requirements and are generally time-poor, making additional NDIS compliance unappealing without clear benefits. In the southwest region of WA, where there are already extensive waitlists and workforce shortages exacerbated by economic pressures, most small businesses would stop serving NDIS participants if mandatory registration is required. Moreover, requiring all staff in these fields to complete NDIS-specific training and checks, in addition to existing police clearances, for a small number of clients is seen as unreasonable.

The Challenge of Mandatory NDIS Worker Screening Checks and Code of Conduct training

The high costs and red tape also impact workers interested in entering the sector, acting as a deterrent to joining a workforce already experiencing extensive workforce shortages, especially in regional and remote Australia. Organisations employing support workers, whether registered or non-registered, typically require that support workers obtain:

- NDIS Worker Screening Check \$145
- Police Clearance \$58.70
- Working With Children Check \$87
- Current First Aid Certificate \$80.50-\$221

The NDIS Worker Screening Check is quite difficult to access in regional WA. The process to apply requires partly online and then in-person application at <u>specified centres</u>. Support workers who are directly employed cannot apply for the NDIS Worker Screening Check. The online part of the application requires an employer number be entered before the application can progress. Sole traders can apply for an employer number, but direct employers cannot.

The next step after the online application for a NDIS Worker Screening Check has been finalised, is to present in-person with 100 points of identification and payment to one of the specific Driver and Vehicle Service Centres authorised to process NDIS Worker Screening Check applications. There are 8 metropolitan centres in WA, and the regional centres are located in:

- Albany
- Broome
- Bunbury
- Carnarvon

- Exmouth
- Geraldton
- Kalgoorlie
- Karratha

- Kununurra
- Newman
- Tom Price

Please refer to the map on page 9 to gain an understanding of the distances between these centres. For context, there are large towns in Western Australia which are located more than 6 hours (one-way) away from the nearest NDIS Worker Screening Check processing centre. The NDIS Worker Screening Check website for WA states "If you are unable to travel to a Department of Transport Driver and Vehicle Service Centre, you may be eligible to have your identity verified by the 'alternate lodgement' method. You can submit a request for alternate lodgement as part of the online application in DoTDirect." SWAN understands that the only way to access a fully online application is if the distance you have to travel to do the in-person part of the application exceeds 4 hours one way.

In Western Australia, a worker can commence working with people with disability while their application is being processed. We note that the <u>website</u> also states "Application processing timeframes vary. Some applications may be processed within days and some can take weeks or even longer."

I have to do the NDIS check which is \$145, so it will take me a few weeks to afford it, because I'm living week-to-week. If I get the job, it will only be a few hours a week.

~ Day care worker interested in becoming a support worker

As indicated by the quote above, the cost of obtaining a NDIS Worker Screening Check is prohibitive for workers, especially where the worker is likely to only be working ad hoc or only a few hours per week.

Currently the NDIS Worker Screening Check is managed individually by each state or territory. There are different application processes and requirements, and different costs.

We note that allied health professionals have annual AHPRA registration costs which are a requirement of their professional accreditation and regulation:

- Podiatrists \$397.00
- Psychologists \$436.00
- Physiotherapists \$194.00
- Occupational Therapists \$127.00
- Nurses \$185.00

Psychologists, for example, also need to have indemnity and liability insurance that ranges from \$200-\$600 per annum, in addition to ongoing professional development costs.

It is unreasonable to obligate cleaning, gardening and building companies to require all staff to undertake the NDIS Code of Conduct training and apply for NDIS Worker Screening Checks in addition to the National Police Clearances already required for their work role – in order to provide services to very small numbers of NDIS participants. Cleaners and gardeners in particular tend to have high workforce turnover – the reality is that the costs

and time away from earning an income would act as a deterrent from providing services to NDIS participants.

Implications of minimum worker qualifications

The independent NDIS Review and the Government have suggested requirement of minimum qualifications (Certificate III in Individualised Support – Disability) for support workers. SWAN note that the Cert III in Individualised Support (Disability) is not fit for purpose, is too general in nature to upskill workers to support NDIS participants with diverse disability needs, and does not teach provision of personal care – the type of support provision frequently mentioned when stating the 'need' for minimum qualifications.

The Cert III in Individualised Support is 15 units, typically delivered over a maximum of 20 weeks. This means that students have approximately 10 days per course unit to learn the content & complete the assessment for each unit. There are only two Core units in the course which focus on empowerment and capacity building, with very limited performance criteria required to prove competency:

- CHCCCS038 Facilitate the empowerment of people receiving support
 - o Demonstrate commitment to empowerment for people receiving support
 - o Foster human rights
 - Facilitate choice and self-determination
- CHCCCS040 Support independence and wellbeing
 - Recognise and support individual differences
 - Promote independence
 - Support physical wellbeing
 - o Support social, emotional and psychological wellbeing

Due to the limited timeframes for completing each unit, there is no in-depth knowledge or understanding achieved. Disability is extremely diverse, and this course is only able to provide very limited, general information to students. All students who complete the Cert III in Individualised Support require significantly more training to learn how to appropriately support people with different disability types, yet tend to leave the course with overconfidence about their level of expertise – which is to the detriment of people with disability.

Increasingly, the quality of the qualification is further diluted, with TAFE campuses offering a combined Cert III in Individualised Support (Aged Care & Disability). It's extremely important to note that the Cert III in Individualised Support is not available everywhere. In regional WA particularly, there are many TAFE campuses that do not offer the course at all, areas which coincidentally have extremely limited supply of support workers.

SWAN wish to draw the Taskforce's attention to the NDIA's requirement that therapy assistants have minimum qualifications. NDIA delegates frequently fund therapy at a rate assuming that therapy assistants will provide the majority of therapy. However prior to February 2023, the Certificate III and IV in Allied Health Assistance were only available oncampus in Perth and Albany in WA (Bunbury TAFE now offer Cert III only). This meant that for all other areas of regional WA, qualified allied health assistants where typically unavailable. Whilst students wanting to study the allied health assistant qualifications could undertake online study, the cost of online study ranged from \$8,000-\$11,000, compared to on-campus at TAFE costs of \$199.60 (resource only fee) for the Cert III, and \$1,293.10 for the Cert IV. Both the Individualised Support and the Allied Health Assistant qualifications

are currently heavily subsidised by the WA State Government, however these subsidies are scheduled to end on 31st December 2025.

It's important to note the impact minimum qualification requirements have on NDIS participants, as evidenced by the requirement of qualified allied health assistants by NDIA and how this requirement has affected participants in regional WA. NDIA delegates made funding decisions based on the assumption that participants would primarily access therapy delivered by allied health assistants supervised by clinicians. As allied health assistants were typically unavailable throughout much of regional WA, this meant that therapy could only be provided by fully qualified allied health professionals, at significantly higher cost. This unsurprisingly resulted in participant therapy budgets being insufficient to meet their needs, and little progress being made toward building the participant's capacity due to therapy sessions being limited by the funding budget. At plan reassessment time, NDIA delegates would often reduce the funding further, citing lack of evidence of benefit to the participant.

This issue is further exacerbated in regional areas, as NDIA delegates typically refuse to include funding for therapist travel costs – further limiting access to therapy for NDIS participants living in towns with no allied health professionals based locally. The below comments from survey respondents describe the increased costs associated with accessing NDIS funded supports in geographically isolated areas:

"They still did not take into account that at least half our funding goes into provider travel, so the therapy they say we have funded doesn't stretch as far as they have allocated for."

"Excellent Core and Capacity Building funding, but Transport component is completely inadequate for even one taxi trip per week if I want to travel outside of my suburb."

"The funding was not enough to cover a travelling speech therapist on their base rates, the therapy provider themselves wrote a letter detailing their costs for the year and this was not provided and the person on the phone told me if the NDIS plan does not cover the costs as a parent I must cover them myself as that is what a loving parent does - which I believed to be invalidating and manipulative and almost insinuate of myself not being a loving parent if I cannot afford to pay thousands in therapy."

"We were unable to afford basic therapies based on our location and the cost of travelling therapists in the area therefore there was not a lot for them to do."

"The cost of the most suitable or even nearest therapies should be taken into consideration when determining the persons plan. And if a travelling therapist is the most sensible/appropriate way to support the person with a disability the travel fees should be considered in the funding amount also otherwise the therapy is not accessible."

It's important to note that minimum qualifications do not teach the appropriate respectful attitudes for working with people with disability. This is either innate to the person, or it is not.

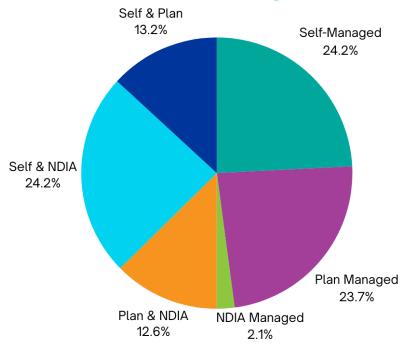
Flexibility to use Non-Registered Providers is Crucial for Sustainability of the NDIS

SWAN is based in the southwest region of Western Australia, the most highly populated area outside of Perth, with 14 towns lacking any NDIS registered providers. This scarcity becomes problematic as the NDIA generally does not fund travel costs for providers, causing participants to face high therapy costs, sometimes nearly \$700 for an hour. The region is not considered remote, yet participants bear excessive travel expenses on top of standard rates, reducing the amount of support they are able to access. Mandatory registration of providers could further limit access to needed services, as many would not be able to use non-registered providers.

For NDIS participants in rural and remote areas, flexibility in their plans is essential. It is common for those under 18 to receive no Core funding, significantly reducing flexibility in how they can use their supports. Even adults often see similar restrictions in their plans. Many school-aged participants face long daily commutes, exacerbating fatigue and leaving little energy for after-school activities. When funding is provided, it is usually under the Capacity Building budget, which restricts use to weekdays, further limiting opportunities for social interaction and community involvement. Thus, there is a critical need for flexible funding that allows supports to be used when and how it best suits the participants, including during evenings and weekends. Limiting NDIS participants in regional and remote Australia to registered or enrolled providers further exacerbates these difficulties, increasing the cost of supports and reducing how much support their NDIS plan will cover.

Currently, Agency (NDIA) managed participants are only able to access registered providers. We asked survey respondents how the funding in their current NDIS plan is managed. Only 2.1% of plans were fully Agency (NDIA) Managed, while 36.8% were partly Agency Managed. As there are some funded supports that NDIA typically require to be Agency Managed (eg. Positive Behaviour Support), it's likely that these NDIS plans included these types of supports. 61.6% of survey respondents were entirely or partly Self Managed, while 49.5% were entirely or partly Plan Managed, as per the pie graph below.





As reflected in the survey results above, NDIS participants in regional and remote areas require access to non-registered providers in order to have their support needs addressed. The NDIA does not report disaggregated data to show how funding is managed for participants living in metropolitan vs regional or remote locations. This, combined with the lack of consultation with geographically isolated participants and families by the NDIS Review panel, clearly show that these issues were not factored into their considerations in recommending mandatory provider registration in their final report.

Other survey respondents raised issues which are unique to participants in rural, regional and remote areas, and frequently not considered by PITC or NDIA delegate planners in making decisions about NDIS participants, their plans, and funded supports.

We asked survey respondents if they use non-registered providers, with 63.7% responding that they do use non-registered providers. 28.2% of survey respondents reside outside of Western Australia, we note that there are regional areas on the east coast with greater access to NDIS registered providers, especially NSW and VIC, which is reflected in the response to this question. As previously noted, in regional WA, there are extremely limited options for NDIS registered providers, with a great many towns having no registered providers at all. This is clearly an issue of concern in other states as well, as evidenced in the survey comments below:

"Don't have a choice in my rural location."

"I only use non-registered providers because registered providers are consistently very dodgy."

"Because they suit our needs and had a less wait time. We couldn't get in with a registered NDIS as their wait list is so long and most of them said they had shut their books altogether for new participants."

"I have to choose who will be the best fit for my daughter's complex needs. Just because a provider is registered doesn't mean they are any good."

"My psych is not NDIS registered I am his only NDIS client. He is AHPRA registered and has supported me since I went into a wheelchair 10 years ago. My SW is not NDIS registered but is excellent and I was unhappy with the registered provider."

"Only suitable providers in my area are not NDIS registered as they see non-NDIS clients too."

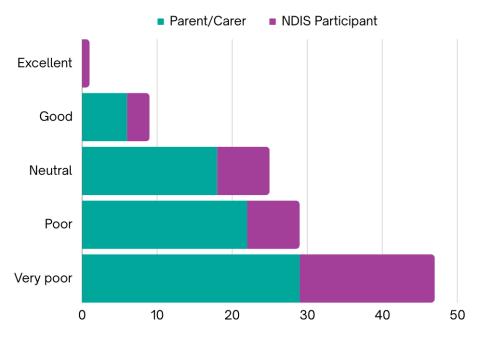
"Our daughter would have no support at all if we didn't use unregistered providers. And the registered providers here are awful."

"There are hardly any NDIS registered providers in my area. They are far more expensive, and offer lower quality supports. For the vast majority of supports I need, there are literally no registered providers in my town. Further, as an advocate I need my privacy protected, and need to be able to advocate with no conflict of interest. I can't help people make a complaint about a registered provider that I'm also forced to use."

SWAN reiterate our concern that the recommendation in the NDIS Review report for mandatory provider registration has failed to consider the experience of people with disability

in geographically isolated communities. Forcing providers to register in order to provide supports to NDIS participants risks disincentivising provision of support to the NDIS participants in that community – especially where they make up less than 5% of a provider's client base.

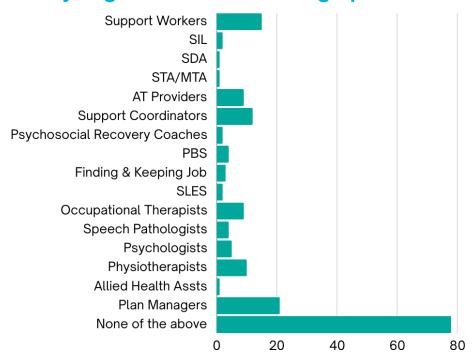
How would you rate the availability of NDIS funded services you use?



As shown in the bar graph above, 68.4% of survey respondents rated the availability of services as poor (26.1%) or very poor (42.3%). Only one person rated the availability of services in their community as excellent (0.9%), and a further 8% rated the availability of services as good. Notably however, 76% survey respondents stated in answer to this question that there were no support services sufficiently available in their community to meet demand.

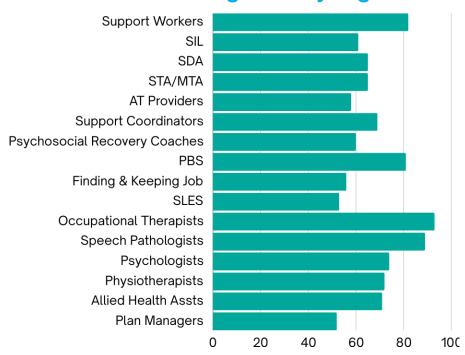
Individuals with disabilities and families who contact SWAN for support, as well as survey respondents, report difficulties in finding NDIS-funded services. According to the survey, 67.8% of respondents indicated a lack of providers in their community, while 32.2% reported that only 1 to 8 out of 16 types of NDIS-funded services are sufficiently available. The most readily available service type, according to the survey, is plan management, with 21 respondents finding it to be sufficiently available - likely because it is typically provided remotely. Conversely, only 15 respondents felt that support workers were sufficiently available, 12 for Support Coordinators, and 10 for Physiotherapists.

In my region there are enough providers:



We also asked survey respondents to indicate which types of support services were in short supply in their community, with responses displayed in the bar graph below. Note also that most survey respondents only answered this question based on services they themselves were seeking.

Provider shortages in my region:



As anticipated, the greatest shortage was for Occupational Therapists (93 responses). NDIS consistently include Occupational Therapy in every NDIS plan, as well as requiring Functional Capacity Assessments, Assistive Technology Assessments, Home and Living Assessments and Driving and Vehicle Modification Assessments all be conducted by

Occupational Therapists. This is extremely problematic given the highly prescriptive nature of the Capacity Building – Improved Daily Living Skills (therapy) budget in most NDIS plans. We frequently see NDIS plans stipulating Occupational Therapy for building emotional regulation skills in autistic participants – which should more appropriately be allocated to Psychology.

This also means that too many rural, regional and remote participants are unable to use all, or part of their NDIS plans for exceedingly long periods of time – due to thin markets and lack of plan flexibility. We asked survey respondents to identify the longest period of time they waited to access support services. Again, the responses from states other than Western Australia where support services are more readily available significantly affected the result, as shown in the bar graph below. In regional Western Australia the wait time to access allied health professionals typically varies between 8 months and more than 3-4 years, depending on the age of the NDIS participant, location, and the type of disability they have. Due to the extreme workforce shortages in regional areas, some families are having no option but to use out-of-town providers to access some supports, at significantly higher cost, as highlighted in the case study below:

Georgia is the child representative for Ethan [names changed to protect privacy], a 6yr old diagnosed with autism level 3. Ethan is non-speaking, uses continence aids, and requires 24/7 supervision and support. The family recently moved from the east coast to regional WA. Ethan's NDIS plan is plan managed, and only has funding for continence aids in the Core budget, so has no flexibility. There are four paediatric allied health providers in their town, all with closed waitlists. Georgia decided to use the only allied health provider with immediate availability, a fly-in-fly-out provider, who charges an additional \$75 per hour per therapist. Georgia has been berated by Ethan's Early Childhood Approach Coordinator and a NDIA representative for using the higher cost provider instead of a local one, despite the fact that none have service availability. Ethan is making progress with the current provider, and Georgia is concerned that if NDIA demand she stop using the provider, Ethan would likely lose skills as the local providers have closed their waitlists — meaning that Ethan is unable to join the queue to wait for access to a local service.

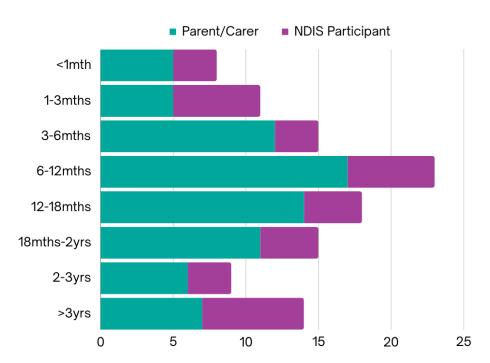
As evidenced in the case study above, even with the current access to non-NDIS registered allied health professionals, wait times to access these services are extreme. We note that if the Government were to proceed with mandatory provider registration or enrolment, this would further shrink the pool of services that people in regional and remote Australia can access, and significantly increase costs. People with disability in regional WA have previously experienced mandatory provider registration, and the reality was that the majority of towns had only one or no providers available. Where there is only one provider, people are fearful of complaining about violence, abuse or neglect. They risk repercussions from the provider, or ejection from the service and being left without support. Where there are no providers at all, people are charged dramatically more for supports due to travel costs, or are completely unable to access support at all. Pre-NDIS, people with disability often moved to Perth to access support services. Due to the housing crisis, however, this is no longer an option. There is no accommodation available to move to. The case study below exemplifies the dramatic difference in access to support services between Perth and regional WA prior to the introduction of NDIS, when there was mandatory provider registration:

Pre-NDIS, Alexa [name changed to protect privacy] and her family were living 4hrs south of Perth. Her 2yr old was diagnosed severely autistic (DSM-4). A relative with autistic kids in Perth told her about how kids under the age of 6yrs in Perth had access

to 4hrs of early intervention therapy per week. Alexa was offered 1 visit per year from a psychologist for her toddler, because the family were located outside the metropolitan area. Alexa asked to bring her toddler up to Perth each week to access the 4hrs of early intervention therapy Perth kids benefited from. The State Disability Services denied her request. Alexa continued to advocate, and was forced to threaten to go to the media to be permitted to travel to Perth at her own cost to access early intervention therapy for her child. Permission was finally granted, and Alexa travelled 4hrs to Perth and 4hrs back each week for 3 years. During that time, her second child was also diagnosed severely autistic, and accessed the same early intervention therapy in Perth. Alexa's children were the only WA children outside the metropolitan area to access early intervention therapy during this time.

As evidenced in the case study above, there is extremely high risk of regional and remote people with disability losing access to critical support services if mandatory provider registration or enrolment is introduced. SWAN asked survey respondents about the longest wait time they experienced to access support services, as shown in the bar graph below and subsequent survey comments:

Longest wait time for services was:



"I had my plan for 2 years, unable to access anything. Everywhere had waiting lists. I was on every waiting list, even Mandurah and Perth. I ended up going Selfmanaged, so I could actually access something."

"Unable to find service providers with capacity."

"There are extremely limited services available to meet the demand, and very long waitlists. No decent PBS or SLES providers in the region at all. Without access to unregistered providers we would have no support at all."

"As my child's carer I know how to research and am very aware of what is needed to help. But trying to access services is difficult. I can't buy sensory aids until I have a report from OT - and it's taken 18 months to get an appointment."

"Because we Self-Manage and can use unregistered providers, we have quite good flexibility. But requiring that Positive Behaviour Support be Agency Managed meant we were unable to use that part of the plan at all."

"I waited 3 years and 7 months to access an Occupational Therapist. I was on waitlists everywhere, but the providers would contact me and say that the OT had left, and to try somewhere else. Meanwhile NDIS kept slashing my funding — I still needed the support, but couldn't access anyone to provide it. So when I finally gained access, there wasn't enough funding for the OT to do what I needed."

"Due to being in a regional area, we have a lack of resources and many services have waitlists."

"Just about impossible to find local registered carers. I want the choice of sole providersam worried that will be an enormous barrier to help."

"Very thin markets. I'm entirely reliant on unregistered providers to be able to access any supports at all. The recommendations in the NDIS Review report for mandatory provider registration is terrifying - I'll lose all supports."

"There has been some increase in services available in our regional centre, but we still need to go to Perth at least twice a year to access services not available locally. That is a round trip of about 900km, with additional expenses of accommodation, travel costs and disruption to our son's structured routine."

"I called therapists sometimes as far as 2 hours away looking for available services and comparing distance and wait times."

"Definitely not enough, we also see therapist from the metro area as we can't get what we need in our area."

"I need to get supports from outside my town, go online, change my requirements or go without."

"Need aboriginal workers, respite and disability housing our mob don't want to live with white people."

"Use services outside area either in the city or town over 400km away"

"Terrible here. And if you do get something elsewhere huge travel costs from workers taking me there and back which you don't get in a plan so the travel cost comes out of support hours so a rural person gets less overall hours of support."

"Just not enough providers in our area to meet the needs of everyone."

We also asked survey respondents if they used Telehealth in order to improve access to support services. 42% of respondents advised that they do use Telehealth, whereas 58% do not. The most commonly accessed Telehealth services were Psychology, Speech Pathology, and Dietitian. Some people also use Telehealth for Occupational Therapy, Physiotherapy, and employability skill building supports.

We asked survey respondents to tell us about difficulties they experienced finding and keeping support services in their community:

"Extreme thin markets, lack of knowledge of my disability. Housing crisis has also meant that cleaners, gardeners and support workers are not able to afford rentals in my town due to being on lower incomes, so have had large gaps in supports."

"Monthly trips to metro area to access Clin Psych was taking a toll on work, school, family and uncovered costs."

"I have struggled to find services that service my area. Often I have to travel a fair distance to receive supports which adds extra pressure - fuel costs, car wear and tear, time from school, time from work, time from other family members etc. We have previously (prior to workers leaving) travelled to Mandurah (45+ mins), Bunbury (30mins+) and Busselton (1.5hours) to receive adequate supports for my child. This is a huge outlay for our family. It also involved having to take my younger son on these travels as we cannot always get day care spots, have the funds to pay for day care or have someone available to baby sit."

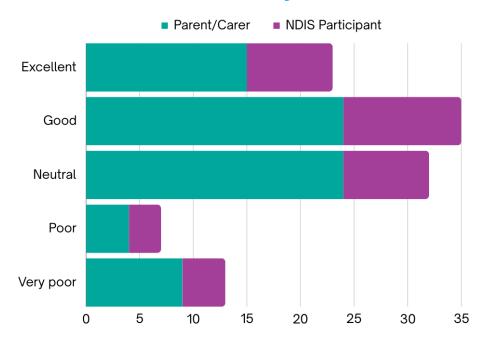
"Service providers find it difficult to retain staff in regional areas."

"Not enough services available in regional areas, lot of staff changes, so when you get near the top of a waitlist, the staff leave and then you're waiting for a replacement staffer."

"There is nothing where we live. I have to drive at least 1 hr to access anything. The plan doesn't take in the fuel money I have to fork out to help my child."

It's important to note that despite the difficulty accessing support services and the high usage of non-registered providers, survey respondents rated the quality of the NDIS funded services they use quite highly. As shown in the bar graph on the next page, 52.7% rated the quality of services used as good (31.8%) or excellent (20.9%), whilst 18.2% rated the quality of services used as poor (6.4%) or very poor (11.8%).

How would you rate the quality of NDIS funded services you use?



Delving further into the comments on quality of support services used, we find some common themes:

"I have a pretty good small team, but that has taken 5 years to build, without help. However, there's no permanence with any of these people: need far outweighs supply in my district."

"Because we can Self-Manage, use unregistered providers and have full control over the supports we use for our family member, we are able to maintain an extremely high quality of support. For example, we direct employ the support workers, saving \$30,000 each year. They are permanent part time employees paid \$42 per hour plus superannuation, tax and insurances are managed for them, and we also organise plenty of appropriate training for them to make sure that they are meeting our family member's needs. All this and we are still saving the taxpayer \$30,000 per year on support workers alone!"

"Because we are using unregistered providers. The registered providers were dreadful."

"Not good so far feel like cash cow people only after access to your funding while doing bare basic services to you."

"The support workers and psychologists that we have accessed for our son through his Self-Managed plan have been excellent but they are in short supply."

"We have had excellent supports from the unregistered providers we use. The NDIS registered providers were absolutely dreadful, and now we actively avoid them."

"Some are truly sucking plans dry and not building skills or capacity."

"My psychologist is excellent in helping me to navigate relationships etc and understand how to live a full life with my disability. Support workers are mostly good, but the upper management and coordinators of the support worker organisation I use are a bit poor, with constant changes to the staff and a lack of continuity. They appear to be understaffed and regularly drop the ball, leaving me waiting for a support worker who doesn't show, or having a support worker turning up when I have told them I don't need support that day, etc. They are frustrating to deal with a lot of the time."

"Those within our team are amazing, but it's taken us a long time and a lot of advocacy to get what we have."

Many comments refer to the flexibility and control of Self-Managing NDIS funding and access to non-registered providers in successfully accessing and maintaining quality supports. Most concerns about quality were related to poor experiences with NDIS registered providers, inconsistency of supports due to staffing shortages, and charging practices. As participants and families in rural, regional and remote Australia are often charged extensive provider travel costs, which NDIS representatives commonly fail to factor into the development of NDIS plans, concerns over high costs for these supports are common.

As previously noted, NDIS representatives frequently fail to take into consideration the additional cost of travel for rural, regional and remote participants – both for therapists to travel to NDIS participants to provide assessments and therapy, or for participants and families to travel to therapists to access therapy. It's common for NDIS representatives to deny the inclusion of travel costs in the Capacity Building - Improved Daily Living budget, telling participants that they must source therapists in their local community. This is hugely problematic for participants in rural, regional and remote Australia. Where there are local therapy providers, they very often have closed or extensive waitlists which may exceed the duration of the NDIS plan. The only option in these circumstances is to use Telehealth or use therapists willing to travel into the area (or the family travel to the therapists). Telehealth is unsuitable for many NDIS participants, and travelling out of town to access therapy is extremely costly, time consuming, and an additional stressor for participants and families who are already time-poor, stressed and often exhausted. Where participants take the only available option of an out-of-town therapy provider and have travel charged to the NDIS plan, the therapy budget is quickly expended - resulting in gaps in access to therapy supports.

Another issue impacting NDIS participants in rural, regional and remote Australia is the narrow scope of clientele that therapy providers typically will see. Many services are paediatric only, leaving adults without access to therapy supports, or waiting in excess of 18 months to 4 years to access supports. There are significant staffing shortages, and many participants and families report being on a provider's waitlist for several months, only to be advised that the clinician has left the provider to return to the metropolitan area, and to try a different provider.

Since the amendments to the NDIS Act in 2022 to introduce a risk assessment for Plan Management to be approved, this has impacted participants in rural, regional and remote Australia. SWAN have received reports of NDIS representatives changing participant plans to fully Agency Managed without warning or discussion, resulting in the participant losing access to all existing support services, and being unable to access NDIS registered providers.

Self-Management

Self-management of funding is a cornerstone of the NDIS, allowing participants the greatest level of choice and control over their supports. This autonomy enables participants to tailor support to their unique needs, fostering a sense of empowerment and personal agency. We urge the Taskforce to uphold and strengthen the ability of participants to self-manage their funds, ensuring that legislative changes support this fundamental right without imposing restrictive barriers.

Innovation and Flexibility

Self-managed funding arrangements have been pivotal in driving innovation within the NDIS. By choosing non-traditional and mainstream service providers, self-managers are often able to achieve more personalised and cost-effective solutions. These innovative practices not only meet specific needs more accurately but also stimulate local economies by integrating community businesses and services into support networks. People with disability are safer when they are seen, included and fully part of their local communities, and retaining the right to use these innovative non-registered providers is vital to achieving meaningful inclusion. Please refer to the case studies below for examples of innovation and flexibility participants are using to meet their support needs, utilising non-registered providers:

Jaydon [name changed to protect privacy] is a 26yr old autistic man who also has a psychosocial disability. He requires 24/7 support, and is currently living with his family, however wants to live by himself one day in future. Jaydon is not eligible for Disability Employment Services, and is using self-managed Finding and Keeping a Job funding to use a local non-registered small business to support him to achieve his career goal of becoming a published author. Jaydon has published three books, with a fourth book soon to be released.

Marnie [name changed to protect privacy] is a 48yr old autistic woman who also has She works full time, and uses a gardener, cleaner, a physical disability. physiotherapist and occupational therapist, all of whom are non-registered. Marnie used her local community Facebook group and peer networks to source recommendations for the services she uses. She checked the AHPRA registration of her allied health professionals, and checked the police clearances of her cleaner and gardener. Marnie's occupational therapist only works with NDIS participants, but for all of her other providers, she is the only NDIS participant using those services. Her physiotherapist has been informed that she is on the NDIS, but Marnie enjoys the privacy of her cleaner and gardener not knowing her NDIS status. physiotherapist charges half the maximum price in the NDIS Price Guide, however the shortage of cleaners and gardeners in her community mean that she has no option but to pay more than the maximum rate in the NDIS Price Guide. Despite this, Marnie's supports are overall cheaper than they would be through NDIS registered providers. There are extreme workforce shortages for gardeners, cleaners and allied health providers in Marnie's community. She recently had no cleaner for 7 months, and waited almost 4 years to access an occupational therapist.

Nathan [name changed to protect privacy] is an autistic young man with epilepsy and psychosocial disability. He has significant challenges with comprehension and emotional regulation, and requires 24/7 support. Nathan's family have purchased assistive technology such as a subscription to <u>Boardmaker</u> to assist in making visual schedules and social stories for Nathan, noise cancelling headphones to support him

to participate in community activities, and assistive apps to support him to learn independent daily living skills. Nathan experienced a lot of Applied Behaviour Analysis (ABA) therapy when he was young, and is overly compliant, putting him at greater risk of violence, abuse and neglect. Nathan had very negative experiences with NDIS registered providers, resulting in additional trauma. His family now self-manage and directly employ his support workers. One of Nathan's support workers has been working with him for 9 years, the other has been supporting him for 4 years. Nathan's family interviewed his support workers, checked that they have police clearances, Working With Children Checks, current First Aid training and current drivers licences. They provided on-the -job training to support Nathan, and over the years have arranged appropriate training for the support workers, including:

- Understanding Autism
- De-escalation Skills
- Disability and Mental Health
- Youth Mental Health First Aid
- Trauma Responsive Practice

The cost of support workers being upskilled in the above training courses is claimed from Nathan's NDIS plan. Nathan's support workers are paid \$42 per hour plus superannuation. As they are direct employed, their tax, superannuation and insurances are all managed for them. They use book-keeping software to manage payroll (claimed from his NDIS plan). Nathan's family decided to employ them as part time permanent staff, so they also have leave entitlements and job security, which enabled both of the support workers to secure a mortgage. Inclusive of all costs, Nathan's family are saving the taxpayer \$30,000 per year by direct employing his support workers, instead of using a registered provider.

42yr old Joanne [name changed to protect privacy] has a physical disability which limits her mobility, as well as chronic illness, She uses a walker for mobility, but is unable to lift the walker into and out of her car. Joanne uses ad hoc support workers to assist her to attend medical appointments and to support her when she needs to deliver community training (transport, set up and pack down) as part of her work role. Joanne pays neighbours and friends as support workers to assist her to do this. She direct employs them on a casual basis, paying \$50 per hour plus superannuation, and manages their tax and workers compensation insurance.

Katrina [name changed to protect privacy] is a 35yr old woman with intellectual disability. She has a team of support workers, and lives in her own home. Katrina's Mum is her nominee, and manages the NDIS claims. Katrina and her Mum chose a team leader, who organises the shifts for her team of support workers, and is involved with Katrina and her Mum in interviewing and training any new staff who join the team. The support workers are direct employed, and Katrina's Mum uses a local bookkeeper to manage the payroll for the team, and simply lodges the claims to the NDIS participant portal and makes payments.

As evidenced in the case studies above, the current flexibility of self-management and access to non-registered providers enables a degree of innovation and cost-effectiveness that is simply not possible with mandatory provider registration or enrolment.

Risk Management by Self Managers

Self-managers are adept at managing risk through personalised planning and informed decision-making. The current system allows for a nuanced approach to risk that respects individual participant's abilities to evaluate and decide on the best course of action for their circumstances. For example, self-managers use a variety of strategies such as employing providers with specialised local knowledge, engaging directly with providers who have been vetted through community reputation, or using personal networks to ensure safety and quality of service. They conduct interviews, check references, and arrange targeted training to meet the individual support needs of the NDIS participant and the knowledge gaps of the support worker.

Proportionate Risk

The current quality and safeguarding framework already has a proportionate risk approach built in. The default model of funding management is Agency (NDIA) Managed, and participants and nominees must pass a risk assessment in order to have their funding Plan or Self-Managed. The recommendation for mandatory provider registration or enrolment in the NDIS Review's final report assigns four levels of registration or enrolment based on the type of support being provided. Determining regulation by type of support alone is completely inappropriate, and inconsistent with a human rights approach. This is a blunt instrument for assessing risk which fails to acknowledge individual capabilities and expertise to assess and manage their own or their family member's risk and safety.

One of SWAN's services is the provision of Youth Mental Health First Aid training, a 2 day, 14 hour training course which teaches adults to identify and provide mental health first aid to young people experiencing poor mental health or mental health crises. A key message we teach in the training is that it is vital to ensure that young people are given choice and control over what happens to them when mental health first aid is provided. All people feel safer when they have choices and control over their own lives – including where they go, who they spend time with, what happens to them, who comes into their home and who touches their bodies. The same must apply to people with disability – choice and control is of utmost importance – the foundation of the NDIS. Recommendation 17 threatens to remove this vital component.

People with disabilities are adept at managing risks and ensuring safety when using NDIS funded supports, demonstrating a comprehensive and proactive approach to navigating their support needs. An important strategy employed involves the development of personalised safeguarding plans which include a combination of formal and informal safety measures tailored to their individual circumstances.

NDIS participants and their families often leverage both community resources and personal networks to ensure the quality and safety of their supports. They use a variety of vetting methods, such as:

- National Police Clearances
- Working With Children / Vulnerable Persons Checks
- NDIS Worker Screening Check
- Word of mouth recommendations from community and peer support networks
- Comprehensive interviews and work trials
- Reference checks
- Personalised training / mentoring of staff and/or buddy shifts

- Ongoing performance evaluations
- Specific qualifications and/or training courses, including but not limited to qualifications in:
 - Individualised Support
 - Youth Work
 - Mental Health
 - Community Services
 - Education Assistance
 - Allied Health Assistance
 - University students
 - Lived experience
- Technology-assisted tools, personal emergency systems
- Meaningful inclusion in the local community (people with disability are safer when seen and included in their local communities)
- Regular check-ins from community members or family

Different people with disability use different combinations of the above to ensure the quality and safety of their supports. NDIS participants and their families self-directing their own supports invest significant time, research and often personal funds in developing effective systems for managing quality and risk in their NDIS funded supports. Moreover, self-managed participants are particularly proactive about their safety. This ensures that the support staff not only match their individual needs, but are also reliable and trustworthy.

Furthermore, the NDIS framework includes regular review and reassessment of the participant's plan, allowing for adjustments to be made based on changing needs or any concerns regarding the efficacy and safety of the supports provided. There are three major gaps in process which are adversely impacting the quality and safety of NDIS supports:

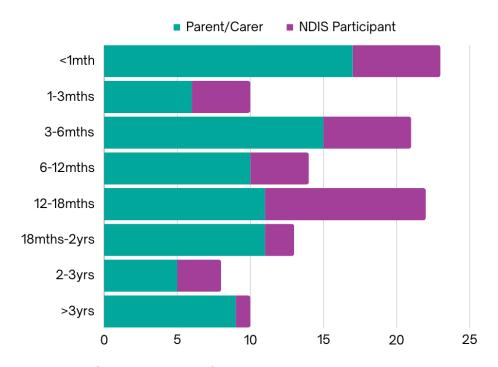
- 1) Poorly conducted risk assessments used by NDIS representatives to determine how funding for various supports can be managed.
- 2) Lack of check-ins and monitoring with participants between plan reviews and reassessments.
- 3) Insufficient regulation and oversight of supports provided in closed settings such as group homes.
- 4) Lack of compulsory separation between support coordination / psychosocial recovery coaching and other NDIS funded supports.
- 5) Funding for supported decision-making, circles of support and microboards to build capacity.

In 2022 the former Government introduced a risk assessment to decide whether a participant's NDIS plan could be plan managed, in addition to the pre-existing risk assessment to decide if a participant can be self-managed. The risk assessment is not being consistently employed by NDIS representatives, leading to people with capacity to self-manage being denied the right; people in towns with no registered providers being made Agency (NDIA) managed (and thus unable to access supports), and people with complex and high support needs and no informal supports being given inadequate protections. SWAN staff have attended numerous NDIS planning meetings as advocates, and note that the risk assessment is commonly skipped by Partners In The Community. To address this issue, the risk assessments to determine how funding is managed need to be codesigned with people with disability and their representative organisations to address these issues, with clear operational guidance to ensure consistency of approach.

The lack of ongoing monitoring and check-ins by NDIS representatives to ensure that participants are safe, their plans are meeting their needs, their supports are appropriate, and providers are charging for supports which have been delivered is significant. SWAN commonly speak with NDIS participants and families who have had no plan implementation support, and again speak with people who have not been contacted by any NDIS representative in 3-4 years or more. One of our survey respondents noted that they were still on their first 12mth NDIS plan from 6 years ago, and had merely received a letter noting the plan would rollover each year, with no other contact. Participants who have not been checked in on for several years typically have a 12mth plan which is rolled over or autoextended annually, with no contact from NDIS representatives.

We asked survey respondents how long ago they were last contacted by a NDIS representative. As shown in the bar graph below and subsequent respondent comments, the results were quite inconsistent:

Last Contact from NDIS Representative was:



"2020 when the S100 was held. Since then the 12mth plan has been auto-extended repeatedly, with no one contacting us. We are too scared to contact NDIS about it in case they slash the funding, as happened to his family member."

"I always have to initiate contact if there is an issue or need clarification. Even when I request LAC to call they don't. Now we have to request appointments and still don't get return follow up calls after the appointment."

"I cannot remember the last time anyone contacted me about my son. I used the NDIS portal to find out information about his review which was scheduled for December 2023. Now it has been rolled forward to December 2024 but no one from NDIS has written or telephoned me about this. I don't know who our current NDIS LAC is as it changes each time I have telephoned or emailed which is not good for continuity of care for participants."

"My plan was rolled over 2 years ago and an NDIA planner rang me. I've not had a planning meeting in 4 years."

"Other than a letter, have never spoken to anyone other than the initial appts to set up the plan."

"Only contacted after emailing repeated complaints to Bill Shorten, NDIS CEO, feedback and complaints emails, Q&SC. The system has been broken from the outset because the goal of governments is to spend the least possible in supporting PWD's, even if that means spending \$72M a year on lawyers to fight vulnerable people at AAT."

"Via email. The person did not answer my question. Yet to hear back again."

"I have had contact more recently as I reached out, my question was unanswered and no follow up was made despite being told it would. The last time someone contacted me was at the beginning of my plan (12 months ago)."

Addressing this gap enables a more dynamic, flexible and individualised approach which ensures that NDIS participants consistently receive support that aligns with their evolving requirements and preferences, while maximising their safety and well-being.

As NDIS representatives typically contact NDIS participants and families from unlisted numbers and planning is increasingly being conducted via phone call only, failing to clearly identify who the NDIS representative is, their role and where they are calling from is deeply concerning. There is high risk of NDIS participants and families falling victim to NDIS scams and fraud through this approach, especially as NDIS representatives phone from a silent number and then require identifying information before proceeding. This issue can be addressed by implementing a technology fix to display 'NDIS' as the caller when contacting NDIS participants and nominees.

SWAN believe that there are specific NDIS funded supports which require a higher degree of regulation and monitoring – supports provided in closed settings (eg. group homes). These supports should be provided by NDIS registered providers, with ongoing monitoring and unscheduled inspections by the NDIS Quality and Safeguards Commission. Every independent review of NDIS supports prior to the 2023 NDIS Review recommended that NDIA mandate that support coordination and psychosocial recovery coaching services be provided by a distinctly separate provider to all other supports. Ensuring that these services are independent of other support services ensures a vital degree of separation which removes conflicts of interest and contributes to improved safety for participants. This is a strategy that the NDIA has consistently failed to implement despite numerous recommendations. And lastly, the NDIS has consistently failed to invest in building the individual capacity of people with disability to make informed decisions about the quality and safety of supports, and likewise failed to invest in formal and informal support systems such as circles of support and microboards, which are effective mechanisms for improving quality, safety and decision-making.

The blunt instrument of mandatory provider registration or enrolment not only fails to acknowledge the exceptional methods employed by NDIS participants and families to manage quality and safety, but also fails to address the systemic issues which are impacting the quality and safety of NDIS participants who do not have the capacity or informal supports to manage risk and safety independently. The NDIS Review Panel instead took the stance

of outsourcing responsibility for quality and safety to providers. As shown in the 6,845 pages of the <u>Disability Royal Commission final report</u>, provider registration does not equate to improved quality and safety for people with disability. Empowered, knowledgeable people with disability and families exercising choice and control in deciding their own supports are what drive quality, innovation and safety.

Quality and Safeguarding

The NDIS Quality and Safeguards Commission accept complaints about both registered and non-registered providers. Non-registered providers are expected to adhere to the NDIS Code of Conduct in the same manner that NDIS registered providers do.

SWAN frequently receive complaints from people with disability and families who have attempted to lodge complaints about providers to the Commission. SWAN were contacted about a registered Supported Independent Living (SIL) provider in Australind by eight people (on separate occasions over a period of four months), expressing concerns about how group home residents were being treated by workers of the provider. People contacting SWAN reported residents being abandoned by support workers in shopping centres and on the side of the road because their shift had ended (and overtime was not permitted by the provider). SWAN encouraged each of the people who contacted us to lodge complaints to both the NDIS Quality and Safeguards Commission and to the police. More than half of the complainants advised SWAN that when the Commission finally contacted them about their complaint, the phone call was to advise that as more than four months had passed since the original incident, they would close the complaint. In October 2023, a SIL resident of the same provider and location was murdered by a co-resident whilst in their care (see ABC article).

Ann Marie Smith died of neglect and malnourishment in April 2020 while in the full time care of NDIS registered provider, Integrity Care (see ABC article). At least eighteen children were subjected to shocking abuse in NDIS registered provider Irabina Autism Services' "Severe Behaviour Program" (see ABC article). Lee-anne Mackey experienced shocking abuse from support workers of NDIS registered provider Scope, as recently reported by 60 These are just a few of thousands of examples of violence, abuse and neglect experienced by people with disability through NDIS registered providers, as evidenced in the final report of the Disability Royal Commission.

Provider registration does not equate to safety for people with disability. This has been proven time and time again. We need only look through the Coroners' reports and the Disability Royal Commission's report for the evidence.

~ Disability Advocate

SWAN notes that people with disability may also experience violence, abuse and neglect through non-registered providers. However, there are decades of evidence that registration of providers does not result in quality, safety, and prevention of violence, abuse and neglect of people with disability. As previously noted, about 16,000 providers are registered, while more than 150,000 are non-registered. To-date, the NDIS Quality and Safeguards Commission has been unable to manage and appropriately respond to the volume of complaints they receive. We have concerns about the Commission's capacity to effectively monitor and manage a significantly larger number of registered and enrolled providers, even with substantially increased Government funding. Currently the Commission are tasked with ongoing monitoring of less than 10% of all providers.

In considering safeguarding of NDIS participants, its vital to look at mainstream registration and regulation systems already in existence. <u>AHPRA</u> provide effective monitoring and regulation of allied health professionals (excluding speech pathologists who are self-regulated by <u>Speech Pathology Australia</u>) and builders are effectively regulated by <u>Master Builders Association</u>.

The flaws in the current safeguarding system include:

- Poorly conducted risk assessment in determining how a participant's funding can be managed.
- Lack of monitoring and check-ins by NDIS representatives to ensure participants are safe, that providers are delivering services charged for, and that participants' needs are being addressed.
- Failure of NDIA to enforce separation of support coordination and psychosocial recovery coaching from other supports.
- Failure of NDIA to deem supports provided in closed settings such as group homes to be high risk, requiring delivery by registered providers.
- Insufficient staffing at both NDIA and NDIS Quality and Safeguards Commission to manage monitoring and complaints, and inadequate IT systems for managing recordkeeping to identify patterns of complaints about providers.
- Lack of understanding in the community about the complaints process, and who to complain to. Some participants do not understand the distinction between the two entities, and remain concerned that lodging a complaint to 'NDIS' will risk their funding.

The wider community are aware of existing mainstream regulatory systems, and where community members witness violence, abuse or neglect, they are more likely to report their concerns to mainstream regulatory bodies such as police, AHPRA, ACCC etc. Community knowledge of the NDIS Quality and Safeguards Commission is very limited. NDIS participants and families often lodge complaints about providers to NDIA and PITC rather than to the Commission due to lack of understanding of the distinction between the two, and it's not reasonable to expect community members to know about the segregated system for complaints in the disability sector.

Further, response to complaints to the Quality and Safeguards Commission are too often dismissed, ignored, or the case is closed simply because Commission staff are so delayed in responding to complaints that several months have passed since the incident occurred. When people with disability and families contact SWAN with concerns about violence, abuse or neglect by a provider to a person with disability, we advise them to contact police and then the Quality and Safeguards Commission. If the concern is about over-charging, we advise them to complain to the ACCC, Consumer Affairs and the NDIA's fraud hotline. Our clients advise that the mainstream regulatory bodies are typically more responsive and effective in addressing the complaints.

Currently, in order to trigger action on a complaint, people with disability and families have no option but to complain to <u>both</u> mainstream and NDIS regulatory bodies and hope that one will respond and take action.

Oversight of Funds

Another issue identified in the NDIS Review's final report is the lack of oversight the NDIA have over where NDIS funds are spent. Again, the panel proposed mandatory provider registration or enrolment as the fix to address this issue. We reiterate our concern that this is a blunt instrument which will create more risk to participants than benefits, as noted throughout this submission, while a more nuanced approach is required.

A more appropriate action to enable the NDIA to have oversight of where funds are spent is to use technology to accurately record funding claims. For self-managers, this would mean entering the following details when lodging claims through the NDIS portal or app, depending on the type of claim being made:

- Australian Business Number (ABN).
- Statement By Supplier legal in Australia, noting that not everyone is eligible for an ABN
- Withholding Payer Number (WPN) Self-managers direct employing support workers who do not have an existing ABN employ their support workers via WPN. Direct employers with a pre-existing ABN or who apply for an ABN for other purposes are required by the Australian Tax Office (ATO) to use their ABN when employing support workers.
- Payroll details for direct employed support workers noting that privacy requirements would need to be changed to enable direct employers to report employee details to a third party (in this case NDIA).
- System for recording overseas purchases and purchase of 2nd hand items at low cost without ABN.

Important note: These systems must also enable the claiming of vital services required by self-managing participants, such as advice from accountants, bookkeepers, bookkeeping insurances for workers, software, subscriptions, training courses (needed for staff and parent/carer training), consumables and 2nd hand assistive technology through Facebook marketplace, overseas sellers and more. Mandatory provider registration or enrolment would prevent NDIS participants from accessing these and many other important supports which are low cost, effective, and improve quality and safety.

Recommendations

To genuinely improve the NDIS for all Australians, including those in regional and remote areas, a more nuanced approach is necessary. This includes:

- 1) Ensure participants retain meaningful choice and control over their supports, including access to non-registered providers through Self-Management and Plan Management. Limiting participants to only accessing registered or enrolled providers seriously limits choice, especially in regional and remote areas. There is high risk of participants being able to access only one provider or no providers at all. Where participants are only able to access a single provider, people feel significantly less able to complain about violence, abuse and neglect due to fear of retribution or loss of vital supports.
- 2) Use existing mainstream regulatory systems wherever possible, such as National Police Clearances, Working With Children / Vulnerable Persons Check, <u>AHPRA</u>, <u>ACCC</u>, <u>Master Builders Association</u> etc.
- 3) The NDIA must co-design improvements to the risk assessment for determining whether a participant (or specific supports) can be Self-Managed, Plan Managed or Agency Managed. The risk assessment must consider the type of supports needed and the capacity of the participant / nominee to manage such risks.
- 4) The NDIS must invest in supported decision-making for participants who need it, circles of support and microboards to improve safety and supported decision-making for NDIS participants who need these supports, improving innovation, quality and safeguarding.
- 5) Ensure that Support Coordination and Psychosocial Recovery Coaching are appropriately funded to meet individual needs, and independent of all other supports.
- 6) Improve Check-Ins and monitoring of participants by NDIS representatives, especially individuals without suitable informal supports who are at higher risk; to make sure that they are safe, supports are appropriate to their needs, and providers are charging for supports that have been provided.
- 7) Improve the NDIA's oversight of where NDIS funds are spent, by recording ABNs, Withholding Payer Number (WPNs), Statement by Supplier, payroll of direct employed support workers, as well as overseas purchases (e.g., Assistive Technology purchased on Amazon, or subscriptions to software such as Boardmaker).
- 8) Require that all supports provided in closed settings (e.g., group homes) be delivered by registered providers and thoroughly regulated, with mandatory, unscheduled site inspections conducted by NDIS Quality & Safeguards Commission.
- 9) The NDIS Quality & Safeguards Commission must significantly simplify the process for provider registration, and ensure that any required audits are available free of charge. There must also be protections put in place to prevent 'bureaucratic creep' from making the provider registration more burdensome over time - thus reducing the number of providers willing to register and the number of registered providers available for participants to choose from.
- 10)NDIA to consider differentiated pricing, enabling registered providers to charge more than non-registered providers. This would assist in incentivising providers to undertake

- advanced and general registration, whilst also assisting in managing the increased cost incurred through applying for and maintaining registration and audit.
- 11)Our recommendation is that the NDIS Worker Screening Check be dropped and replaced with the pre-existing Police Clearance and Working With Children / Vulnerable Persons Check. If the Taskforce determines that this additional check be required, it should only be applied to support workers. Applications for the check must be nationally consistent, cost less than applying for the National Police Clearance or Working With Children / Vulnerable Persons Check, and the application must be available either online or inperson via Australia Post offices (not a combination of both).
- 12)Create a public community education to improve understanding and motivation of community members to report suspicion of violence, abuse and neglect (domestic violence, child abuse, elderly abuse and abuse of people with disability).

The NDIS Review's recommendation 17, while well-intentioned, risks leaving too many people without access to support – especially those living in regional and remote Australia. As we work towards a fairer, more inclusive NDIS, it is crucial that reforms reflect the diverse needs of people with disability across our vast nation. By aligning policy with the lived experiences of all participants, we can ensure that the NDIS realises its promise of choice, control and meaningful inclusion of all people with disability.

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