Exercising meaningful choice and control in the NDIS

Why participants use unregistered providers

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Executive Summary

The NDIS is Australia's most significant social policy reform of the past fifty years. NDIS participants receive a package of funding to purchase required disability services in an open market.

The market includes providers who are registered with the NDIS Quality and Safeguards Commission and those who are not (known as unregistered or non-registered service providers. Service providers must undertake various compliance and auditing processes in order to identify themselves as NDIS registered service providers.

There has been some debate concerning the quality and safety of unregistered providers compared to that of registered providers. While these debates generally feature the voices of providers and public servants, the voice of NDIS participants is often absent.

This research aimed to capture *the voices of NDIS participants and some plan nominees explaining why they choose to use unregistered providers and the steps that they take to ensure the quality and safety of services for themselves and their workers.*

Our research approach

We conducted online semi-structured interviews with 30 NDIS participants or plan nominees who purchased one or more supports from unregistered providers at the time of interview.

We did not talk to any people who avoided using unregistered providers or who previously used unregistered providers but stopped doing so. This means that we can talk about why people choose unregistered providers but cannot talk about why some people might choose not to use them.

Participants came from all states and territories except the Northern Territory. About two thirds lived in urban areas, while one third lived in outer urban, regional or rural areas. They (or the NDIS participants they represented had a wide range of disabilities, including physical, psychosocial, neurological, intellectual/cognitive, sensory, and energy impairments.

Findings

Interview participants purchased four main types of services or supports from unregistered providers, which participants reported come with some different considerations in terms of managing issues of risk, quality and safety:

Consumables such as basic pieces of access equipment, medical supplies and assistive technologies. Purchasing these items from unregistered providers often represented significant cost savings and reduced delays, with no difference in the quality of these products and in many cases, items of the same brand.

Household services such as cleaning and gardening. Participants felt they did not experience discrimination or an elevated sense of risk in the delivery of these services. Participants described liking the option of being able to utilise local and small businesses that hired local staff and noted that this made them feel more connected to the community and happy in supporting local businesses.

Allied health and various therapies. While many allied health providers and therapists are not NDIS registered, these providers typically hold registration or accreditation with their appropriate professional bodies, particularly occupational therapists, physiotherapists and psychologists. Participants often reported feeling that NDIS registration would not provide any additional level of safety or quality.

Support workers employed either as sole contractors, via online platforms, or through direct employment. This category of supports is arguably the most controversial in discussions about registration given that some of these supports involve personal care often delivered in domestic contexts. Participants

however described advantages associated with using unregistered support workers, including increased flexibility with shift times, having choice of workers, having consistency of workers, being able to set worker wages, being able to move away from 'agency rule book' limitations, and increased empowerment and control within the support interaction. Several participants told us that they'd had negative experiences with support workers from registered agencies and felt safer and better supported using unregistered workers they were able to choose.

Overall, we found that **participants were positive about their experiences using unregistered providers and wished to continue using them**. For participants in our study, using unregistered providers was about **empowerment and exercising choice and control** – in other words it was fundamental for achieving effective service provision arrangements through the NDIS. There were several reasons offered to explain this.

Many participants felt they received better quality and cost effectiveness through using unregistered providers. Despite the potentially increased administration involved for self managed participants using unregistered providers, the option to choose providers that best suited both their budget and goals (and having services delivered by people they had developed strong working relationships with) was viewed as crucial and life changing. Unregistered providers were also seen as being more innovative and more flexible in the types of services and supports they can deliver. Further, the immaturity of the disability market (often referred to as 'thin markets') also meant that if participants did not use unregistered providers, they would have to go without services in some areas.

In addition, many participants communicated that they **actively avoided purchasing services from registered providers where possible**. They felt at greater risk from coordinators at registered providers who often acted as gatekeepers around staff and times of shifts, and frequently sent 'just anyone' to work a shift (including workers unknown to clients). Participants noted that having no connection with support workers increased their sense of risk and anxiety. Other participants reported being aware of the debate around risk and safety in the use of unregistered providers – particularly support workers – but felt that **registration was no guarantee of safety**. Choosing and assessing risks in relation to selecting a provider and receiving services was seen as a regular element of any service usage, and for people with disability, something viewed as essential in allowing participants to live full and meaningful lives (sometimes termed 'the dignity of risk').

Participants reported a number of processes they use to ensure that they keep themselves and staff safe when using unregistered providers. They told us about how they deal with issues such as hiring and training staff, organising their workforce, managing occupational health and safety, ensuring accurate invoicing, and resolving problems.

Key lessons and possible solutions

From our findings we have devised a series of key lessons for the NDIS and possible solutions to improve the system. These centre around i) better supporting NDIS participants to make the most effective decisions regarding their choice of providers, services and supports; ii) improving guidance for small unregistered providers; and iii) introducing a 'light touch' registration process for unregistered support workers to ensure that basic information about the workforce is kept in a centralised location.

Introduction

The NDIS is Australia's most significant social policy reform of the past fifty years.[1] This has involved substantial new investment in disability support services and the creation of a new disability services market. Through the provision of individualised funding, the NDIS aims to give choice and control to people with disability by allowing them to purchase the services that they require to support them in achieving their life goals.

A significant element of the NDIS is that participants receive a package of funding, based on an individual assessment (hence the term individualised funding, to purchase required services in an open market. This market includes both NDIS registered service providers and unregistered service providers (also known as non-registered service providers that NDIS participants can choose to purchase from. Service providers can choose to undertake various compliance and auditing processes in order to identify themselves as NDIS registered service providers in the market. Ongoing cost is associated with registration, and cost is tiered based on the size of the service provider. All service providers offering behavioural support services must be NDIS registered.

There has been some debate concerning the quality and safety of unregistered providers compared to that of registered providers.[e.g. 2, 3] While these debates typically feature the voices of providers and public servants, the voice of NDIS participants is often absent. ***This research aimed to capture the voices of NDIS participants, and some plan nominees, explaining why they choose to use unregistered providers and the steps that they take to ensure the quality and safety of services for themselves and their workers***.

We begin this report by setting out the background to this research and explaining the various different options for managing NDIS budgets and what is meant by registered and unregistered providers. We then describe our research approach and participant sample. We set out our results in four main sections: why people might choose not to use registered providers; why people choose to use unregistered providers; issues to consider when using unregistered providers; and key lessons and possible solutions to current challenges in the NDIS based on participant suggestions.

Overall, we find that participants are positive about their experiences using unregistered providers and wish to continue using them. This is not surprising given our participant group, but nonetheless we can report a strong preference for using unregistered providers and a sense that this preference extends well beyond the 30 people we were able to interview for this project. For participants in our study, using unregistered providers is about empowerment and exercising choice and control – in other words it is fundamental for achieving effective service provision arrangements through the NDIS. They reported being aware of the debate around the use of unregistered providers – particularly support workers – but felt that registration was no guarantee of safety in any case. In discussing these issues, many interviewees referenced cases of abuse and neglect involving registered providers. Choosing and assessing risks was seen as a standard element of any service usage, and for people with disability, something essential in allowing them to live full and meaningful lives (sometimes termed 'the dignity of risk'.

The possible solutions offered therefore centre around:

- supporting NDIS participants to make the most effective decisions regarding their services and supports
- improving guidance for small unregistered providers, and
- introducing a 'light touch' registration process for support workers to ensure that minimal information about the workforce is kept in a centralised location.

Background

In this section we set out some important background as context to the findings from our interviews with NDIS participants. We explain the different ways that participants can manage their budgets, the various kinds of providers they can purchase services from, and why debate around registration has started to emerge.

Options for managing funds

Once an NDIS participant enters the scheme and receives a funding package, they can choose from three options for how they manage their funds: agency managed, plan managed and self managed. These processes offer various levels of ease and complexity. The mechanisms allow for different degrees of flexibility and require different various amounts of activity and administration from the NDIS participant or their plan nominee. Briefly these options have the following characteristics:

- *Agency management* - Under this arrangement the NDIA makes payments directly to service providers based on plans.

- *Plan management* - This involves using a registered plan management provider. This is essentially a brokerage model where a financial intermediary supports participants to manage aspects of their plans. Their main function is to pay invoices on behalf of participants and to provide accountability through NDIS plan budget reports and budget oversight. This relieves some of the administrative burden for the participant, while allowing for more flexibility (such as the use of unregistered providers). Participants are still responsible for decisions about service providers, and can direct the purchase of support services, equipment and consumables. Participants may undertake recruitment of support workers, negotiate wages of support workers and undertake ongoing rostering of service supports.

- *Self management* - This allows NDIS participants, or their plan nominee, to manage their individual funding package and directly choose, control and purchase support services, equipment and consumables. Individuals can choose providers and make decisions regarding the type, quantity, cost and timing of services within the constraints of their funding package. The participant then arranges payments of invoices for these services via the NDIS portal. Participants can also choose to directly employ support workers under this option. Administration for this may involve recruitment of support workers, negotiating wages of support workers, paying wages, superannuation and insurance for support workers, and organising rostering of support workers.

Participants can choose one or a combination of the above options.[4] For example, someone might automatically pay for some regular therapies through agency management as per plan allocation but choose to self manage personal care services.

Provider options

In addition to participants having options regarding budget management, there are also a variety of provider options they can choose from in the NDIS market.

Traditional service providers are most often used within the NDIS. These tend to be service providers with capital investments around buildings, a specified management structure and a pool of directly employed staff on a variety of arrangements. The providers will often train employees and arrange staffing. To some extent the organisation operates as a gatekeeper between service recipients and workers. The organisation is responsible for arranging worker rosters, monitoring of ongoing training requirements (such as first aid and CPR training, worker screening and payroll, insurance and superannuation (including setting and controlling support worker wage levels. This can have significant implications for how much NDIS participants can influence processes of service design and delivery. Traditional service providers have come under criticism for being inflexible to the needs of NDIS participants,[5] although some are seeking to address this and gain a competitive edge. Some also operate on a model of casualised employment for disability support workers.

Online providers: digital platforms have emerged as an innovation in the NDIS market, based on gig-economy principles. Some of these platforms are registered NDIS providers (e.g., Hireup, Humdrum), while others are not (e.g., Mable). There is some possibility to pay workers above award rates, provided this is within the parameters of individualised funding arrangements. The wage rate is either set by the platform or negotiated between the worker and NDIS participant. The key characteristic of all online platforms is that NDIS participants can choose the support worker they want from the pool of workers registered with the platform and control all the rostering elements. Some online providers (such as Hireup) still provide considerable scaffolding for workers, such as online module training requirements, monitoring of ongoing training requirements (such as first aid and CPR training), worker screening and payroll, insurance and superannuation payments and critical incident reporting frameworks. In contrast, other online providers simply act as a matching service for NDIS participants and support workers and take a percentage fee for providing this matching service.

Sole traders: usually support workers, cleaners, gardeners, allied health or therapists. They have their own Australian Business Number (ABN) and invoice participants for costs of services provided. The sole trader sets service fees (although this can sometimes be negotiated), and is responsible for paying their own tax, superannuation and insurance. Sole traders act as contractors rather than as employees when providing services. Sole traders may or may not be specific disability specialist providers. No minimum training or qualifications in disability are required by sole traders.

Direct employment: under these arrangements NDIS participants can employ support workers directly. This is only possible for participants who self manage. Direct employment removes the gatekeeper of the traditional service provider, and the participant takes on all service provision responsibilities (such as recruiting, employing and rostering staff and organising wages, superannuation and insurance). Effectively, under these arrangements the NDIS participant becomes the user of the service, employer and the service provider. A range of software may be used by participants to support administration and paying wages.

Some individuals and groups have raised concerns about sole trader and direct employment models as they reduce the sort of oversight mechanisms used by traditional providers. With the lack of an intermediary, some have expressed concerns that these models may allow for exploitation of both NDIS participants and workers. Some tensions here are:

· For NDIS participants, support workers are not required to undertake worker screening, there is no minimum training, and they are not required to have supervision. There is potential for power imbalances to emerge within the support interaction where workers have no training in client empowerment, human rights or inclusion, and where participants are highly dependent on these support workers for their personal care needs and may feel obliged to accept poor quality or unsafe support just to obtain required personal care.

· For support workers, there is no oversight of working conditions such as whether award wages are being paid, whether workers are appropriately insured, whether Occupational Health and Safety guidelines are being adhered to and who is responsible for identifying and securing training options. There are also no critical incident reporting frameworks or avenues for workers to seek guidance or feedback about the support interaction, and they are most often working in the isolated environment of the participant's home.[3]

However, we lack an evidence base to demonstrate whether or not these issues are present in current NDIS services.

Registered and unregistered providers
All providers delivering services funded by the NDIS are to some degree regulated by the NDIS Quality and Safeguards Commission, but only registered providers are required to meet the NDIS Practice Standards. Registered providers are those who have gone through a process of registering with the NDIS Quality and Safeguards Commission.[4] Registration requires organisations to go through significant quality compliance processes, undertake auditing reviews, have incident reporting structures to the NDIS Quality and Safeguards Commission, support their workers with training in areas relevant to the NDIS Practice Standards, and support and screen workers in line with the NDIS Code of Conduct. NDIS registration can be costly for an organisation, with audit processes being undertaken by private providers (and not the NDIA or Quality and Safeguards Commission. There are scaled costs for registration depending on the size of the organisation and the complexity of services being provided. Service providers providing behavioural supports or using restrictive

practices must be NDIS registered providers. All agency managed NDIS participants must use registered providers only.

As noted above, plan and self managed NDIS participants can also purchase services through *unregistered providers*. Here the provider has not undergone the process of registration with the NDIS. As such these providers are more accurately called non-registered providers. However, in this report we use the language of unregistered providers as this has been most widely used to date in debates about registration in the NDIS. One potential element of appeal in using unregistered providers is that the cost can be lower because there are no overheads associated with NDIS registration compliance. The cost for the service can be negotiated between the NDIS participant and the contractor independently and can be above or below award rates (although must meet the national minimum wage. Unregistered providers may or may not be disability specialist providers.

Unregistered providers still fall under the remit of the NDIS Quality and Safeguards Commission. They must be able to effectively manage NDIS participants' complaints concerning the quality and safety of supports and services they provide. Where issues cannot be resolved at a localised level, NDIS participants may also make a complaint to the NDIS Quality and Safeguards Commission about any service purchased using NDIS funds. The NDIS Quality and Safeguards Commission can help NDIS participants in making a complaint. They also have the power to take action against an unregistered provider (such as banning them from providing services to NDIS participants if the complaint raises a compliance issue or cannot be effectively resolved.

In March 2022 there were 115,000 plan managed participants engaging unregistered providers, equating to around $1.12 billion in payments.[6] This means that around two fifths of NDIS spending is going to unregistered providers. Unregistered providers tend to be smaller in size than registered providers, meaning that the spend with unregistered organisations is often smaller. For example, if we look at the spend figures for plan managed participants, 39% of payments went to unregistered providers. However, according to the NDIA, 'the market of unregistered providers is large, which means there are many providers receiving smaller total payments. So although only ten per cent of providers paid through plan managers are NDIS registered providers, they represent 60 per cent of total payments in the quarter. Further, 26 per cent of NDIS registered providers received over $100k in NDIS funding for the quarter, compared to only two per cent of unregistered providers receiving over $100k in funding'.[6: pg. 92]

Concerns over misuse of funds
There are some recent suggestions that fraud might be occurring at rates of up to 5-10% of total scheme spend,[7] an issue that has gained significant attention in recent months. This fraud has not been detected in how NDIS participants are using the scheme but is thought to be a combination of organised crime networks seeking to appropriate scheme funds and providers overservicing or overcharging for service provision.

The NDIS has a pricing policy that sets the maximum prices registered providers can charge NDIS participants for specific items (set out in what was previously known as the NDIS Price Guide and is now known as the NDIS Pricing Arrangements and Price Limits.[1] Concerns have been expressed that service providers are charging participants the maximum Price Guide rate as a standard or minimum, rather than as a maximum. In NDIS Joint Standing Committee hearings[8] we have heard NDIS participants describe how some providers operate a two-tier system of pricing whereby non-NDIS clients are charged at one rate and NDIS participants are charged at a higher rate for the same service.

The Royal Commission into the Abuse and Neglect of People with Disability has shown that incidences of abuse of people with disability are all too common in Australia.[9] Given concerns for quality and safety for participants, and the desire to achieve good and effective use of NDIS funds, questions have been raised about the operationalisation of safeguarding and issues of exploitation within both registered and unregistered service markets. There is no indication within current datasets that these issues occur at a greater rate for those buying services from unregistered providers, and in fact prominent cases of abuse and neglect have involved registered providers.[10]

Some groups have written critically about issues of regulation in the NDIS. For example, a report from Per Capita,[2] which was funded by Hireup (a registered provider), came to the following conclusion: *'As the users of disability services are often amongst the most vulnerable in our society,*

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[1] Despite the updated name, interviewees referred to 'the Price Guide' and so we have followed their convention in this report.

the regulation of care service provision becomes more complex, and necessitates greater oversight … The admittance of unregulated unregistered NDIS service providers into the care and support market is the antithesis of such care obligations. …Without effective regulation, the disability services industry risks a race to the bottom on care quality, as pressure to cut worker costs leads to a reduction in safety protections and [reduces] the time spent on essential care and support procedures'.(pg. 27) However, many NDIS participants reject such a position and have specifically chosen to purchase services from unregistered providers (or directly employ workers). They have anecdotally spoken about the benefits of using unregistered providers – for example increased flexibility and reduced costs.

To date, discussions about registration and related implications for quality and safety of services have seldom featured the voices of people with disability. A number of studies have explored issues of quality and safety from a workforce perspective,[3, 11] noting the potential for worker exploitation in providing support work where there is no traditional oversight or compliance process in place. But the perspectives of people with disability are less present in the literature. NDIS participants are typically spoken about and cast as a 'vulnerable' population in need of protection and lacking agency in decisions about plans. This may be the case in some instances for some NDIS participants, and safeguards should certainly be put in place to avoid the exploitation of this cohort of participants. However, many NDIS participants are empowered, run their own lives, have relationships, work, are university educated and are quite capable of undertaking decision-making around the quality, risk and safety of services they purchase. As such, the design of the entire scheme needs to be flexible enough to incorporate the needs of both of these groups to allow participants to effectively achieve goals and live meaningful lives.

Despite the complexities of the registered and unregistered landscapes, defined by the context of the issues noted above, ***there is currently no research exploring why NDIS participants choose to use unregistered providers and what the implications and benefits of this might be***.

Therefore, this research sought to explore the experience of NDIS participants and plan nominees within the unregistered provider field, looking at choice making, benefits, pitfalls, and the implications of receiving disability services within an unregistered market environment.

Our Research Approach

In this project, we sought to interview adult NDIS participants or plan nominees who purchased one or more supports from unregistered providers at the time of interview.

This project received approval from the UNSW Human Research Ethics Committee (HC220514). We recruited participants through social media advertising on Twitter and Facebook, with the help of disability advocates and disability community organisations. The advertisement explained the purpose of the study and asked potential participants to contact a member of the research team via email or phone. The team member determined whether they met the inclusion criteria, provided them with more information on the study, and asked whether they had any accessibility requirements for an online interview. We received a large initial response and interviewed the first 30 people who responded and met our inclusion criteria.

We conducted interviews over Microsoft Teams. Participants provided consent either through a written consent form (available in standard and easy read formats) or through a verbal consent script at the start of the interview. Interviews were conducted in a semi-structured format, meaning that we had a pre-determined list of questions but did not necessarily ask them all in the same order, and we were able to ask follow-up questions or pursue new lines of questioning as appropriate. Questions covered the following topics:

- why people used unregistered providers or independent contractors or directly employed
- what percentage of their plan was spent on unregistered providers
- whether they had any negative experiences using unregistered providers and if so how they had resolved those issues
- how they employed their support workers and negotiated wages (if relevant)
- what advice they would give to people thinking about using unregistered providers for the first time
- what it would mean for their lives if they were required to use only registered providers for their NDIS services

We provide a full list of interview question at Appendix 1.

After the interview, we thanked participants for their contribution by sending them a $50 pre-paid Mastercard.

We audio recorded the interviews and produced full transcripts of each interview, replacing the names of participants with pseudonyms. We then thematically analysed the transcripts.

Interview sample
We interviewed 30 people for this study (see Table 1). They ranged in age from 20s to 60s. 8 interviewees were male, 20 were female, and 2 were non-binary. 7 of the female interviewees and one non-binary person were plan nominees.

22 interviewees were NDIS participants, 6 were plan nominees, and 2 were both NDIS participants and plan nominees (the eight plan nominees represented 10 NDIS participants between them). Regarding funding management, two thirds were self managed and one third were plan managed, with one participant having a combination of self managed and plan managed funding.

Participants were located in all Australian states and territories except for the Northern Territory. 18 lived in urban areas, 11 lived in regional or outer urban areas, and one was rural.

As the focus was on participant choice across a range of disabilities, we did not systematically collect information about each participant's impairments. However, in describing their disability service experiences, participants often described their impairments or those of the NDIS participants they represented. Participants had a wide range of disabilities, including physical, psychosocial, neurological, intellectual/cognitive, sensory, and energy impairments.

Table 1. Participant demographics

Characteristic	Detail	Number
State or Territory	Australian Capital Territory	1
	New South Wales	7
	Queensland	5
	South Australia	2
	Victoria	9
	Tasmania	1
	Western Australia	5
Type of geographical area	Urban	17
	Regional or outer urban	12
	Rural	1
Gender	Female	20
	Male	8
	Non-binary	2
NDIS involvement	NDIS participant	22
	Plan nominee	6
	NDIS participant and plan nominee	2
Funding management	Plan managed	10
	Self managed	19
	Combination	1

Limitations

The purpose of this project was to explore why and how NDIS participants use unregistered providers through their NDIS plans, because there has not been any published research on why people choose to use this service option. For this reason, we spoke only to people who used unregistered providers at the time of interview. We did not speak to people who avoided unregistered providers entirely or who had previously used unregistered providers and ceased doing so. ***Therefore, we need to be careful in interpreting our findings: the nature of our research design meant that we were likely to speak largely to people who had positive views of unregistered providers and much less likely to speak to people who had neutral or negative views or experiences***. For example, people who no longer use unregistered providers due to negative experiences with them would not be captured in our sample. This means that we are limited to explaining why some NDIS participants find it valuable (and even necessary) to use unregistered providers, and how they organise these services. We would welcome future research exploring the views of those who do not use unregistered providers, to provide a fuller picture of NDIS participants' experiences and decision-making in this area.

A second limitation is that due to our social media recruitment strategy, we primarily interviewed participants who were active on social media, spoke English as a first language, and had no barriers to participating in an online interview. This means that certain cohorts (such as people from non-English speaking backgrounds, people with intellectual disability speaking on their own behalf, and people without reliable internet access) were not well represented in our sample.

A third limitation is the relatively small sample we were able to interview as part of this initial qualitative study, meaning results (as with any interview-based design) are not generalisable to all NDIS participants. However, we received an enthusiastic response from the disability community regarding this topic and anticipate that quantitative research such as a survey would generate useful data to explore this topic further.

Findings

In this section we provide an overview of the findings gained through interviews. Overall, our interviewees were very positive about the unregistered providers that they purchased services from, and saw unregistered providers as being crucial in the provision of appropriate supports for their lives. *For many, the use of unregistered providers was described as fundamentally being about choice and control*.

We begin the findings section by explaining the different types of services and supports that can be purchased from unregistered providers. We then explore issues of decision-making and service quality by examining the same question from two different angles: firstly, why NDIS participants might not use registered providers, and secondly, why do some NDIS participants choose unregistered providers. We finish by describing some of the techniques interviewees used to plan and organise their unregistered services safely and smoothly.

Registration is a complex issue

When talking about the issue of registration and NDIS-funded services, the situation is a little more complex than it might first appear. NDIS funds can be used to pay for a variety of different services, and each comes with different implications for registration. There are at least four broad types of services that NDIS funds might be spent on. Not all participants used unregistered providers from all categories, but we had examples of each – and some people felt very strongly that they preferred unregistered providers for all types of services.

Many interviewees spent funds on NDIS services such as allied health and various forms of therapies. While many of these providers are not registered with the NDIS, they typically hold registration or accreditation with their appropriate professional bodies (e.g., Australian Psychology Accreditation Council, Occupational Therapy Board of Australia). In being accredited with these bodies, interviewees could be assured that their providers have gone through appropriate background checks, are required to adhere to certain standards, and undertake continuing professional development. As such interviewees did not see the need for these providers to undergo NDIS registration as a marker of quality or safety:

> Gabrielle: They already have professional registrations. They already have- like our speechie came to our school and she already has to have working with children clearances and vulnerable people clearances and, you know, 68 clearances and then having to have all these [NDIA] audits and all this expense on top of it, and people just opt out of that space.

> Kim: I don't want to be precluded from working with my art therapist, who's a sole trader, just because she's not registered with NDIS. She's registered with her professional body. She's got all of the relevant qualifications for her profession. I don't see that it makes me safer that she's done this bit of paperwork for the NDIS.

A number of participants mentioned that their allied health providers were not interested in becoming NDIS registered due to the time and cost involved in registration, and because they already had enough business as unregistered providers.

The second category of providers are those who supply consumable goods and low-cost accessible equipment, medical supplies and assistive technologies. This might include everyday items such as disposable gloves, iPad accessories, or continence products. Interviewees told us that it makes no difference for the quality of the products whether they are purchased from a registered or unregistered provider. However, many did describe that they were able to obtain the same items at lower prices if purchased from unregistered providers:

> Khin Yi: …what I have found is that anything with a disability tag is like a wedding tag. So, you know, sometimes if I use a registered provider and buy from a disability shop,

it's way more expensive than sometimes I can buy it from Bunnings. So, you know, eBay, things like that. Why pay three times more just because they are registered?

Kim: …a lot of the cheap places I get my consumables and my assistive technology …like I get things off Amazon and eBay and, you know, regular places where regular normal, non-disabled people shop and those are always cheaper than getting things from quote-unquote disability providers.

Often interviewees would be on constant watch for consumables to go on sale or special and would stock up to ensure that their funds would go further in securing these types of items.

The third category of providers are those who provide non-disability-specific household services such as gardening, house maintenance or adjustments, and cleaning services. Typically, NDIS participants are provided assistance with these supports so they are able to live and work independently. As with therapists and allied health professionals, some providers in this category may also be signed up to professional industry associations such as those associated with home builders or plumbers. Other providers, such as cleaners, may not have industry associations, however most interviewees told us that they did not believe they were taking on significant risks in consuming these services. Moreover, participants described support workers as often being often reluctant to clean or garden, resulting in poor service, so participants felt that mainstream gardeners or cleaners were a much better option.

Khin Yi: I feel like things like helping me with my garden or cleaning, my experience so far is support workers don't really clean very well. So, it's easier to get a standard cleaner and I feel like that's probably more value for money anyway, because they do a better job.

The final category of provision relates to support workers, which is arguably the most controversial and hotly debated category regarding quality and safety of NDIS services. Support workers are involved in fulfilling a range of different roles including physical support with personal care, transportation, meal preparation, community access (including shopping), laundry, basic cleaning, administration of medication, and sometimes emotional support for individuals and their families. This work is often undertaken within domestic contexts. Support workers may also be involved with developing personal skills and engaging participants in leisure, social, cultural and community activities.

Why participants choose not to use registered providers

In our research, interviewees indicated a number of potential benefits of using registered providers. The backgrounds and qualifications of staff will have been checked with referees before being engaged, there is likely to have been screening to check whether a support worker is on any worker exclusion list, and relevant police and working with children/vulnerable people checks will have been undertaken. Onboarding may have included staff induction and basic training modules, and required workplace insurances, tax and superannuation should be in place. Yet despite this, interviewees told us clearly that *registration is no guarantee of quality and safety*:

> Kayla: I think with registered providers people can be given a false sense of security thinking that they're going to get a better level of care. Where, in my experience, that's not the case at all.

> Gabrielle: …the fact that they're registered doesn't make it any safer. It may mean that there's a clearer process to go through if things go wrong, but I don't have a lot of faith that process actually works.

> Wendy: I feel safer with non-registered providers to tell you the truth.

Further, for some of those we interviewed, the registration status of providers was irrelevant, with purchasing decisions being driven by other, more personal markers of quality:

> Kim: I honestly had to go and look up some of them to be able to answer your questions because I don't keep a list in my head of who is registered and who is unregistered …It doesn't matter to me whether people are registered or unregistered, I care about their qualifications. I care about their suitability to be able to work with me. I care about do they understand my disability? Do they understand my circumstances? Do they mesh with me as a provider? I don't have to worry about have they done this specific bit of paperwork for the NDIS. Which means that I have a larger pool of people that I can pull from, which makes me feel safer and gives me more options.

> Kayla: I had to actually look one of them up. I didn't even know if one of them was or not. All I care about is the person working with my daughter and the processes and procedures of their employer.

Our research set out to explore why it is that NDIS participants and plan nominees choose to use unregistered providers. However, early on within our interviews one participant suggested that this might not be the right question and instead we should also be asking why individuals avoid purchasing services from registered providers. Indeed, some interviewees described *actively avoiding using registered providers*. They reported a number of reasons for this and we explore some of these below.

Registered providers can be difficult to find
One reason given by some respondents is that registered providers can be challenging to find and it can be difficult to identify from websites if a provider is registered. The Provider Finder application on the NDIS website was reported as difficult to use so people struggled to find registered providers through this route.

> Davina: [When I was agency managed] I was like, how do I even find a provider? How do I find who's registered, and you know, they're like, "oh, well, we've got the links on the NDIS website". But a lot of providers weren't even listed there. …It really wasn't helpful at all and it left me in an absolute panic because I didn't know where to start, what to do.

> Neil: …if you can find me one person who likes the Provider Finder I'll give you a unicorn. It's just a shitty version of Google.

Previous experience of bad behaviour from registered providers
A number of the interviewees reported having had negative experiences in interacting with registered providers. Often these centred around the type of disability organisations that had carried over from pre-NDIS times and were not seen to be responsive to individual needs:

> Eugenie: There was this whole thing [with a registered provider] about fixing and not really supporting us to be the best that we could possibly be as a family. So it was that difference between the deficit model and the strengths model. That's the basic version of the story. There wasn't any mistreatment that would fall under the terms of reference of the [Disability Royal Commission], but just they weren't setting us up for success. They were more about, you know, this is what we can do for you.

> Harriet: I've been disabled a long time. I've got an illness that is degenerative and until the NDIS, the providers told you what you could have, when you can have it, if you can have it, no, you can't have it now. …The NDIS came along and the first thing I realised was that I was going to have choice. I could decide when I wanted something. And then the registered providers did the same thing. "No, you can't, you have to fit in with us, we know what's best for you". And I was so angry. Because what's the point? I'm self managed, but I was still hitting this brick wall of what I could and couldn't do.

As these quotes from Eugenie and Harriet illustrate, registered providers were often perceived to have a sense of knowing what was best for individuals and this led to a lack of control. As such, these organisations were often seen to lack flexibility in supporting individuals around the timing of services and choice of staff members, and to overly scrutinise all areas of a client's life. Interviewees spoke of registered providers having an 'agency rule book' with copious rules and guidelines that they were required to adhere to if they wished to receive services, such as strict cancellation policies and excessive occupational health and safety requirements, and that 'everything' needed an occupational therapy risk assessment.

An exception to this was Ivy, who had been using the same support worker agency since 1999. Her agency had become NDIS registered when the scheme was implemented in her state. She noted she had always received great services from them, with low turnover of workers: *"they're always obliging, care about me as I care about them, and it's a wonderful thing"*.

However, most participants felt disempowered by their experiences with traditional registered agencies:

> Lyra: My experience of traditional providers has been that- because if you're hiring from an agency, you're not in control of who's being hired and who turns up, you know, and they give you the option to get rid of people that you don't gel with. But the workers know that. They know that you're not the hirer. They're there to tick boxes, they're not there to please you.

A number of interviewees reported experiencing what they described as bad behaviour from registered providers. Examples of this included unreliability, unsafe practices, bad attitudes, pestering potential clients to choose their services, poor quality of work (e.g., cleaning), attending shifts while COVID-19 positive, charging for hours that had not been worked, difficulty having feedback heard, difficulty passing on messages, delays in report writing, and lack of choice in staff members. On the morning we interviewed Yasmin, she was caring for her son because a registered support worker had cancelled at the last minute. She told us she was also 'reeling' from having gone through a four-month consultation process with a registered provider regarding a housing option for her son, only to have them give the place to someone else just as her funding came through. She was now very wary of engaging with registered providers at all:

> Yasmin: It takes time to find the right fit and also, it can be quite mentally and emotionally exhausting because you're having to put in a lot of effort and I don't want to do that with a registered provider when I have been burned that many times. So, I think I could say there's a bit of trauma.

While it is important to note that bad behaviour is not restricted to registered providers, **many of our participants felt they received worse service from registered providers**. They explained the difference with reference to organisational size, organisational culture that disempowered people with disability, and profit-seeking behaviours as described below.

Cost and 'price gouging'
A very commonly cited issue with registered providers was cost and so-called price-gouging behaviours. Many large, registered providers charge the maximum allowed NDIS price as standard, which they are entitled to do given the additional costs associated with registration and audit. However, although interviewees understood that the higher prices of registered providers often stemmed from these kinds of overheads, many did not see the point in paying these higher prices given they perceived unregistered providers as offering equal or better service. As Ben told us of his experience with a registered provider, "I was paying top dollar and getting crap service". Interviewees often found that registered providers did not offer 'value for money', and that their plans would go further if they used an unregistered provider. For example, it could mean the difference between accessing physiotherapy once a week or once a fortnight.

Further, some felt that the extra cost of using registered providers was often simply profit-seeking rather than due to genuinely incurred overheads:

> Harriet: I'm having home modifications done, but by using non-registered, I actually ended up with a huge choice of companies to do my build. ...And it's come in $15,000 cheaper than the registered builder. $15,000. So, the government really needs to look at the rorting ...um, it's not rorting and it's not even corruption, it's just opportunistic. Money that can be spent just because a company is registered with the NDIS.

Several people also reported that registered providers were 'nosy' about their plans, demanding to see details of their funding so they could know how much to charge and what categories they could extract the most from.

> Wendy: [The physio] kept asking how much my funding was. Why would you wanna know how much my whole funding was? ...He was telling me, "oh, we can get the money out of this capacity building and one out of core", and I'm thinking, "leave me alone", you know.

> Leonie: ...we still get health professionals regularly asking us for our NDIS plan because they want to see how money, how much money we've got in our budget.

> Pernille: I was aware as an NDIS participant that I wasn't obligated to provide the details of my NDIS plan to those [cleaning] providers if I didn't want to, but they were very insistent and said that they couldn't deliver the services for me unless they had my NDIS plan, and kept specifically asking me for figures in terms of like how much in your plan can you allocate to this service, which I was really confused about. ...having spoken to other friends who are NDIS participants and who've had similar experiences, I've heard that they will actually, kind of based on what is in your plan, they would like increase their prices or like charge you the maximum price based on what your NDIS plan is.

Lastly, participants also reported more financial transparency when using unregistered providers, which allowed them to keep better track of what was happening to their funding. Typically, NDIS participants using unregistered providers would bear some of the associated administrative burden themselves through checking and paying invoices, however most participants described this as not necessarily being onerous, and in fact taking on this role gave them individual control and empowerment regarding the costs and processes associated with their plan budget. Further, a number of interviewees noted that using registered providers did not necessarily cut down on the amount of administrative work they were required to do.

Registered providers tend to be larger
The costs associated with registration mean that in general the organisations that can afford to go through the process are quite large. Participants often saw larger organisations as less desirable due to depersonalisation of services provided through a conglomerate of different departments and staff, and a perceived distance from their mission and values of providing quality support services:

> Caleb: Bigger companies that are trying to buy out all the small companies and getting bigger and bigger ...They just have no care for their workers and no care for their clients. They're just caring for the bottom line and that's it.

> Jill: With my non-registered providers, they know me, they know me well, whereas when you're with a big company you get a bit lost in that company. You're just more of a number and a profit sign, that's how I feel anyway.

Participants often explained that they found working with larger organisations to be unpleasant, due to the inflexibility and communication difficulties associated with the extra layers of management and bureaucracy.

> Ben: You've got people who have a direct relationship with you in your house, but you don't have a relationship with them because you deal with them via a third party, which is their employer. So the communication's indirect and they don't tell you things and it's frustrating ...so all kinds of shit went on.

Uniforms used by some larger providers could also be an issue for participants:

> Owen: I don't like to go out with people who are wearing a uniform, and I feel like a pet on a string.

Some of the larger traditional disability service providers are also run by religious groups, which was a problem for participants such as Owen who had negative associations with religious organisations.

Training is not always a good thing
While one of the positives often cited of registered providers is that staff are more likely to have undertaken some disability-specific training and have qualifications, a number of interviewees told us that this was actually a negative for them. Given that this training is generalist, participants felt that the staff often did not have specific knowledge related to their impairments or their goals and aspirations.

Most interviewees felt that they were able to better train staff themselves to deliver service in the way that best suited them (as Lyra said, *"I can train people myself for my needs"*). Moreover, some interviewees felt that where staff had disability training, they tended to believe they knew better than their clients, sought to 'improve them', or sought to impose particular ways of working on them.

> Andy: So, what I've found is that people's perceptions are that disabled people are all the same. And that if they supported another person with a disability then they know what to do. They try to take what they learnt about that person and try to impose it on you. And then you have to, like, untrain them. I'd prefer a clean slate. And for them to just, you know, learn what it takes to support me and not tell me what they think.

> Kim: I used to put physical notices up in the local area because I like getting people that haven't worked in disability before, so they're not super like enculturated into that kind of, like, 'I will save you', that horrible disability thing that sometimes people fall into. That works well for me. I don't need any very specialised disability knowledge and I'm articulate so I can teach people everything I need them to know, which is good for me.

> Lyra: I have not enjoyed previous experiences with agency staff at all. And you know, they're all qualified. They've all done certificates.

Why choose unregistered providers

In addition to the reasons not to choose registered providers, participants told us there are also a range of reasons why they actively choose unregistered providers. We focus on these in this section.

Better service
One reason given by many interviewees is that they feel they get better service from unregistered providers.

>Kayla: …this could be coincidental, but I get a better level of care from the unregistered providers. I get more feedback. I get more direct contact with the support worker themselves. Umm, I get immediate feedback. Whereas, with the registered providers it just feels like the bureaucracy's there and like they are…not afraid, but reluctant to give me all the feedback that I ask for.

>Owen: So, usually an unregistered provider or a small independent contractor … provides a higher level of service than a registered provider. A better level of care. More understanding. They listen more. They always seem to take on board a lot more of what you ask. And they have a bit more of an understanding of your requirements.

This assessment of quality extended to unregistered allied health providers and various therapy providers. Several participants reported these as providing better service with regards to both therapy and report writing.

Flexibility and stability
Better service was often about being able to determine when the participant receives services and which providers or members of staff they will work with. Having this choice enabled both the flexibility and the stability people needed to design good long-term care arrangements. Regarding stability, many people emphasised how important it was to have continuity of support workers and therapists, because good service was about rapport, consistency and familiarity. For example, they felt that utilising a registered support worker provider often entailed putting up with whoever was sent (often with high churn in staff), whereas utilising direct employment or sole traders meant more likelihood of being able to work with the same trusted people consistently on a regular basis. Other participants reported using the same providers for many years (including before the NDIS) and needed the stability of continuing to work with providers who knew their needs and understood their lives. Ivy had been working with the same unregistered physiotherapist, who was trained in a particular treatment modality that she required, since the 1990s:

>Ivy: There's no-one as qualified or expert in me, or experienced, and that's where unregistered is so important.

Regarding flexibility, choosing the timing of services was incredibly important for people to feel they had control over their lives:

>Wendy: …if they're registered they think they have, like, more control over your choice or your wellbeing. I've got a [support worker] coming today at 4pm. I like to take a shower between 4 and 6, you know, because that's my preference. If I'm with a registered provider, they'd be telling me what time they're coming. So, I'd have to work my life around them.

Claire was employed full-time and needed to use services on the weekend, but the only two registered providers for her disability did not operate on the weekend, so moving to unregistered providers had opened up her ability to access services on a weekend. Pernille needed to organise cleaning services at a particular time when she knew she would have the most energy to deal with people being in her house:

>Pernille: So for instance, with my unregistered cleaner I can be like okay please come in the mornings and please come for like X amount of time, whereas when I was looking

through different places that provided cleaners or support workers that were NDIS registered, they required you to have like a like a minimum shift of X amount of time, or you could only book like a support worker or something [at a particular time]. In which case the flexibility and the fact of not having those limitations or restrictions in using unregistered providers, for me has been quite beneficial.

Pernille also pointed out that NDIS participants may need maximum flexibility to receive services in a way that keeps them safe in the context of relaxed COVID-19 restrictions. For her, it was important to be able to engage hydrotherapy services at a time and place that minimised her exposure to other people, which required her to use an unregistered physiotherapist.

Flexibility was also about being able to organise services with support workers that aligned with people's lifestyles, goals and priorities. In some cases, individuals had sought out people who could deliver services to them who were from the same culture or linguistic background. In others it was a case of seeking out people who may have the same sorts of interests (such as going to the football or art galleries or recruiting a fellow university student), so they had something to bond over. It was important to work with someone they had a connection with and wanted to have around, particularly for community access activities. For example, Simone needed support to run a social group for people with autism, and she found it most useful to hire support workers she'd met through autism groups who might be interested in attending the group anyway:

> Simone: With the people that I've hired through the autism groups, it doesn't even feel like a support worker relationship some of the time.

Flexibility also meant participants being able to choose what support workers do, or set different tasks depending on support worker skill sets:

> Lyra: …different people are stronger at different things, so you can- you know, I've got some support workers who are really good at cooking, and some who are not. And there's the bulk meals and then there's just the helping. So I obviously get them to do different things. But an agency would just give them all the same role.

> Terry: [Independent workers hired through Mable are] more constant usually, more reliable, cheaper, more respectful and more person centred. Whereas I found with agencies, "Oh, we won't do this. We won't do that. We only assist, we don't do". …"We don't clean for participants, we assist" …"Oh, we don't care if you need after-hours support".

Lastly, flexibility meant being able to cancel shifts or appointments with fewer than seven days' notice, which was important for people with fluctuating impairments or complex health conditions. Participants reported that unregistered providers were often more willing to be flexible regarding cancellation arrangements and fees, as opposed to the stringent cancellation policies used by most registered providers:

> Ben: …sometimes people have to change their availability with me and I have to change it with them or they've got to pick up their kids or whatever it is or they're running late or finishing early. I'm trying to be flexible, but all I expect in return is the same respect in return.

Innovation
A number of respondents described how they could engage more innovative services with unregistered providers. For example, Yasmin's son loved water and she was looking for a therapist who could engage with him in a recreation centre or out in nature: "That would be really beneficial for him because you actually get some engagement with him when he's in the water". Further, he would not engage with therapy at home, and the constrained working hours of registered therapists did not work well with his non-standard sleeping schedule:

> Yasmin: Well, I find the [registered] therapy providers quite rigid in what they can offer, so they can offer you home visits. They can offer you school visits, but they do not like to offer you sessions in the community. So I'm thinking an unregistered therapy provider might work …because they are also not allocated 9 till 5 so they may do things after 5. They also might consider doing something over the weekend and not just a Monday to Friday like a registered therapy provider. And they're willing to go and do sessions out in the community.

Likewise, Fern had engaged an unregistered provider to help her son "achieve his goal of becoming a published author". This provider supported her son to write and organised the printing and publication process. As such, this is a highly specialised service:

> Fern: And he's got another two books coming, so that wouldn't have happened if we couldn't use non-registered providers. …There's no registered providers doing that kind of thing.

Caleb had devised a new method for transferring in and out of his wheelchair, and he found that people with disability training tended to insist on using a hoist. Therefore, he preferred to use unregistered providers who would work with him to learn his preferred transfer methods.

Thin markets
A number of interviewees talked about using unregistered providers out of necessity. This was common for participants based in regional or rural areas, although we also encountered participants from metropolitan areas who spoke of the existence of 'thin markets'. What this means is a lack of suitable and available providers in their local area – either not enough providers, providers with large waiting lists, or providers not offering quite the services participants needed. Many participants mentioned supply issues with support workers, citing reasons such as health and immigration issues stemming from COVID-19 and related restrictions, and a porousness between the disability and aged care sectors. Participants also mentioned extremely long waitlists for most registered allied health providers, particularly occupational therapists, speech therapists and psychologists. Registered allied health practitioners were also often described to be inexperienced graduates who did not possess the necessary skills or experience for specialised needs. Market failure could also stem from exclusion of complex clients, and large registered service providers 'cherry picking' participants with large plans or those who were 'easy' or 'lucrative' to serve:

> Simone: I actually did approach one large provider, [provider name], but they said a minimum of 15 hours a week of support, and I had nowhere near that much funding. …they're a registered provider. But that was my sole attempt to engage with a with a larger provider. So that didn't work out.

> Terry: There's lower supply than demand so [registered agencies] can choose the easier clients that don't need as much help and charge them a fortune.

A lack of providers means that if they were only able to purchase services from registered providers, some people would go without services given the paucity of provision in their local area:

> Gabrielle: …we'd be stuffed because unless they made the registration process a lot easier, we've already got such a thin market out here that we wouldn't be able to get any supports at all.

> Fern: And if I look around [my area], there are actually lots of towns here, although we have a large population base, there's lots of towns that have no registered providers at all. None. So if they force us to only use registered providers, that then means that everyone living in those areas potentially misses out on any support at all.

A related issue was that some disability types, such as vision impairment, have such a small cohort and such specific needs that if people were required to use registered providers, there would only be one or two options. Therefore, exercising choice meant using unregistered providers:

> Claire: I think it's really important for participants to have choice and control over who provides their service, and I think anything less really doesn't underpin what the NDIS says it stands for. I guess in the blindness field there are two very predominant service providers who have probably 85 to 90% of the market share.

Inclusion and community support
Other interviewees spoke about a desire to support local businesses or their local community. By buying services from unregistered providers, they could employ people who are local to them and who understand the area. This also can cut down on time spent travelling by support workers.

Lyra: I think the flexibility of being able to hire people who are really local and really close means you've got people who attend 15 minutes, 5 minutes. I've got a couple of people who just walk across the road. So they'll come and help, and if they can't help you for the full time, they'll help you with your urgent needs. Yeah, because you know, it's a good little income for them as well. So it's very win win.

For those purchasing services like gardening or maintenance, there was a strong theme related to inclusion. In using unregistered providers, individuals do not have to identify as a person with disability.

Leonie: …there are genuine benefits for full community inclusion to use unregistered providers as well. We're not having that segregated system of, "oh, you're an NDIS participant. I'll charge you this amount". If I can just employ people, it's none of their business how we're paying for it.

Wendy: I just have more faith in [unregistered providers] when it comes to it, and I feel more part of the community as a whole than the disability community.

The flexibility to pay less (or even more)
Many interviewees spoke about choosing to buy services from unregistered providers because it can be cheaper and can make their plan go further, which can be important in the context of their funding being reduced. Harriet told us she needed to use unregistered providers to make up for having gone from $80,000 in her first year to now $150,000 over three years: "So, if you think about how much they've chopped off my plan, I wouldn't have any of the things I'm doing now". Another participant reported:

Fabio: I've spoken to people whose plans were very small and where they can't buy the assistive technology stuff that they need to get because if they did, they'd run out of funding for support and some of those people use unregistered providers for that very same reason.

Some participants also described wanting to lower their costs to be more responsible taxpayers and reduce waste. Unregistered providers were described as being more willing to negotiate their rate and less likely to charge the maximum price in the NDIS Price Guide (and as described earlier, some types of providers need not even know their fees were being paid through the NDIS).

Conversely, some participants also appreciated the flexibility to pay more than the NDIS Price Guide for unregistered providers who had particular expertise they required. For example, Jill purchased services from a physiotherapist whose expertise in the neck and jaw area supported her to continue being able to eat and talk. She reported that he was expensive, but that no registered physiotherapists had the same skill set. Another factor participants appreciated was the ability to pay support workers at a higher rate than they would receive if they worked for a registered provider, but still pay less overall because none of the fees were going to a company. This was seen as a win for both worker and client.

However, some interviewees did report that unregistered providers can try to charge the full NDIS Price Guide rate despite not incurring the overheads associated with registration. Others warned that care has to be taken in working with unregistered providers to ensure that all the appropriate processes and insurance are in place. For instance, Neil worried that insufficient funding could drive people to cost-saving behaviours without appropriate evaluation of the risks involved:

Neil: …it's because there's a lack of appropriate funding generally, that means people have to then try and save money through using unregistered providers. Which potentially could be a risk because they may be cheaper simply because they don't have insurance.

Things to think about in working with unregistered providers

One of the topics we asked interview participants about was what actions they take in order to ensure that they and their workers are safe and that they receive quality services. Interviewees reported engaging in a series of different management activities, many of them particularly relevant for using unregistered support workers. While we do not have scope here to go into detail regarding all the activities raised during interviews, people reported using techniques and processes such as:

Hiring
- Recruiting through known networks
- Recruiting for rapport and skills rather than qualifications
- Conducting meet-and-greets and interviews
    - Having the confidence to say no if there are red flags or if something does not feel right
    - Conducting two rounds of interviews – one off-site and one in the home
- Checking references
- Checking insurance and qualifications, if relevant

Training and onboarding
- Putting in place written service agreements
- Communicating expectations of support interaction early and clearly
- Supporting sole contractors to get an ABN, create invoices, and organise insurance and superannuation
- Training staff using
    - Documentation
    - Videos
    - Buddy shifts
- Having trial periods
- Making sure all arrangements are in writing

Ongoing arrangements
- Using software and apps:
    - Specialised: Plan Tracker, Podio, Ability8, myNDIS
    - Universal or free: Excel, Google Documents, Google Sheets, Google Calendar
- Having support workers text upon arrival and departure, to ensure clarity of hours worked
- Checking all invoices (even if plan managed)
- Having a back-up plan in case of support worker cancellation
- Communicating clearly and often about how things are going

Resolving problems
- Having 'tough' conversations (e.g., if there is an incident, asking support workers to write down what they did wrong and what they would do to prevent this in the future)
- Not being afraid to let support workers or providers go if something does not feel right (i.e., not waiting for quantifiably bad behaviour, but trusting intuition)
- Reporting a support worker to the NDIS Quality and Safeguards Commission if there has been a serious incident

At all stages, participants recommended tapping into wider disability support networks for advice, through channels such as social media. Facebook groups were frequently mentioned as being a useful resource for finding providers and navigating the NDIS more generally.

Different models of support worker employment
Not all participants used unregistered support workers. Some reported using registered online platforms such as Hireup or Humdrum (a Western Australian online platform that connects NDIS participants directly with providers). Participants often used a combination of registered and unregistered providers including sole traders and support workers from platforms such as Hireup. As these platforms are registered, some of the requirements (e.g., police checks, wages and training) may be done by the platform. Some saw this as a way to mitigate the perceived administrative burden, risk or confusion associated with hiring unregistered providers, while still giving clients more control and

avoiding traditional or larger agency provider models:

> Kim: I spent 20 years trying to get away from traditional providers. That's not what I want. I want a model [that] gives me choice and control and also gives the workers some protections. Surely, we can have both of those things at once. Like, we shouldn't have to throw workers under a bus just to be able to help us as well.

For example, some participants felt that the guidance from the NDIA or the Australian Taxation Office was not clear enough for them to understand their legal obligations in hiring unregistered support workers or did not trust that sole traders would have appropriate insurance. Others did not have the confidence to hire unregistered support workers:

> Kim: So, then they have the benefits, superannuation and all those things, through Hireup. So, I think that's better for everybody and safer. And I don't have to worry about do they have insurance or, you know, whatever.

> Pernille: I don't feel confident enough necessarily to say like find support workers and kind of navigate that kind of stuff, like it kind of feels like, in regards to support workers, having an organisation [such as Hireup] there as like an intermediary is kind of like a safety net I suppose, or like it kind of alleviates the administrative burden, perhaps you could say.

While many interviewees used sole traders, Fern preferred the direct employment model, and raised a note of caution around hiring sole traders without knowing if the support worker had included tax, superannuation and insurance costs in the hourly rate that had been negotiated:

> Fern: I personally don't like the idea of paying support workers as contractors. I feel like that's less safe and it doesn't look after that support worker very well. …I see people saying it's not private and it's not domestic, so I don't have to pay superannuation. Well no, because you're not paying out of your own pocket. This is taxpayer money. This is not your personal money, it's not private and it's not domestic. So that lack of understanding around that is problematic.

Administrative burden
The high administrative burden of engaging with the NDIS has been well documented from both the client and provider side.[12, 13] This is certainly true for self managed and plan managed participants compared to agency managed participants. Dealing with providers can entail significant administrative burden, whether the providers are registered or unregistered. In this context, interviewees often felt that the administrative burden associated with using unregistered providers was not necessarily higher. For those with plan managers and support coordinators, they often did not notice the difference between registered and unregistered providers. Some participants reported a steep learning curve, but felt that with greater experience, system improvements and new technologies such as software and apps, their day-to-day administrative experience became relatively smooth:

> Eugenie: There's lots of things easier now than it was when it was first set up in 2018, but I probably would spend, in both the paying and claiming and organising, probably no more than an hour a week. At the most it would be five hours a month and that might be because we're doing some ordering of stuff or I filed the invoice in my inbox in the wrong place or you know, something like that. But the app that they've released, I can do it all from my phone now because I've got internet banking, I've got my e-mail on my phone and I've got the NDIS app on my phone.

> Anh: I've got a system. I've been doing this for, like, five years or so, so I kind of, you know, just have a system. …it's not long at all. Again, I don't use that many providers. I have a few. So it's not really like I have many different types of invoices and I'm generally just on top of that admin side of things 'cause like, I enjoy it.

Some participants reported more complexity and administrative burden associated with direct employment of support workers but felt that this trade-off was worth it for quality and reliability of service. However, they did note that this more intensive option would not work for everyone, and some interviewees also felt that direct employment would be too complex and burdensome for them. Some participants suggested hiring an accountant to help with initial set-up of small businesses for direct employment.

> Ash: …once you set up it's fairly easy. But setting it up takes a bit of time and can get a bit complicated

We should note again here that we only interviewed people who currently use unregistered providers, which would exclude those who might find using unregistered providers to be too administratively burdensome. However, we can conclude from these insights that using unregistered providers does not necessarily entail more work, depending on the plan management arrangements, support needs and individual capacities of the participant or plan nominee.

Setting and negotiating rates
Participants who used unregistered support workers had a number of different techniques for determining and negotiating rates. They often used benchmarks such as the Social, Community, Home Care and Disability Services Industry Award (SCHADS Award), the NDIS Price Guide, or rates published by platforms such as Hireup to inform their decisions. Some people described offering a figure somewhere between what participants would be paying a registered provider and what a support worker could expect to receive as take-home pay if they worked for a registered provider, to ensure a 'win' for both sides. They often reported adjusting for factors such as experience, skills, age and length of service. For example, some increased their workers' rates on a yearly basis. Some paid higher wages to keep or reward valuable workers, or on an ad hoc basis to compensate for only needing short shifts of 1-2 hours, or to incorporate travel time. Sometimes it was a case of support workers setting their own rates and participants agreeing to those if they felt the rates were reasonable. This flexibility in setting rates was seen as very important for participants to be able to organise services in the way that best suited their needs and lifestyles and retain good support workers with wages that acknowledged the skills they brought to the role.

For non-disability specific services such as cleaning, gardening and some types of allied health, some participants recommended not mentioning NDIS funding at all and just asking for regular invoices so as to obtain the standard price for a service.

Dignity of risk
Participants felt there could be no guarantees about safety. While interviewees generally acknowledged some risk inherent in purchasing disability services – particularly from support workers, who often work in people's homes and perform intimate tasks – many genuinely did not feel more at risk purchasing those services from unregistered providers. Further, some felt that it was important to be able to choose the level of risk they felt comfortable with rather than have it dictated by externally imposed standards:

> Lyra: I would see it as a dignity of risk thing. Like, I'd prefer to choose who's in my life than have the people that the police checks deem are safe pushed onto me.

> Claire: I think that I know what keeps me safe. I can train my staff in the ways that work for me. And I don't think that in my situation is any better than what the NDIS can legislate for me.

> Ash: I'm really scared to have my autonomy taken away again because it's already taken away so much because of disability. …this will be one more way they take away my autonomy and say, you know, "we're going to make your choice for you, because we don't think you're enough of a person to make it yourself", and I am. I can't physically do things and I'm autistic and I have ADHD and a whole number of other things, but I don't need somebody looking out for me. I've been doing that since I was 16.

All service delivery activities with humans are co-produced between the service provider, the person delivering the service and the recipient. A number of interviewees therefore spoke about having a role in ensuring the quality and safety of services and being able to take the level of risk that they felt comfortable with at any point – keeping in mind that no service delivery is ever completely free of any risk.

The interviewees we spoke to for this project strongly agreed that NDIS registration is no guarantee of the quality or safety of NDIS-funded services. In fact, many reported that they used unregistered providers specifically because they felt able to secure safer and better quality services more tailored to their needs through this route. Therefore, a key lesson seems to be that NDIS participants should continue to have the option of purchasing services from unregistered providers. However, there are several ways forward that may improve safety, clarity and quality in purchasing services from unregistered providers.

Key lessons and potential solutions: improving the quality and safety of NDIS-funded services

Capacity building for NDIS participants

Most interviewees reflected on the fact that at present, the system seeks to ensure quality and safety through its focus on the providers of services and worker screening. But there is less of a focus on the co-producers of these services – the NDIS participants. There is little formalised support in the way of capacity building for NDIS participants and plan nominees. As discussed earlier, **no service is or can ever be risk free**. A number of interviewees felt that within the current system some individuals were taking risks of unknown quantities as they did not know what should be expected or who to turn to in the case of an issue. Some individuals may have a support coordinator who can do some of this work, but not everyone has funding for a support coordinator, and quality is reported to vary. In some cases, plan managers may be involved in doing some of this work, but again this does not apply to everyone, and some people reported that plan managers could be gatekeepers regarding spending or service choice. Since the establishment of the NDIS there have been cuts to advocacy services in many areas of the country and so not all NDIS participants or plan nominees know who to ask for advice about issues relating to services or what to do if something goes wrong. For example, Pernille reported having difficulties trying to talk through issues related to unregistered providers with her very busy Local Area Coordinator (LAC):

> Pernille: ...when I have questions I tend to just email [my LAC], and she's lovely, and at the same time, like oftentimes she'll just be like ohh Pernille check the self management guide, here's a link to the guide. And I almost wanted to reply and be like thank you, but I find the prospect of reading through that whole booklet both overwhelming and also like often unclear. And kind of vague. So I wanted to have an actual conversation with an actual person so that it would be less overwhelming and I would kind of achieve more clarity.

Building the capacity of NDIS participants and plan nominees so they are clear what should be expected of services and what to do in situations of bad practice or misconduct would be a good way to help with quality and safeguarding issues across both registered and unregistered providers. Further, empowering participants and nominees to better operate choice and control over their services would have broader benefits for the overall effectiveness of the scheme.

For example, Eleni felt *"there needs to be more education and skill building in helping people to be able to discern and reflect. It's not a skill that's taught"*. Similarly, Claire suggested *"empowering participants and the support networks around participants to have more idea of their rights but also making it clearer cut and making it easier"*. Lyra suggested it would be useful for the NDIA to provide training for NDIS participants on practical elements of support worker organisation such as rostering and calendar maintenance. She also suggested resources empowering people with disability to respond when support workers are behaving in abusive or controlling ways. Another idea was a basic guide for hiring sole traders, written in plain English and with clear statements on legal parameters of utilisation, and with links to documentation with more detailed information where necessary. As Caleb commented:

> Caleb: ...there's no kind of simple NDIS cheat sheet for if you're going to employ an external contractor ...A four page or two A4 pages is what you should expect to be provided. There's nothing like that. It's all spread out over 120 pages of NDIS gobbledygook.

It has been well documented in the research literature that the role of LACs is operating in a different way to that initially envisaged within the design of the scheme.[14] LACs could play a helpful role in building the capacity of participants and nominees and have a good understanding of the local service context.

> Fern: ...if you're going to do local area coordination, do it properly, not someone who's just tasked with drafting up a plan that they can't even make a decision on. You know,

we're just winding up with two separate gatekeepers to the supports that we need. If you're going to have an LAC, why aren't they checking in with you regularly to make sure that you're okay? That your supports are meeting your needs, that your service providers are doing the right thing? That's missing, that role.

As Fern is describing here, as the system operates at present there is no requirement for NDIS staff to check in with participants and so we do not have a sense of whether people are being appropriately supported or whether issues are arising.

Capacity building for sole trader support workers

In addition to building the capacity of NDIS participants, there is further work that could be done on the provider side. Several participants described frequently encountering young or inexperienced support workers through unregistered platforms such as Mable, who expected to charge Price Guide maximum rates (intended for registered providers) and had little idea of how to operate a small business. Participants felt that the current support worker scarcity, driven by COVID-19 related market turbulence as discussed earlier, facilitated such behaviour. Conversely, some participants mentioned needing to explain to workers how to charge high enough rates to cover insurance, superannuation and tax obligations.

Consequently, development of the sole trader market could be beneficial, through such mechanisms as targeted training or plain English resources made available through the NDIA and/or ATO. Such development would need to include reasonable pricing expectations based on experience, qualifications and registration status, and sole traders' obligations with respect to invoicing, tax, superannuation, and insurance.

'Light touch' registration for support workers

One option for support workers specifically could be a process of registration that is light touch, in that individuals sign up with their details and demonstrate that they have no criminal record. The NDIS Quality and Safeguards Commission does have a worker screening system, which is required for registered providers and voluntary for unregistered providers. It is operated via the various States and Territories, although uptake is low in some areas. While the scheme is national, worker screening happens at the level of states and territories, meaning the process has to be repeated if workers or participants move across jurisdictions. Most interviewees did not mention any form of screening service so it may not be well understood or utilised. Kim reported exposure to the service through registered platform Hireup, and felt it led to delays (for example it may not be suitable if someone needs to engage a support worker at short notice). Fern also talked about the system but said it was 'arduous' to gain access to the database.

'Light touch' registration is an option that Leonie, who was the plan nominee for her husband, told us she would appreciate going forward. She had a very negative experience with an unregistered support worker who had abused the family's trust and NDIS finances over many months. He eventually became abusive and threatening, and she took out an intervention order against him and reported him to the NDIS Quality and Safeguards Commission. However, Leonie was still willing to consider using unregistered support workers: "I suppose I'm not so much thinking about registered versus unregistered. I'm just thinking about dodgy versus not dodgy, and I don't think being registered means you're not dodgy." In this case, the support worker had actually worked for a registered providers in the past without reported issues, before setting up as an unregistered provider. Leonie felt that what she called a 'semi-registered' option would allow her to complain more easily to the NDIS Quality and Safeguards Commission if things started going wrong, because there would be a central record of who the support worker was.

Jill, who disliked registered agency providers but needed to hire people who had first aid training, suggested something similar like a 'governing body':

> Jill: Something that I've been thinking about and talking to others about, with support workers, not having them have to be all registered, but having a body like AHPRA, the one that regulates allied health professionals. Something where all support workers, no matter how they work under NDIS, they don't have to be registered but they have some

kind of body where they get a number or something, and if they join it they have to have first aid, all the checks, and if there's an issue you can report them so they don't get lost in the system like a lot of unregistered ones do.

Such an approach may have additional positive implications. For example, one of the concerns raised during the COVID-19 pandemic was a lack of information about who was employed to perform support work, meaning it was not possible to quickly disseminate information around infection control or use of appropriate protective equipment.[15] Such a register would provide a means to do this and also have the potential to mobilise a workforce response in the event of widespread illness in an area.

This kind of light touch approach might be situated within a tiered approach to registration with different expectations and requirements according to the characteristics of the organisation. Given the anecdotal evidence for how useful NDIS participants find it to use unregistered providers, we expected to collect many interesting and detailed accounts of this practice through our research. But we were surprised by the intensity and enthusiasm of the response: we received enough enquiries to fill our interview slots within hours of first advertising the project. Often interviewees shared not only their own opinions, but broader opinions they perceived through being embedded in the disability community.

The message we received from our interviews was that for this cohort of NDIS participants, they find it not only desirable to purchase services from unregistered providers, but often essential. Interviewees described many push and pull factors – reasons they disliked or preferred to avoid registered providers, and reasons they preferred or even required the services of unregistered providers.

Conclusion

Push factors included negative experiences with or perceptions of registered providers, often relating to the kinds of services they had received in the "bad old days" of pre-NDIS block funded services, where they received little or no choice in service provision. Participants' reasons for avoiding or disliking registered providers included bad behaviour, incompatible 'deficit' culture, inflexibility, 'price gouging', and a dislike of large organisations.

Conversely, pull factors included perceptions of better, more person-centred service, flexibility, innovation, social inclusion, and improved cost effectiveness associated with using unregistered providers.

Thin markets also contributed to these decisions: an overall lack of providers, long waiting lists, or a lack of registered providers with the required expertise meant interviewees often had no choice but to use unregistered providers. Participants described market turbulence resulting from COVID-19 and related policy changes affecting the supply of support workers in many areas.

Another surprising finding was the strength of participants' reactions when we asked what the impact on their lives would be if they were required to use only registered providers. Nearly everyone mentioned inconvenience or hassle, but beyond that many used phrases such as *"it would be absolutely devastating"* (Davina), *"I'd lose everything"* (Harriet), *"I would be extremely upset about that and cause a huge fucking ruckus"* (Kim), *"it would be chaos"* (Gabrielle), *"[makes] me feel sick in my stomach"* (Yasmin), *and "I get anxious just thinking about it"* (Owen). This indicates the importance of unregistered providers in the lives of these participants and their families.

Ultimately, the ability to use unregistered providers is about exercising choice and control through the NDIS. Consequently, the implications and possible solutions we have set out are centred around preserving the two kinds of providers in the disability service market and allowing NDIS participants the 'dignity of risk' involved in choosing freely between registered and unregistered providers. Our findings indicate that both clients and providers may need support to safely navigate the unregistered provider space, so we suggest improving capacity on both sides to understand their options, rights and obligations with regard to operating in the open market. In particular, capacity development of NDIS participants is likely to have positive implications far beyond the unregistered provider space and support better outcomes with regard to the scheme as a whole.

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Appendix 1: Interview schedule

- What motivated you to participate in this research?
- How long have you been an NDIS participant/plan nominee?
- Can you recall when you first purchased services from an unregistered provider or independent contractor? Or when did you begin with direct employment?
- Have you used registered providers?
- Why did you want to use an unregistered provider or independent contractor?
- How do you find unregistered providers or independent contractors?
- How many unregistered providers or independent contractors are you currently using? [Approximately what percentage of your plan would this be?]
- What has been your experience in using unregistered providers or independent contractors? [Prompt expectations, quality of service, admin burden, staff recruitment, staff turnover? Interested in difficulties]
- Have you had to negotiate and manage any difficulties in using unregistered providers or independent contractors? [Prompt abuse, poor quality, nonattendance, mechanisms used]
- How have you negotiated wages for the workers as a part of this experience?
- Overall, how have you felt about making the decision to use unregistered providers or independent contractors or direct employment?
- What piece of advice would you give to someone who is thinking about using an unregistered provider or independent contractor for the first time?
- If the government decide to make all participants use registered providers, how would this impact your life?
- Is there anything else you want to tell us about unregistered providers or independent contractors?

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