

Self Manager Hub Position Statement -NDIS Review Final Report on recommendation 17.

About the Self Manager Hub

The Self Manager Hub is the leading organisation representing people who self manage their NDIS plan. We are building our profile as a national peer-led organisation promoting self direction and supporting the practice of self management so that people with disability can lead the lives they choose. We believe self management is key to the success of the NDIS by driving innovation in the sector.

Our purpose is to:

- educate and raise awareness about self-management and how to exercise choice and control over our supports so that we can uphold our human rights and live the lives we choose;
- share knowledge and experiences of self-management in order to inform policy and government decision-making.

We provide information and resources on self management and self direction, run regular peer network meetings and admin a Self Manager Hub Facebook page with 15,400+ members who self manage NDIS plans.

We thank the many members of the Self Manager Hub community who have shared their experience and contributed to this submission.

Background

This Submission looks specifically at <u>NDIS Review FInal Report Recommendation</u> <u>17</u>. We note other recommendations also concern us, however recommendation 17 poses the most significant threat to participant choice and control and the human rights principles of self-determination and autonomy upon which the NDIS is built upon. specifically Article 3 – General principles of the UNCRPD¹

NDIS Review Report Recommendation 17 is "to develop and deliver a risk-proportionate model for the visibility and regulation of all providers and workers, and strengthen the regulatory response to long-standing and emerging quality and safeguards issues" (page 216).

NDIS Review Action 17.1 says "[t]he Department of Social Services and the new National Disability Supports Quality and Safeguards Commission should design and implement a graduated risk-proportionate regulatory model for the whole provider market", followed by Action 17.3: "[t]*he Australian Government should amend the National Disability Insurance Scheme Act 2013 to remove the link between a participant's financial management of their plan and the regulatory status of their support providers*"

In plain English this recommendation is that all providers will be required to either be NDIS registered or enrolled to deliver services and support to NDIS

¹ The principles of the present Convention shall be:

[•] Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

[•] Non-discrimination;

Full and effective participation and inclusion in society;

Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

Equality of opportunity

Accessibility

[•] Equality between men and women;

[•] respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

participants. The Report says the intensity of regulatory requirements of registration or enrollment would be determined by the risk and complexity of different supports and providers.

The Report recommends 4 levels of registration or enrollment with accompanying provider obligations:

1. Advanced Registration - high-risk supports (e.g. daily living supports in group homes).

<u>Provider obligations</u>: NDIS code of conduct training, NDIS Worker Screening Check, subject to complaints process, incident reporting, practice standards, performance measurement, in-depth audit, suitability assessment of provider and key personnel, ongoing monitoring and compliance.

2. **General Registration** - medium-risk supports (e.g. high intensity daily personal activities, complex bowel care or injections, and supports with significant 1:1 contact with people with disability).

<u>Provider obligations</u>: NDIS code of conduct training, NDIS Worker Screening Check, subject to complaints process, incident reporting, practice standards, performance measurement, proportionate audit, suitability assessment of provider and key personnel, ongoing monitoring and compliance.

- 3. Basic Registration lower-risk supports (e.g. sole traders, smaller organisations, social and community participation supports, and supports with more limited 1:1 contact with people with disability). <u>Provider obligations:</u> NDIS code of conduct training, NDIS Worker Screening Check, subject to complaints process, reporting of incidents, simplified practice standards, performance measurement, suitability assessment of provider and key personnel, ongoing monitoring and compliance.
- Enrolment lowest-risk supports (e.g. consumables, equipment, technology, home and vehicle modifications, gardeners and cleaners).
 <u>Provider obligations</u>: NDIS code of conduct training, NDIS Worker Screening Check, ongoing monitoring and compliance.

This recommendation effectively mandates that all NDIS participants use registered or enrolled providers for NDIS support.

Why do we choose to self manage?

We wish firstly to discuss why empowerment, choice and control is so paramount for participants. To meet our diverse disability related support needs, we need to ensure we have the *right* support at the *right* time, delivered with the *right* skills by the *right* person. Let's add the *right price* to these requirements. This enables us to meet our support needs with the full range of possibilities in our communities, enabling us to innovate and find creative ways that save us (and the government) money while still giving us quality goods and services.

This means we can access the same goods and services available in the community as everyone else to meet our disability related support needs. From the the local welder to fix the wheelchair footplate, the surf life saver to assist a young person with disability at the pool, the support worker in a small town to assist a person's inclusion in a family wedding, the neighbour to support a person to join their family in Ramadan celebrations, the purchasing of continence supplies from the local chemist at a discount price.

These are not 'lesser' quality supports. These are local, trusted relationships matching our specific individual disability support needs, but not isolating us to 'disability service land'. They may also be our only option to access the support as in many areas 'registered' options do not exist, are unavailable or not well matched to the support we require. "The supports that fit with my need to build or maintain functional capacity are individual /one person providers They are just providing the best possible service for the entire community, not necessarily disability clients. eg a dance teacher specialising in falls prevention". (NDIS participant)

"I want to keep the right to use unregistered NDIS providers. It allows me to choose the right provider for my disability/impairments, because NDIA just doesn't get my disability, and keep the cost as low as possible". (NDIS Participant)

Innovative supports that are mainstream, that help build my capacity.... my grocery delivery subscription (much cheaper than support worker doing my shopping and I'm actually doing it, I want to do my shopping)". (NDIS Participant)

With the bureaucratic burden of enrollment or registration to engage these services, they may not be provided at all. We will have to wait for the foot plate to be sent off to a 'NDIS registered provider'. We will not get to participate in Ramadan, go to the pool when it suits us, or connect with our communities without stigma, or the privacy concerns and sharing knowledge that we are NDIS participants, therefore increasing our risk of potential exploitation or price hiking.

"I don't want my gardener or cleaner to know that I am an NDIS participant. That is none of their business. That [is] between me, my family and my health team. The minute they hear that you are an NDIS participant they want the NDIS number, increase the fees and try to force their own service agreement and terms and conditions. No thanks. I want to be treated like every other citizen." (NDIS participant)

"The minute they hear NDIS I am no longer a person. I'm a disabled cash cow made for milking and walking over." (NDIS Participant)

""My physio doesn't need to know I'm paying them with NDIS funds. If I can get the same specialist skin tape or dressing from Amazon US for 40% less than an NDIS registered aged/disability care provider... why wouldn't I?" (NDIS participant) Self managers have learnt through experience and practice, we have tested the market for available, consistent and responsive services and voted with our feet. We have often not been able to achieve workable arrangements with registered providers. For example, support offered where we have no choice over the worker providing support, times available that do not suit our life, no say in the cost or flexibility of that support including worker suitability. In response we have developed our own cost effective, individualised and safeguarded arrangements which we rely on to have our support needs met².

"I self manage my son's plan so we can directly employ support workers and a lifestyle coordinator. We recruit, train and supervise workers and have direct influence over culture and practice within the support team. This enables my son to have supports tailored to his needs, supporting him to be actively included in the community," (Plan nominee)

"I can make more informed decisions and feel safer with independent workers. I no longer have vacant shifts and uncertainty. I can buy consumables on a genuine special. I can use my NDIS funds in a way that actually enables me to be part of the community." (NDIS Participant)

"People need to be able to choose who they want to support them. Some will want registered providers and others like myself will prefer to employ directly from my community and do not want career support workers. Direct employment has allowed for recruitment of people with interests and skills that match needs and have not been indoctrinated by service providers mindsets" (Plan nominee)

Many self managed participants have chosen to directly employ/engage support workers. The term "directly" is really important here. It means that we have a direct relationship with the workers who support us, without a third party gatekeeping or determining the terms of the support arrangement. We are empowered to design the support arrangement that suits us.

² Dickinson, H., Yates, S., & West, R. (2022) Exercising meaningful choice and control in the NDIS: Why participants use unregistered providers. Canberra: University of New South Wales, Canberra.

"We employ our sons' support workers because their needs are complex and they require consistency and trust. Not just whoever the registered provider decides to send. We have built a strong team for them who are committed to supporting them people we trust and our sons' trust. Employing has given us the opportunity to look outside the box and find staff who enjoy the support from us as a family, work with us as a team and prefer the regularity of work." (Plan Nominee)

"My daughter (and me as her nominee) directly hire support workers as employees with payroll, superannuation, PAYG and STP reporting. We have been doing this for 14 years because the support workers and providers have loyalty to my daughter and not any other parties. They have commitment and regard for my daughter, know and understand her well. We see improvements and outcomes because the focus is solely on my daughter and no-one else." (Plan Nominee)

These arrangements are significantly more cost-effective and deliver a high standard of individualised support³. Where directly employed, support workers are typically paid at higher hourly rates than through a registered provider, with tax managed, superannuation, worker insurance and training provided, all at a cost significantly less than the NDIS benchmark pricing.

"I need flexibility and choice to make things work. I need to be able to incentivise early starts and difficult shifts. I can take the administration component that would have gone to the provider and make sure that my workers have great pay and conditions. I can't do that with a registered provider. I have worked out an individualised solution that works for me. Please do what you can to help me and other people who have individualised arrangements to maintain these". (NDIS Participant)

"I choose my own supports and they are self-employed and they are the best supports I have ever had. I know who I am getting and when I am getting them. Big Providers send anyone who is "free". I do not want strangers doing my personal care and how dare the Govt says I must! Plus, by using self-employed, they are a lot cheaper than the big providers so in fact, I am stretching my funding further and saving the NDIA a heap of money!!" (NDIS Participant) Self management has been vital for NDIS participants in regional and remote areas of Australia where there are thin markets with little or no availability of registered providers. Many towns in regional and remote Australia have no registered providers at all, meaning access to unregistered providers in these areas is vital to having any support. Given many providers work across other systems, within the mainstream consumer market, it is unlikely they will be interested in registering specifically to enable them to provide support to a separate cohort of NDIS participants (e.g. a small town sole trader nurse who provides drop-in support across in-home aged care, disability personal care and medication support and worker's comp injury recovery support). If required to NDIS register they are more likely to leave the NDIS market, thereby exacerbating already thin NDIS markets.

"There are no NDIS registered providers in my town. I need access to unregistered providers or I have no support at all. There are so few NDIS participants in my town that there is no incentive for them to register or enrol. They would just stop supporting us." (NDIS participant)

"Mandatory provider registration will be catastrophic for people in regional and remote Australia. There are not sufficient NDIS participants to warrant providers going through any form of registration / enrolment process. They will refuse to do it, and we will lose all support. Further, our supports will cost a great deal more". (NDIS Participant)

Implementing Recommendation 17, as it stands, will be a significant barrier to participant choice of the providers and all the benefits that we achieve by self managing our NDIS plans.

The Problem Posed by Mandatory Registration

1. <u>Removal of the right of everyday citizens</u>

Recommendation 17 potentially threatens participant choice and control and the human rights principles of self-determination and autonomy which the NDIS is built upon.

If this recommendation is implemented by the government, NDIS participants who choose to self direct their support through self-management and plan management will lose the right to engage unregistered providers. This will remove the opportunity for us to utilise our whole communities, flexibly accessing the right support or solution and deciding who provides support to us. In its place, it proposes a service system-centric safeguarding framework that all participants will be forced to fit into regardless of individual need, self-safeguarding capacity or circumstances. This approach makes the participants fit into the system, rather than the system fit the participants.

Further, if this service-centric approach is implemented as in Recommendation 17, an individual participant will likely be interacting with multiple providers with different levels of registration/enrolment with different provider obligations and processes, making it more complex for us to act as well informed consumers or directors of our own supports. It has the potential of bureaucratising the lives of people with disabilities whether we want or need it or not.

"[T]his change will bureaucratise people's lives unnecessarily and stifle many innovative, reciprocal and low-cost initiatives that have been working very well for people. Many of us place a higher value on character, commitment of a support worker we find for ourselves and trust, than on the training and mindset a worker will likely acquire at a registered service. I have real concerns that my family member's complex needs will bump his required provider registration level up so high that we can no longer use people we've trained ourselves and want to retain". (Plan Nominee) "It is against human rights to force us to use all registered providers. We will lose good supports, it will cost more, they may not be able to be replaced, we will decline with loss of support". (NDIS Participant)

Self-management (and plan management) are the current mechanisms for self direction of support and maximising participant choice and control in the NDIS. Self managers (and plan managed participants) can choose to seek services from the full competitive market including mainstream market and disability provider market, or to develop innovative tailored supports not offered by the existing market. This provides full choice over who provides our support and from where we access this support.

"I rely on mainstream businesses to conduct support work because they are cheaper, higher quality, maintain more dignity... I do everything everyday to keep living an ordinary life, but if I'm forced to rely on poor quality, badly trained, jack of all trades, master of none support staff to fulfil every single role in my life, I won't be able to live". (NDIS participant)

People with disability in regional and remote areas have solved the problem of thin markets by using unregistered providers. Other proposed solutions such as block funding or "direct commissioning"⁴ providers in thin markets completely erode the possibilities of self direction of supports and choice and control.

Direct commission proposes to contract a single provider to service regions without registered providers. Where people with disability have only one option for the supports they rely on to live, they are too often unable to make complaints about violence, abuse, neglect, or fraud. To do so risks losing that support - even when the quality and safety are poor.

⁴ NDIA. <u>Marketing, monitoring and intervention</u> 26 July 2023

Many of us have rejected disability service development orthodoxy and have worked out ways to build unique and bespoke service responses that are directed by ourselves and/or with the assistance and support of our families and allies. We have worked hard to create individualised safeguards involving person centred, personalised strategies and systems: worker training plans specific to our needs, personally designed quality systems, complaints processes, communication strategies such as team meetings, guided handovers, and technology assisted information sharing, as well as community inclusion, informal support inputs and high frequency monitoring. We have created individualised, robust multi-level safeguards which are unachievable within traditional service provision.

"I mostly use unregistered sole traders for my support, it is a much less stressful, better value for money and I actually have my support covered rather than going through a larger registered agency. I am all for ensuring people are not ripping off the system, but just because a provider is registered doesn't mean they are not dodgy" (NDIS Participant)

"In my many years of experience, working with registered providers is way less satisfactory in a number of ways: they are unreliable, their staff is often overworked and incompetent, they are higher-priced and they are more likely to regard the participant as just one of many clients (a 'sausage factory' style of delivery). Unregistered providers often offer a direct interface with the participant, without having to go through a clunky rostering process, they are often more committed to the individual, they can be trained in a tailored, individualised way to meet specific needs, they may cost less and stay longer." (Plan Nominee)

"Registered providers are not as flexible or available in my area. By using unregistered retired providers, who only work for me some hours a week and one who does other jobs, I have shifts covered. Registered provider companies are reliably unreliable and give little notice. I can't risk not having workers help me get up and go to bed". (NDIS Participant)

"Just because people are trained it doesn't make them appropriate I have had so called trained SW and all they want to do is sit around in coffee shops" (Plan Nominee)

"My supports know each other and if one can't come for a shift, it can be offered to one of the others. Sometimes a new support worker will be recommended by one of my team. I really like this way of recruiting new workers when needed - they are not like the strangers from agencies." (NDIS Participant)

"Registered providers insist on 2 support workers for all transfers as their standard protocol. Instead, my OT and I have trained my unregistered workers to safely assist *me 1:1.*" (NDIS Participant)

2. <u>Registration does not keep people safe!</u>

The Recommendation 17 service-centric approach is built on a flawed assumption that risk to participant safety is primarily determined by support type. The NDIS Review Report puts forward that registration will deliver quality support and keep people safe without providing any evidence that this is the case. Police and coroners reports as well as years of research and Royal Commissions clearly show that registration does **not** keep people safe⁵. Indeed many self managers have chosen to directly engage and train unregistered providers because of unsafe and abusive experiences using registered providers. This is not surprising given that legacy providers from the pre-NDIS broken system⁶ now operate as registered NDIS providers and in our lived experience have changed very little in terms of individualisation or frontline support practices.

My wife and I are both self-managed. We have an outstanding team of 5 people who do incredible support not to mention our unregistered allied health that has seen my wife enter the workforce for the first time. I require small but often

⁵ Disability Royal Commission Report - Public hearing 14 - Preventing and responding to violence, abuse, neglect and exploitation in disability services (South Australia); Disability Royal CommissionReport - Public hearing 20 -Preventing and responding to violence, abuse, neglect and exploitation in disability services (two case studies)

⁶ Productivity Commission (PC) 2011. Disability Care and Support. Draft Inquiry Report, Canberra.

personal care. I'm a survivor of sexual assault so I am particular about who sees my body and who touches it." (NDIS Participant)

My support worker was chosen for having all the skills I needed and specifically not having disability training and all the baked in ableism and assumptions that can come with." (NDIS participant)

"As the Royal Commission showed us registration does not guarantee safety - all the worst abuse occurred by registered providers. Let us manage our own lives and take care of ourselves". (NDIS participant)

"I employ our own team of support workers to look after my daughter. I train them and have better policies, procedures, training and practices than any registered provider I have previously used. My daughter is safe with the supports I employ. She is not safe when in the care of registered providers. This has been proven numerous times." (Plan Nominee)

Lessons from wider human services concerned with personal safety (child abuse and neglect, domestic and family violence, sexual exploitation, elder abuse) show that isolation is a major risk factor, that is, not having relationships with trusted friends, family and connection to community outside the home or service⁷. The Recommendation 17 service-centric approach does not address this key driver of participant safety.

> "Vulnerable groups, such as people with disability, have their agency withheld, behaviour monitored, and are subject to segregation—all for their own apparent protection. Rather than see 'the vulnerable' as other, however, vulnerability should be understood as a product of our embodiment, which carries the ever present possibility of harm, disability, violence, and death. Vulnerability is thus universal, central to

⁷Beadle-Brown, J., Beecham, J., Leigh, J., Whelton, R., & Richardson, L. (2021). Outcomes and costs of skilled support for people with severe or profound intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 42–54.

Race (2007 cited in Bigby et al 2018) Bigby, C., & Beadle-Brown, J. (2018). Improving quality of life outcomes in supported accommodation for people with intellectual disability: What makes a difference?. *Journal of Applied Research in Intellectual Disabilities*, *31*(2), e182-e200

the human condition. Affirming its universality can free vulnerability from its negative and othering associations and provide a basis for the development of policy and institutions that lessen our vulnerability by empowerment rather than control. In the context of disability, this entails ensuring that people have access to the material assets and social supports they need to maximise their strength and resilience in the face of the risks related to their particular embodiment⁹⁸

The evidence shows that a network of informal supports, capability building to make decisions and raise concerns, and being part of a community are key preventative factors to address the serious issue of violence, abuse, exploitation and neglect of people with disabilities⁹. We also know that having access to non-traditional support outside of "disability service land" is needed to end segregation, to enable people with disabilities to have a good and safe life in the community.

"The most important safeguard is that my daughter is well known in her community and her neighbourhood. She has a housemate we found in the community. Her life is full and she has valued roles as a neighbour, customer, volunteer, small business owner. Being visible and heard is what keeps her safe. Having a team of trusted people in her life who are attentive to any changes and their collaborative approach to support requires that they must report to me any concerns. We have a comprehensive policy and procedure manual, shared calendar/rosters mandatory training, continual improvement approaches." (Plan Nominee)

Simon Duffy's concept of "citizenship"¹⁰ highlights the risks of trapping people with disabilities in traditional disability services, and the benefits of social inclusion

⁸ Clifton, S. Hierarchies of power: <u>Disability theories and models and their implications for violence against, and</u> <u>abuse, neglect, and exploitation of people with disability. Research Report for Royal Commission into Violence.</u> <u>Abuse, Neglect and Exploitation of People with Disability</u>; October 2020, Page 26

⁹ Walker, M.; Fulton, K. Bonyhady, B. <u>A Personalised Approach to Safeguards in the NDIS</u>, Citizen Network 2017 ; Cocks, E.; Thorsen, H Individual Supported Living Manual, 2nd Edition, 2017; Williams, R,<u>The Model of Citizenhood</u> <u>Support</u>, Purple Orange, 2013

¹⁰ Duffy, S. and Brown, M. Redesigning the NDIS: an international perspective on an Australian Disability Support system. Citizen Network Research.

and choice and control. In their recent report on the NDIS, Duffy and Brown¹¹ recommend NDIS participants having full control over how our allocated funding is spent and warn against bureaucratic barriers that limit participant choice, control and social inclusion.

Furthermore, there already exists a <u>legislated risk assessment</u> for Self Management and Plan Management. The National Disability Insurance Scheme (Plan Management) Amendment Rules 2017 Part 3, describes circumstances when self-management of funding will pose unreasonable risk to participants. This responsibility remains with the NDIA delegates to assess this risk and determine whether a participant or plan nominee is able to self manage or plan manage an NDIS plan. This proportionate risk approach focuses on the individual's personal needs, circumstances, risks and preferences. Any instances of delivery of unsafe services in the current unregistered market points to failure of NDIA delegates in assessing risks, self-safeguarding capacity and individual safeguarding support available for participants when determining type of plan management. It also points to insufficient capacity building support and check-ins.

Instead of fully implementing the current legislative framework based on the individual participants' identified risk factors, the NDIS Review Report recommended a "graduated and risk-proportionate provider registration and enrolment". This approach assumes risk on the basis of the service delivered by the *provider*, rather than the individual risk and relevant safeguarding strategies of the *participant*. This misses the opportunity to understand the personal

safeguarding plans and other co-regulation¹² strategies we have in place to keep ourselves safe in the context of the provision of our supports.

"Our son's team gets credentialed in specifics to his needs, do the online NDIS modules and give appropriate nursing, allied health, Cert 3/4 Disabilities qualifications along with enhanced on the job training from myself and other family members." (Plan Nominee)

"I use Police clearance, NDIS worker screening check and I train workers myself. I also use a comprehensive set of interview questions, seeking references and making clear that any offer is subject to a satisfactory review of performance at the one and three month milestones." (Plan Nominee)

"I source businesses who are recommended with Fair Trading NSW. I source recommendations from genuine and trusted sources, I provide a contract, and source comparisons to find the best 'fit' and if not a 'fit' then the engagement is ended. Reference checking, AHPRA registration are what I access" (NDIS Participant)

"Having good [safeguarding] processes in the home specific to the PWD. Making the supports accountable to each other. Having a team leader - this needs to be a funded support at a higher level." (Plan Nominee)

"We organise training for our support workers, such as Youth Mental Health First Aid, Trauma Responsive Practice, De-escalation Skills, Accidental Counsellor, and other autism and mental health specific training". (Plan Nominee)

"I do not want anyone who has been 'trained' as this leads to them thinking they know what they are doing. They do not know how to meet the needs of my family members". (Plan Nominee)

As citizens we are not on an island with no regulatory systems. We believe it is a false dichotomy to suggest that regulation is only achieved through registration with the NDIS Quality and Safeguards Commission. Other regulatory structures -

¹² Yates, S., Dickinson, H., & West, R. (2024). 'I've probably risk assessed this myself': Choice, control and participant co-regulation in a disability individualised funding scheme. *Social Policy & Administration*, 58(1), 1–17. https://doi.org/10.1111/spol.12940

such as Australian Competition & Consumer Commission, State based Fair Trading, professional worker registration and regulatory bodies (eg. AHPRA), health and safety regulation - are available to us as citizens and consumers.

"The whole point of self management and taking on the time and responsibility of being a SM for my daughter is for the very reason of finding THE best team of allied health professionals and support workers to suit HER needs. None are registered to ndis but are registered with their respective professional governing bodies. So I don't understand. We have consistently shown value for money and progress by using everyone in my daughter's team. This is the most ridiculous thing I've heard so far with NDIS. Especially as I just fought for her new plan and was recognised for using such a "great and diverse team" (Plan Nominee)

"God, we actively seek out non registered NDIS providers as we get MUCH better service and supports that are flexible and relevant. Being registered by the supports governing body or association etc is much more important in my opinion". (Plan Nominee)

"I interview my supports, I manage them, I negotiate the amount I pay, I self-manage so I pay them - I make my funding go a hell a lot of further than I ever could with the registered providers. So if this was taking away, then I hope the NDIA is prepared to double and triple all of the planning funds???????? (NDIS Participant)

"Many non registered providers, that is just normal businesses in the community eg (my cleaning company) which does my cleaning already do police and background checks on all staff. My wife is also available to supervise and check during initial training". (NDIS Participant)

3. An intrusive overreach for visibility of NDIS spending

While the NDIS Review recommendations talk of safeguards, there is also the issue of fraud, misuse and non compliance. We understand "visibility" of all payments and funding use is also an objective of recommendation 17. We believe however, it is a significant and intrusive overreach to mandate the use of registered providers in order for NDIA to have visibility of all payments, particularly as there are other ways to achieve this. This action will remove opportunities for innovation, inclusion, flexibility and savings in the cost of support delivery. It will also pose significant risk to many of us who rely on unregistered providers to have our disability support needs met.

Visibility of NDIS spending can be achieved at the point where claims are made. The new PACE operating system can be updated to require self managers and plan managers to record ABN, Withholding Payer Number (WPN), Statement By Supplier, invoices, and payroll details for direct employers. We note, however, that legislative change would be required to permit direct employers to report employees personal details to the NDIA without breaching privacy requirements.

Similarly a light touch worker registration process for support workers (at no cost to them) can ensure that information about the workforce is maintained in a centralised location.

Currently the worker screening database is not fit for purpose for self managers or for workers. It is expensive and unwieldy particularly for workers in regional areas. In addition it could be joined up with state based worker screening (such as NSW Working With Children Check) so that individual workers who work across systems do not face disincentive from NDIS work by having to do multiple similar worker screening processes.

"As a Self Manager I have tried to register to access the NDIS worker screening database. However to satisfy verification of identity I must have either a drivers' licence or passport. Since I have neither I have been unable to access the database. It is beyond belief that a system designed for people with a disability would be created this way." (Plan Nominee)

Adverse consequences of implementing Recommendations 17.

The NDIS Review fails to consider the adverse consequences of mandating the use of registered providers only. These adverse consequences include:

- Workforce shortages will be severe as unregistered providers exit the NDIS workforce and at the same time it becomes harder for new people to enter the NDIS workforce.
- Participants relying on unregistered providers, especially in regional and remote areas, will be left without support. Anecdotally we hear in many areas NDIS participants are less than 1% of a provider's client base. Mandatory provider registration creates a disincentive to supporting NDIS participants, putting them at serious risk of harm from unmet essential support needs.
- Undermining of individualised arrangements that enable individuals to develop innovative and more cost-effective solutions for our specific needs.
 For example, microboards and direct employment.
- Stifling innovation and new, cost-effective supports Small unregistered providers are nimble, able to pivot fast as needed, able to work in innovative, flexible and cost effective ways with participants.
- Less opportunity for individualised support as service centric support will dominate in a less competitive market.
- Rigid service protocols, over reliance on risk assessments and erosion of the dignity of risk.

- Increased segregation as participants can no longer access services in the open market and are forced into more costly segregated, congregate disability service models, further distancing us from meaningful inclusion in our local communities.
- The cost of support will increase as a result of reduced competition and workforce. People will no longer be able to shop around and find the best value and most suitable supports and consumables on the open market. At the same time, registered providers in the closed market will increase their prices and will be a stronger lobbying group when it comes to NDIA pricing arrangements,
- Increase in the overall cost of NDIS to the taxpayer.

We contend recommendation 17 is a blunt instrument with no consideration of the diverse individual needs, circumstances and existing safeguarding support of people, nor consideration of the research evidence on what works for safety and service quality.

Changes to policy and legislation must:

- Uphold the Convention on the Rights of Persons with Disabilities and the current NDIS legislation (article 3.1 (e)). Inherent in having choice and control over one's life and circumstances is the right to make decisions, even where these may come with attendant risks.
- Recognise the diversity of people with disability. These differences extend far beyond our impairments and include our diverse needs, preferences, capabilities, self-safeguarding and citizen capital. NDIS participants experience differences in isolation induced vulnerability, in informal support networks and safeguarding allies, differences in capacity and

capability to understand and manage risk and differences in our support needs for being able to speak up for ourselves. Recognising the diversity of people with disability and circumstances is especially important when developing policy related to good quality supports and safeguards.

- Protect existing and advance opportunities for the innovative, inclusive, personally tailored and safeguarded support arrangements.
- Approach participant safeguarding in a way that builds a person centred ecosystem of developmental and preventative safeguards focused on capacity building and reflecting our individual needs and circumstances. This includes supporting the development of circles of support, microboards and similar individual safeguarding strategies, around a person with disability.
- Have significant investment in capacity building of supported decision-making.
- Be co-designed and co-produced by self managers and people with disability in regional and remote Australia.

Self Manager Hub Recommendations

- Low risk and ad hoc supports available to be claimed without registration or enrolment. For example: a neighbour transporting a participant to a medical appointment; purchasing continence supplies from local chemist, peer worker coaching a participant in key word signing; a local music teacher being a support buddy for a participant to try out busking; local welder fixing a wheelchair footplate..
- Visibility of NDIS spending using PACE operating system to record ABN, Withholding Payer Number (WPN), Statement By Supplier, invoices, and payroll details for direct employers.
- 3. Creating a worker screening database that is easy to use for participants and workers and that links workers to each of their workplaces.

- 4. An easily accessible banned provider database.
- 5. A 'light touch' worker enrolment process for unregistered support workers to ensure that basic information about the NDIS workforce is kept in a centralised location.
- 6. Ensuring there remains viable avenues to use unregistered providers, including direct employment and/or direct engagement of support. This could be done by creating an avenue for agreement with NDIS and the participant. Such an agreement could set out how the plan applies to us in relation to our specific circumstances, including our location recognising thin markets and with an emphasis on our rights and freedom to use unregistered providers to meet our support needs.
- Free provider registration and accreditation for small providers and <u>service</u> for one.
- A positive duty owed by <u>all providers</u> to provide good quality support, free of abuse, neglect and exploitation, with legal repercussions for failing to provide safe, quality support.
- 9. Improving access to capacity building to ensure that people with disability and our nominees understand the responsibilities of self management and directly engaging support people. This might include Accountant and Human Resources advice, assistance with bookkeeping and recording keeping, peer support/ peer mentoring, circle of support or Microboard, self-management mentors.
- 10. Investment in all participants and families to build capacity to understand our rights, recognise good quality and safe support.
- Consider and utilise existing mainstream regulatory bodies such as ACCC, Fair Trading, professional regulatory bodies such as AHPRA, Master Builders Association etc, rather than requiring professionals and business regulated under such authorities to undertake additional registration burden for NDIS.

- 12. Support the development of individualised quality and safety plans that build an ecosystem of quality and safeguarding supports around the person. This would include support to develop and maintain circles of support and Microboards - friends and family (freely given relationships) who are a part of the person's life and ensure that our needs and preferences are recognised and that we are safe and well supported..
- 13. Greater access to participant-led training and the recognition of micro credentials, competency-based training with assessment carried out by person receiving support.
- 14. Support to develop and maintain a documented and shared understanding of the characteristics, knowledge, skills, experience and qualifications required by the person receiving support.
- 15. Develop a suitable risk assessment framework, within the current legislation¹³ that can effectively determine whether the person is capable of successfully self managing (including choice to use unregistered providers) with the necessary support in place. This framework should be supportive rather than punitive and include capacity building and an independent appeals process.
- 16. Compulsory provider registration and accreditation audits (by regulator allocated auditor, rather than self selection) for providers of shared support and in closed settings - eg, group homes, centre-based day programs, respite houses. Providers must demonstrate they are meeting outcomes for individual participants in line with CRPD in order to maintain registration.
- 17. Community visitor programs to regularly visit congregated and shared support environments and have real authority in ensuring our support needs are met and human rights upheld.
- 18. Mandatory separation of housing and support.

¹³ NDIS Act Section 44

- 19. Supportive pathways out of congregated support to individualised approaches.
- 20. The separation of intermediary supports (plan manager, support coordinators, local area coordinators, navigators) from the delivery of direct supports.
- 21. Formal and regular contact with a planner, support coordinator or navigator to monitor participant safety, provider charging and reduce fraud.
- 22. Increased access to individual advocacy, especially in regional and remote Australia where there is currently extremely limited access.

Working together with the disability community, we can co-design and co-produce a pathway for the future of the NDIS that protects our fundamental human right to decide who supports us, while improving the safety of NDIS participants and the sustainability of the scheme.