# Self Manger Hub Submission to the NDIS Review

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 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.

To protect the fundamental NDIS principles of choice and control and the rights of participants to self manage and be in charge of our lives, the new Quality and Safeguarding Framework needs to:

**1. Protect self management**. It's an important tool to maximise choice and control, find value and improve outcomes. The right to self manage should be protected for people who have the desire and capacity to do so. The flexibility and choice available through self-management can achieve great outcomes and in many cases deliver great value for money. Many of us have developed innovative and individualised support arrangements that have been made possible through self-management and access to unregistered providers. Access to self-management enables innovative solutions to be built with the individual's unique needs and preferences at the centre.

**2. Do NOT force us to use registered providers.** Many of us rely on unregistered providers and taking away our rights to access them will put our lives in danger and force us to go without services, especially in regional and rural areas.

**3. Do NOT make disability qualifications mandatory.** When we choose to have workers without formal disability qualifications supporting us, our choice must be respected. For many of us, attitudes and values are more important than formal qualifications in disability support work. Mandatory qualifications would make it harder for us to find support and could put us in danger.

Training is important and necessary but we do not want a one size fits all mandatory qualification that would make it harder for us to find support and that delivers poor outcomes. The answer to upskilling the disability workforce (please read the link and include as evidence to the NDIS Review) requires people with disability at the centre, recognises and builds our capacity to train our support workers and makes available targeted microcredentials. People with disability are the experts in what good support looks like in our lives.

**4. Uphold the principle of dignity of risk.** This means that people with disability have the right to live the life we choose, even if our choices involve some risk. We should be supported to understand risks and manage them. NDIS participants are diverse and we have the different needs and preferences when it comes to services and risk-taking. Regulations need to recognise this and consider the individual’s age (whether they are an adult or minor), capacity support for decision making and whether the risk impacts on themselves or others. Regulations should accommodate risk-taking preferences and the person’s capacity and support they need to understand and manage risk.

**5. Invest in participant capacity building** to increase our capability to self manage and feel safe. Participants should be empowered with information and support to self manage and support to make decisions and choices about our lives. This should be made available through peer support and by investing in a trusted network of self managers.

**7. Support the building and maintenance of developmental safeguards. Family**, friendships and being part of community is often the greatest safeguard. Participants should be supported to develop and maintain friendships and unpaid relationships. These developmental safeguards have not had the priority they deserve in the quality and safeguarding framework but they are fundamental to addressing violence, abuse, neglect and exploitation of people with disability.

**8. Invest in advocacy supports, including a community visitor program.** We may need support to speak up for our rights, but it's really hard to find that support from a trusted person when you need it. Being supported to speak up when things aren't going right and raising issues early before things turn bad is critical.

**Why we MUST NOT make disability qualifications mandatory**

The current approach to training the disability workforce is built on 2 false assumptions that need to change. These assumptions are:

1. That able-bodied people know what’s best for us and

2. That people with disabilities are all the same and have the same needs.

These false assumptions underpin the current ineffective training system that has a one size fits all certificate, delivered by able-bodied people.

As a result, we have so-called “qualified” staff who think that they know what’s best for us. "Qualified" staff too often think that they are the experts and fail to listen to us, failing to recognise that we, disabled people ourselves, are the experts about how to support us. It's not the support workers' fault, it's what they are taught and it is the unfortunate consequence of what often happens when we attempt to professionalise an occupation without codesign principles, without a values and human rights basis and without the consumer at the centre. The provider becomes the expert and the consumer becomes the disempowered and devalued subject.

A recent research study into what quality support looks like from the perspective of people with disabilities found that, to provide quality support, disability support workers need to recognise the person with disability as an individual and the expert in their support needs and preferences. The study also found that having authentic choice over their support arrangements and daily living is critical to facilitate quality support, and in turn help the person with disability to feel in control.

We, disabled people, are the experts in our lives. No one knows what we need better than we do, so there is no one better to decide who supports us, and no one better to deliver training and make decisions about the training of the disability workforce than people with disabilities ourselves.

**Why use unregistered providers**

These are some of the key reasons why people with disability use unregistered providers:

1. Better value for money and can pay workers at a higher rate which is necessary to attract and retain staff. As a result of self-management and engaging workers directly, there is no middle person between the NDIS participant and the worker and therefore more of the funding can go directly to the worker. Higher rates attract more candidates and workers are more likely to experience greater job satisfaction and stay longer if they are earning more.. It takes a lot of effort and time to train a new worker so it is important to keep turnover down to a minimum.

2. We want to decide who comes into our homes and who provides our support, we can only guarantee this if we directly engage my workers.

3. We want to have direct communication with our workers. Going through a third party, such as a registered provider, makes communication more difficult and time-consuming. It is also less personal, less effective and more bureaucratic and increases the chance of misunderstandings taking place.

4. Registered service providers need to be in control and make decisions and as the employer, that is both their right and responsibility. Handing over control to a registered provider is not a suitable option for many of us. That is why we choose to self manage.

A recent study into the use of unregistered providers highlighted the importance of this option for many NDIS participants.  The option to choose 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. Participants in the study 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.

The study found several participants who had negative experiences with support workers from registered agencies and felt safer and better supported using unregistered workers they were able to choose. This is something that I can strongly relate to. The following excerpt from the study also rings true for me:

> "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. 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." Page 3. [1]

### What would be the impact on people with disability of forcing us to use unregistered providers and/or workers with disability qualifications?

Thousands of Australians with a disability have choice and control over our support by deciding for ourselves, who is best suited to support us. If our right to decide is taken away, there would be very serious consequences. Forcing us to use registered providers or workers with disability qualifications would undermine the principles of choice and control that are central to the promise of the National Disability Insurance Scheme.

It would adversely impact on our quality of life and our ability to engage supports that enable us to be more fully included in the community, socially and economically. It would be a serious step backwards in the upholding of human rights and self-determination for people with disabilities.

We have the right to dignity of risk, choice and control and to be treated as adults who can take responsibility for our own decisions.

Many of us have taken on self-management having been rejected by agencies (because our needs were considered too complex) or because agencies were unable to meet our needs. Some of us do not have any suitable registered providers in our local area, or we have specific needs that existing unregistered providers are unable or unwilling to support. If we were not allowed to self manage it is possible that we will have much less effective support or, in some cases, no support at all.

Some of us will be left without support or with unsuitable support options.

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[1] 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. Page 25.

Many workers do not want to work for an agency and are not prepared to experience a reduction in their hourly rate. It is a serious concern that many will leave the sector if they are forced to work for a registered provider or to register themselves. It is already very difficult to find support workers and any changes that will reduce the number of people working in the sector must be avoided.

The consequences are especially serious for people with disabilities in regional and remote areas and marginalised communities. It is already the case that people's cultural background, interests and culture are often not reflected in available workers. This is widely recognised for marginalised groups including First Nations people, Culturally and Linguistically Diverse communities and members of the LGBTIQ community to name a few. Removing access to unregistered providers in already thin markets, such as rural and remote locations and also in under-represented cohorts, will intensify the challenges of finding workers who are appropriately and sensitively matched to people's needs.

By limiting our options, our safety is at risk.

We must consider the impact on safety by removing access to effective workers who want to work flexibly and making it harder for people with disabilities to find support when we need it.

Abuse, violence, neglect and exploitation against people with disabilities is more likely when people with disabilities do not have choice over who supports us and when we are not empowered to escape from a violent and abusive worker or provider. Reducing our options around who can provide us with support will put us more at risk of neglect, exploitation, violence and abuse. If our choices are restricted, abusive and violent workers will have more power over our lives and we will have less power to find other people to provide the critical day-to-day assistance that we need to survive.

**Recommendation 1: Ensure that people with a disability are able to self manage our support,** including the option to choose unregistered providers and workers without disability qualifications. DO NOT force us to use workers who are registered and/or have disability qualifications.

**Recommendation 2: Fund peer support and capacity building for people with disabilities** to build our capacity to self manage and to understand and manage risk.

Helen Dickinson and colleagues from UNSW recommend[2]:

> "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

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[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. Page 25.

> 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."

The government should invest in training people with disability to:

- understand our rights
- build knowledge skills and confidence to be a discerning consumer of disability supports
- recognise and report violence, abuse, neglect and exploitation
- assess our workers abilities to do the tasks to the standard that we require
- understand our responsibilities as an employer and
- support our workers to do their best work and feel valued and committed to working with us.

**Recommendation 3: Put people with disabilities at the centre of developing the disability workforce.**

Putting people with disabilities at the centre starts by supporting us to develop a training plan for our workers. This plan should clearly describe what we need from our support workers and the capabilities that the workers would need to support us well. The training plan should be individualised with the needs of the disabled person front and centre.

We need a disability workforce with the right attitudes, values, skills and capabilities to deliver support effectively, safely and in a way that supports us to achieve great outcomes. What these skills and capabilities look like will vary greatly depending on the person, our goals, our capabilities and the kind of support we need.

So we need to transform the current system, do away with a one size fits all qualification where able-bodied people are seen as the experts, making the decisions about the training that our workers need.

**Recommendation 4: Support people with disabilities to develop and deliver training**. There should be support to develop and source relevant courses including microcredentials. Microcredentials would provide a fast and effective way of teaching specific skills that are unique to the person’s support needs. For example, how to use a ventilator, a wheelchair, a communication device or a catheter. If the existing courses are poor quality or don't exist, there would be support to codesign courses with people with disabilities and other experts.

**Recommendation 5: Support a diverse provider marketplace that includes registered and unregistered providers, small providers (including independent contractors) and large providers, and platforms.** Each model is needed to attract the workforce required in communities around Australia and to meet the diverse needs of people with a disability. It is important that the NDIS Review recognises the vested interests of some large registered providers advocating for a one size fits all requirement of mandatory registration, forcing all NDIS participants to use their services and in doing so, eliminating their competitors and reducing choice for NDIS participants.

**Conclusion**

Some people with disability want their providers to be registered and to have certificate level disability qualifications. It is important these needs and preferences are respected. At the same time, some of us need access to unregistered providers and to choose workers without disability qualifications. Others need a combination of these options.

**The key message of our submission is that all of these options should be available, blanket rules around qualifications and registration should not be applied or mandated in the disability sector**. Doing so would infringe on our rights, limit our choices and increase our risk of violence, abuse, neglect and exploitation. The current quality and safeguarding framework that enables self managers to choose who supports us must be maintained.

People with disabilities are diverse with different needs and preferences that must be recognised and respected. That is our right and what we fought for, when we advocated for an NDIS based on the principles of choice, control and individualised support. It is essential that these principles are respected and upheld in the recommendations of the NDIS Review.

# Appendix: Insights from Self Managers for the NDIS Review

Listed below are direct quotes from self managers about what we want the NDIS Review to understand from our perspective. They were collated from a forum that we hosted with the NDIS Review Team in April of this year and through our Facebook group.

According to self managers Supporting Self-Management to flourish is critical- "self management enables self-determination, autonomy, flexibility, innovation and creativity and authentic choice and control"

"Self-management enables participants to seek the right person with the right skills for the right support" (eg cleaners to clean, personal care workers, trained the way the participant wants and needs to do the task). It enables participants to curate their team around the needs of a specific cohort-eg meeting needs of children or older people or people with psychosocial or physical disability.

**1.Improvements sought from the Agency**

*"We need for consistency and accessibility of information and messaging from the agency regarding rights, rules and responsibilities for people who self-manage- would lead to more transparency of decision making, less confusion and distress".*

Need for recognition that it takes time to learn to self-manage and resources are required which assist and support people to understand what's possible and how to use their plans for their best outcomes. There was a suggestion that resources and training in self-management should be available, free and funded by the agency.

Requirements identified for support to learn to be a 'savvy consumer's, how to use the entire mainstream and specialist market, including mainstream and community to access the best support.

*"Need for more informed, consistent, compassionate, and skilled LAC's and planners to assist with plan development and understanding which is focused on person centred practice and disability informed*"

There is a request for a further review of the website, its design, accessibility of information provision and available resources so they are more useful for participants.

*"The agency should provide funding in recognition of the effort required to ensure support workers are adequately trained and supported to carry out their roles."*

Funding buddy shifts are often required to ensure support workers are adequately trained.

*"There is a requirement for funding for supervision and support for support workers as they experience challenges and need to debrief and continual improvement"*

Several participants had experienced highly negative experiences attending the ADT on the basis of support and funding disagreements with the agency.

Participants had the experience of planners making decisions without understanding the participants' disability or needs and this is creating massive stress. *“I believe it's part of controlling blowing out the cost of the scheme’*

“*I think that at times Plan extensions and rollovers are for the convenience of the LACs. My daughter's Plan was due for review in October 2022, then it was extended for 12 months, but in March I was contacted by the LAC regional office to give my daughter a 'duplicate plan' and all residuals in the extended plan were removed and so effectively just a new start and end date. This would be extremely distressing and disturbing to some self managers. It was ok for us, but the reports I gathered for the review will probably be seen as out of date by March 2024!!!’*

## 2. Workforce

Finding the right support workers is an issue for many participants. *“I'm worried about not using my funds because I cannot find reliable and competent support workers and I might end up with a reduction in future funds”.*

There was a clear theme that for self-managers, registered providers doesn’t mean better or safer service delivery in practice.

There is a significant experience of the challenge to find workers in rural and thin market areas, yet experienced and appropriate ones.

Persistence is required to seek the right person for the right support, *“you can’t give up”* .

*“There is a need for cohort specialists with appropriate knowledge of specific impacts and requirements for some disability experiences”*

Workforce qualifications and skills were identified as an area of concern- assumptions could not be made on the value of qualifications for specific participants and many workers need to be trained by their participants and families as best practice.

*“There is a lack of availability of supervision and monitoring options for workers, to enable workers to seek external support and supervision along with diverse professional development opportunities”*

*“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”*

*"I believe registration of direct support providers (including any directors, and support workers) should be prefaced with a check of any complaints of abuse, neglect, coercion, financial misuse, and whether the investigation and outcome was resolved satisfactorily.*

## Training

There was discussion regarding training workers and that Participant led training is so important. Participants need to codesign formal training and also train their support workers and team in their own needs. *I decide what worker need to know about me, specifically", "I do need them to know information about ndis, but the things about me are about me only, they can't learn that anywhere else"*

There was an experience shared that NDIS service providers have actively coerced participants to sign service agreements that are not only unfair, but a "template" one size fits all system. "*Allied Health professionals and others seem keen to charge cancellation fees for anything that is less than 48 hours' notice and often include the travel fees. They also ask for blanket consent to share information without offering the Participant to determine with whom, how much information or when it should be shared. They also ask for blanket consent to take images and videos to be used for anything from sharing with other providers, the NDIA or even just for promotional purposes". "THIS IS NOT ETHICAL. Even the use of templated schedules of fees and charges for generic number of visits, hours to research and write reports can be individualised especially if there is already sufficient information to that end"*

*"Choice and Control in the "market model" of the NDIS should enable anyone to have their services tailored to their needs and that includes the wording of service agreements*

## 3. Capacity Building

There was recognition that self-determination and self-management takes practice, confidence and support for the best outcomes. *"This stuff is hard, it takes time and energy and practice"* This support is often sought from the self-manager Hub, and it was stated: "*how helpful SMH is for many self-managers as it provides a space for peer support and information sharing*". The overall feedback about self-management was that the outcomes were so different and positive from plan and agency managed and that this effort was worthwhile.

The need for additional support from family, friends and others was recognised as often required, to assist with ideas, manage challenges with workforce, service gaps and feedback. "We need help sometimes form family and friends, *"I'd be worried about someone with a cognitive incapacity self-managing without support""* Some participants do not have access to these informal supports and this can create real challenges for people.

Self Manager Hub

Many NDIS participants don't have an advocates or cheerleaders or supporters who are not paid to assist them- ‘*we have to make sure that everyone is supported’*

*“Not every participant has a family to fight for us. I’m just exhausted from the battles and it's still going. I haven't get to the point to focus on my goals... It's depressing”*

**Other**

There were frustrations voiced that the cost of AT items have all suddenly risen to $14995 now that the cap has been raised for medium cost AT. Issue with suppliers. Still can’t get around this as a self-manager.

*“Let's ensure that Participants are not the focus of any robo-debt type investigation into fraud. Nor should independent support workers who actually deliver support be treated with suspicion. Instead, there could be a focus on those who only offer 'experiences' or 'activities' and promote it as 'therapeutic' or 'mentoring' without actually providing any disability support. I'm not suggesting that some aren't valid, but it appears there are a host of these types of offerings, that sometimes are charging fees that would equate to a 1:1 basis , but on a group activity, and yet the Participants who need support, must supply their own worker!”*

Further frustration was voiced around assessments and parental responsibilities.

*“It takes a long time to get to know my daughter and to understand her well. Recruitment and training can take ages. Assessments are useless unless the person doing the assessing already knows the person well. I provide all the information and the practitioner writes it up and charges the plan heaps of money!*

The table below lists the concerns, experiences and solutions expressed by self managers across the country:

| Theme of Concern | | Quotes |
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| 1. **Continue to support Self-Management to flourish** | Self Management is critical to scheme outcomes- it enables self-determination, autonomy, flexibility, innovation and creativity and authentic choice and control.<br>It enables participants to seek the right person with the right skills for the right support. (eg cleaners to clean, personal care workers, trained the way the participant wants and needs to do the task). It enables participants to curate their team around the needs of a specific cohort-eg meeting | |

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| | needs of children or older people or people with psychosocial or physical disability.<br>Themes for Improvement | |
| **1. Improvements sought from the Agency** | -Need for consistency and accessibility of information and messaging from the agency regarding rights, rules and responsibilities for people who self-manage-<br>-Need for recognition that it takes time to learn to self-manage ,resources are required which assist and support people to understand what's possible and how to use their plans for their best outcomes. -Resources and training in self management should be available, free and funded by the agency.<br>-Need identified for support to learn how to be a 'savvy consumer, how to use the entire mainstream and specialist market, including mainstream and community to access the best support.<br>-Need for more informed, consistent, compassionate, and skilled LAC's who are person centred and disability informed.<br>-Request for a further review of the website, its design, accessibility of information provision and available resources so they are more useful for participants.<br>-Funding should be provided in plans in recognition of the effort required to ensure support workers are adequately trained and supported to carry out their roles. (including funding buddy shifts) | *"I believe it's part of controlling blowing out the cost of the scheme'*<br>*"My daughter's Plan was due for review in October 2022, then it was extended for 12 months, but in March I was contacted by the LAC regional office to give my daughter a 'duplicate plan' and all residuals in the extended plan were removed and so effectively just a new start and end date. This would be extremely distressing and disturbing to some self managers. It was ok for us, but the reports I gathered for the review will probably be seen as out of date by March 2024!!!'*<br>*"I believe registration of direct support providers (including any directors, and support workers)should be prefaced with a check of any complaints of abuse, neglect, coercion, financial misuse, and whether the investigation and outcome was resolved satisfactorily.* |

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| | -Need for funding for supervision and support for support workers.<br>-Several participants had experienced highly negative experiences with the ADT<br>-Participants had experience of planners making decisions without understanding the participants' disability or needs and this is creating massive stress. "I think that at times Plan extensions and rollovers are for the convenience of the LACs. | |
| **2. <u>Workforce</u>** | -Finding the right support workers is an issue for many participants.<br>-Registered providers don't mean better or safer service delivery in practice.<br>- Finding workers in rural and thin market areas is challenging, yet finding experienced and appropriate ones..<br>-Persistence is required to seek the right person for the right support, "you can't give up" .<br>-There is a need for cohort specialists with appropriate knowledge of specific impacts and requirements for some disability experiences.<br>-Workforce qualifications and skills were identified as an area of concern- -Assumptions could not be made on the value of qualifications for specific participants and many workers need to be trained by their participants and families as best practice. | *"I'm worried about not using my funds because I cannot find reliable and competent support workers and I might end up with a reduction in future funds"*<br>*"I Want to keep the right to use unregistered NDIS providers. It allows me to chose the right provider for my disability/impairments, because NDIA just doesn't get my disability, and keep the cost as low as possible"* |

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| | -There is a lack of availability of supervision and monitoring options for workers, to enable workers to seek external support and supervision along with diverse professional development opportunities. | *"I believe registration of direct support providers (including any directors, and support workers)should be prefaced with a check of any complaints of abuse, neglect, coercion, financial misuse, and whether the investigation and outcome was resolved satisfactorily.* |
| **Training** | There was discussion regarding the need to train workers and that Participant led training is critical. Participants need to take part in codesign formal training also.<br>-Challenges with service agreements and the need to ensure they are individual. not templated. Choice and Control in the "market model" of the NDIS should enable anyone to have their services tailored to their needs and that includes the wording of service agreements<br>-Cancellation fees -Allied Health professionals and others charge cancellation fees for anything that is less than 48 hours notice and often include the travel fees.<br>-Consent to share information- blanket consents are requested without offering the Participant to determine with whom, how much information or when it should be shared, also to take images and videos to be used for anything from sharing with other providers, the NDIA or even just for promotional purposes. | *"THIS IS NOT ETHICAL. Even the use of templated schedules of fees and charges for generic number of visits, hours to research and write reports can be individualised especially if there is already sufficient information to that end"* |
| 3. Capacity Building | -There is a need to understand that self-determination and self-management takes practice, | *'we have to make sure that everyone is supported'* |

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| | confidence and support for the best outcomes but that the outcomes were so different and positive and that this effort was worthwhile.<br>-There is often a need for additional support from family, friends and others as required. Some participants do not have access to these informal supports and this can create real challenges.<br>- | *"Not every participant has a family to fight for us. I'mjust exhausted from the battles and it's still going.I haven't get to the point to focus on my goals... It's depressing"* |
| **<u>Other</u>** | -All AT items have all suddenly risen to $14995 now that the cap has been raised for medium cost AT. Issue with suppliers. Still can't get around this as a self-manager.<br>Further frustration was voiced around assessments and parental responsibilities. | *"Assessments are useless unless the person doing the assessing already knows the person well. I provide all the information and the practitioner writes it up and charges the plan heaps of money!"*<br>*"Let's ensure that Participants are not the focus of any robo-debt type investigation into fraud. Nor should independent support workers who actually deliver support be treated with suspicion. Instead, there could be a focus on those who only offer 'experiences' or 'activities' and promote it as 'therapeutic' or 'mentoring' without actually providing any disability support. I'm not suggesting that some aren't valid, but it appears there are a host of these types of offerings, that sometimes are charging fees that would equate to a 1:1 basis , but on a group activity, and yet the Participants who need support, must supply their own worker!"* |

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| | | *"It takes a long time to get to know my daughter and to understand her well. Recruitment and training can take ages'.* |
| SIL | | *'I'd really like to see the NDIS reformed so that congregate living is not an attractive option for service providers. SIL and SDA is still often a conflict of interest with providers doing both. Group homes are prevalent and on the increase!'* |