

Self-Directed Supports Submission:

**Children and Young People with
Disability Australia's (CYDA's)
submission to the Department of
Social Services Consultation on Self-
Directed Supports Registration**

*"We self manage and
employ workers who suit
my daughter's needs.
Those needs are cultural,
practical, situational."*

*(Parent/caregiver of child or young
person, Registered Provider Survey).*

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Children and Young People
with Disability Australia



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A note on terminology:

Children and Young People with Disability Australia (CYDA) uses person-first language, e.g., person with disability. However, CYDA recognises many people with disability choose to use identity-first language, e.g., disabled person.

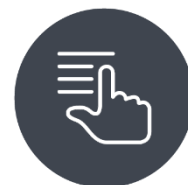
CYDA refers to self-directed supports as **self-registered participants** in line with our recommendations to change the term.



Content note: Discussion of ableism

Acknowledgements:

Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the Lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this Land since the Dreamtime. We pay our respects to their Elders past and present. This is, was, and always will be Aboriginal Land.



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Summary of recommendations

Recommendation 1: Ensure accessibility and clarity for NDIS self-registered participants by:

- a. Renaming self-directed supports to self-registered participation to avoid confusion or conflation.
- b. Providing missing detail about the process for self-registration, including assurances of privacy for participants.

Recommendation 2: Build trust through showing that the rights and dignity of NDIS self-registered participants will be upheld alongside the fulfilment of their responsibilities, by:

- a. Changing the language of obligations to shared rights and responsibilities.
- b. Ensuring that the proposed list of obligations also act as safeguards for self-registered participants.
- c. Enabling children and young people to participate in self-registration, with sufficient support and safeguarding.
- d. Addressing any barriers to self-registration by ensuring suitability assessments are fair and transparent, and people with high levels of support needs can still exercise choice and control over providers.

Recommendation 3: Ensure that children and young people are supported to authentically engage with self-registration processes by:

- a. Giving opportunities for genuine co-design of check-in process.
- b. Creating new resources that provide information and support about self-registration.
- c. Facilitating an independently moderated discussion board or group for self-registered participants to share information and supports.
- d. Funding a peer support program for peers to mentor each other about self-registration.

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has extensive national networks of young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability in Australia will fully exercise their rights, realise their aspirations and thrive in all communities. We do this by:

- Raising community attitudes and expectations
- Championing initiatives that promote the best start in the early years for children with disability, and their families and caregivers
- Leading social change to transform education systems to be inclusive at all points across life stages
- Advocating for systems that facilitate successful life transitions to adulthood
- Leading innovative initiatives to ensure the sustainability and impact of the organisation and the broader sector.

CYDA welcomes the opportunity to respond to the Department of Social Services' consultation on the registration of NDIS participants who self-direct their supports. We commend the Taskforce in listening to the disability community and creating provision for participants who feel strongly about maintaining choice and control over their NDIS plans.

This submission builds on our previous work on Registered Providers, which highlights concerns in our community about the impacts of registration, including narrowing the provider market and removing people's ability to create carefully selected teams of people to support themselves and their loved ones.

The quotes below demonstrate how the limitations that exist can be exacerbated for regional and remote participants and those with intersectional needs.

"There are no registered providers in our town. This recommendation is a disaster for regional and remote people." (Parent/caregiver of a child or young person with disability, Registered Provider Survey).

"I'm trans and queer, and my disabilities are generally not well understood; I've had uniformly terrible experiences with registered providers, and rely completely on my unregistered support workers". (Young person with disability, Registered Provider Survey).

This submission draws on evidence from our submissions and the lived experiences of our community:

- [CYDA's 2024 submission to the NDIS provider and worker registration taskforce](#)
- [CYDA's 2024 registered provider survey](#): conducted to inform our submission to the NDIS provider and worker registration taskforce. 161 children and young people with disability, their families and carers responded.
- [CYDA's 2024 NDIS listed supports survey](#): conducted to inform our submission to the NDIS consultation on this topic. 212 children and young people with disability, their families and carers responded.
- **Staff consultations, 2024**: Short interviews seeking insights from CYDA staff members who have personal and/or family experience of disability and NDIS participation.
- **NDIS consultations, 2023**: Data collected as part of a series of consultations with young people with disability and parents/caregivers for the NDIS review panel (used with permission).
- **Youth Council consultations, 2023**: Online consultation with members of CYDA's 2022 and 2023 Youth Council (n=8, majority NDIS participants).

Direct quotes drawn from the data collected are indented from main text, italicised and in inverted commas, anonymised (or pseudonyms used) to protect privacy and minimally modified for brevity and/or clarity.

The submission is structured in three parts, each leading with a recommendation followed by a more detailed response to the DSS Consultation Paper questions.

Part 1 responds to question one of the consultation paper relating to the definition of self-directed supports.

Part 2 responds to questions two to four of the consultation paper relating to obligations, compliance and assessing registration.

Part 3 responds to questions five to eight of the consultation paper relating to how the NDIS Commission can support self-registered participants through check-ins, information and support structures for sharing innovative practice.



Part 1: Ensure accessibility and clarity for NDIS self-registered participants

Recommendation 1: Ensure accessibility and clarity for NDIS self-registered participants by:

- a. Renaming self-directed supports to self-registered participation to avoid confusion or conflation.
- b. Providing missing detail about the process for self-registration, including assurances of privacy for participants.

In response to question one of the DSS Consultation Paper relating to the definition of self-directed supports, CYDA raises the following two points to ensure accessibility and clarity for NDIS self-registered participants:

Change self-directed to self-registered

CYDA is concerned that the definition and terminology of “self-directed” will be unclear and inaccessible to NDIS participants. The term self-directed is problematic as it sounds similar to self-managed and may create unnecessary confusion when the terms apply to two very different processes.

Instead, CYDA proposes that the term “self-directed” be changed to “self-registered”. This makes sense as “self-directed” applies to a category of registration and is thus in keeping with all other categories that have the word “registration” in their description. The change to self-registered will ensure NDIS participants understand the term as part of the registration model rather than the management model (including self-managed, plan-managed or agency-managed). The categories of registration would then become:

- Advanced registration
- General registration
- **Self registration**
- Basic registration.

Provide missing detail about registration process

CYDA notes that the DSS Consultation Paper states, “a process should be developed whereby the participant will register themselves for self-directed supports, and thereby all their support providers would then also automatically become registered and visible.”

CYDA asks DSS to clarify the missing detail in this process, as it is currently unclear and raises further questions such as:

- how support providers will be rendered visible
- whether NDIS participants will be expected to list all their support providers
- under what circumstances NDIS would be able to contact providers, and
- how privacy of participants and providers would be ensured and safeguarded.

The below quotes highlight the need for clarification regarding NDIS processes and language:

“...you shouldn’t need a qualification to figure out how to work the NDIS”. (Parent/caregiver of a child or young person with disability, NDIS consultations).

“I think once you learn the words that they use and the way that they explain things, you can read what they mean, but I think just general, it’s not accessible. They use a lot of words and terms and ideas that just most people are not familiar with until you work in this area with the NDIS, with healthcare professionals for a while.” (Young person with disability, NDIS consultations).



Part 2: Build trust through shared rights and responsibilities

Recommendation 2: Build trust through showing that the rights and dignity of NDIS self-registered participants will be upheld alongside the fulfilment of their responsibilities, by:

- a. Changing the language of obligations to shared rights and responsibilities.
- b. Ensuring that the proposed list of obligations also act as safeguards for self-registered participants.
- c. Enabling children and young people to participate in self-registration, with sufficient support and safeguarding.
- d. Addressing any barriers to self-registration by ensuring suitability assessments are fair and transparent, and people with high levels of support needs can still exercise choice and control over providers.

In response to DSS Consultation Paper questions two to four which relate to obligations, compliance, and assessing registration, CYDA raises the following four points to ensure that the NDIS does not replicate punitive welfare deterrence language, prioritising building trust through showing that the rights and dignity of NDIS self-registered participants will be upheld alongside the fulfilment of their responsibilities:

Shared rights and responsibilities of self-registered participants and the NDIS Commission

A key aim of the NDIS Review was to restore trust, confidence and pride in the NDIS.¹ The Review also acknowledges that positive changes are needed for people with disability.²

CYDA suggests that a key part of building this trust is to uphold the dignity and rights of children and young people with disability as well as their families and caregivers in line with the Australian Government's responsibilities under the United Nations Conventions on the Rights of the Child and Persons with Disabilities.

Upholding rights and dignity involves removing any ableist or punitive language that makes NDIS participants feel like a burden or that they will be punished or criminalised.

¹ [The NDIS Review | NDIS.](#)

² [Landmark independent NDIS Review report released | NDIS.](#)

Language such as “obligations”, “suspending” or “revoking” can be traumatising to the disability community, who already have a low level of trust in government due to the NDIS reform process and feel that they are at risk of losing their NDIS status at any moment:

“Obviously there’s a lot of horrible debate going on about, ‘This NDIS costs too much, disabled people are being a burden.’ I was at the post office the other day and there was this dude on the phone just ranting to his friend about how much it sucks that we spend so much on NDIS, and I’m like, ‘Bro, I’m right behind you, be very careful.’ (Young person with disability, CYDA Youth Council consultation)

One respondent to CYDA’s survey on the ‘NDIS list of stated supports’ shared a sentiment felt by many others in the disability community:

*“I’m too exhausted from caring, and feeling like the Government, media and community hates us, to go back to list at the moment.”
(Parent/caregiver of a child or young person with disability, NDIS Draft List Survey).*

While CYDA understands the need for the NDIS Commission to ensure the accountability of NDIS self-registered participants, we urge the Commission to consider:

- reframing obligations through the language of responsibilities
- balancing these responsibilities with upholding the dignity and rights of NDIS self-registered participants
- using the terms “pause” and “redirect” instead of “suspend” and “revoke”
- providing accessible guidance to participants on how they can avoid suspension, only doing this as an absolute last resort with the opportunity for registration to be reinstated, and
- emphasising that these responsibilities are shared between NDIS participants and the NDIS Commission.

Relating to this last point, the NDIS Commission has responsibilities to NDIS participants, and stating these clearly would go some way towards restoring trust with the disability community. These responsibilities include upholding standards of safety

for NDIS participants and supporting participants to maintain autonomy and control over their lives and plans as per the original intention of the NDIS.³

CYDA's response to "proposed list of obligations"

Providing that DSS reframes the list of obligations as responsibilities, CYDA supports those items in the proposed list that entail responsibilities but also act as safeguards for self-registered participants. These include:

- adherence to the NDIS Code of Conduct
- screening workers, with screening criteria to be determined by the NDIS participant
- reporting any incidents
- undertaking their own assessment for practice and quality according to self-defined standards.

CYDA has the following further comments on these proposed list items:

- complaints process: CYDA seeks clarification of whether this process is for participants or workers.
- suitability assessment – undertaken by participant - how?: CYDA seeks clarification on whether this refers to the method of applying to be self-registered. If so, the assessment process needs to be easy to undertake and accessible.
- regular check-ins with the NDIS Commission: CYDA agrees and provides further comments on check-ins in Part 3 of this submission.
- audits: CYDA is unclear on what audits entail and whether they will be internal or external. The DSS Consultation Paper (p.6) also states, "The Taskforce's advice proposed that due to the nature of self-direction, participants who are registered in this category would not be subject to external audits." CYDA supports the proposal that no external audits should be required for self-registered participants.
- ongoing monitoring: CYDA is unable to support this item without more information about what this would entail.

Extending supported self-registration to children and young people

³ "[E]nabling people with disability to exercise choice and control in pursuit of their goals and the planning and delivery of their supports". Part 1.2, section c, of the NDIS (Supports for Participants) Rules 2013.

A further opportunity to promote dignity and rights would be for the NDIS Commission to extend the opportunity for self-registration to children and young people.

CYDA notes that the DSS Consultation Paper specifies that there are no present criteria for a participant to qualify for self-directed supports (p7). Presumably this means that there is no age limit specified.

CYDA's work has demonstrated strongly that young people value support in making decisions for themselves and building their capacity to be more independent:

"I personally really value my autonomy and getting control in how my information is handled and what is told about me. I think I do like there to be a more individualised approach in decision making." (Young person with disability, NDIS consultations).

Many children and young people with disability could successfully participate in the self-registration process with adequate support and safeguarding. This participation would foster empowerment, provide opportunities for skill development and capacity building, and help them transition to greater independence, such as when they reach milestones like leaving the family home.

Addressing self-registration barriers

CYDA notes that the DSS Consultation Paper mentions that criteria may be applied to self-registration in terms of:

- NDIS Commission assessing suitability for self-registration, and
- Choice of providers for high-risk supports.

In terms of suitability assessments, any assessment process must be conducted in a way that upholds the rights and dignity of potential self-registered participants. CYDA notes that the DSS Consultation Paper mentions that currently the NDIS Commission is considering whether to apply the criteria for assessing participants who are self-managed to self-registered participants as well (p7). Participants are currently assessed as unable to self-manage if they are bankrupt or insolvent under administration, or if self-management poses an unreasonable risk to the participant.

CYDA cautions against the blanket application of these criteria to self-registered participants, and instead recommends that the criteria be revisited for both self-managed and self-registered participants. In particular, it is crucial that there are clear and transparent criteria for assessing whether there is an "unreasonable risk" to participants to safeguard against arbitrary or inaccurate assessments.

In terms of "high-risk" supports, CYDA understands that there needs to be safeguards in place to ensure that providers are qualified to provide such supports, including the need for advanced registration. However, CYDA is concerned about:

- how high risk and high needs are defined, and the emphasis being placed on needs based on the service or provider being used, and

- limiting the choice and control of self-registered participants who may need high-risk supports. Restricting the pool of providers removes options and does not account for the fluctuations in people’s support requirements or the nuance of support needs that can managed by a self-registered participant.

CYDA recommends that any self-registered participants who may require higher levels of support and engage high-risk providers, are not restricted to using high-risk providers for their entire NDIS Plan. Instead, these self-registered participants should be afforded the choice to engage a mix of registered and non-registered providers to meet their various needs. This means that alongside using high-risk providers, they would be able to engage other providers who do not require advanced registration to deliver any other services or supports not classified as high-risk.

“I am self managed and value the opportunity to choose who supports my son. I provide specialised and personalised training particular to my sons needs and this includes personal care. I am concerned that because my son requires personal care supports that we will be forced to used providers with higher registration requirements and that may exclude some of his current support workers”. (Parent/caregiver of a child or young person with disability, Registered Provider Survey).



Part 3: Support from the NDIS Commission

Recommendation 3: Ensure that children and young people are supported to authentically engage with self-registration processes by:

- a. Giving opportunities for genuine co-design of check-in process.
- b. Creating new resources that provide information and support about self-registration.
- c. Facilitating an independently moderated discussion board or group for self-registered participants to share information and supports.
- d. Funding a peer support program for peers to mentor each other about self-registration.

In response to DSS Consultation Paper questions five to eight which relate to how the NDIS Commission can support self-registered participants through check-ins, information and support structures for sharing innovative practice, CYDA raises the following four points to ensure that children and young people with disability are enabled to engage authentically with the new registration process:

Co-design of check-ins

CYDA strongly agrees that the check-in process should be carefully co-designed with the disability community. In particular, children and young people with disability must be meaningfully included in the co-design process to ensure their needs are accounted for in the design.

CYDA makes these initial suggestions on the check-in process, based on what our community has told us about NDIS processes during CYDA-run consultations and engagement. These suggestions come with the caveat that no concrete decisions about check-ins should be made without genuine co-design:

- The check-in process should be easy to understand, accessible and clear. Expectations of what is needed and what opportunities for support can be provided should be made clear well in advance.
- Check-ins and engagement with the NDIS or government can be a source of anxiety for NDIS participants. We recommend that check-ins are not undertaken more than necessary, especially given the other responsibilities that self-registered participants need to meet. Annual check-ins should be sufficient to ensure consistency and current information sharing.
- There should be the option for participants to elect what form they would like check-ins to take. This could include face to face, a phone call, virtual meeting, or a survey with the option for additional contact and support.

New resources to support self-registration

CYDA agrees that further information is needed to assist self-registered participants with the new process. We recommend the development of new resources that provide information on self-registration, including how the NDIS can support choice and control over providers.

Any new resources must be developed in clear, accessible formats, as these NDIS participants highlight:

“They really need to give – infographics would be helpful, but they need to change their language to be more concise, accessible to the everyday person because there’s so many words that could easily just be changed. So many paragraphs that could just be summarised in one sentence with infographic points.” (Young person with disability, NDIS consultations).

“[NDIS communications are] not very accessible. It’s not very easy to understand and if they can put it in plain English or simplified English, it would be a little bit easier”. (Young person with disability, NDIS consultations).

The need for resources on how to find, screen, manage and train providers and workers is clear from the below quotes:

“Currently, we are able to employ supports who have specific skill sets to directly support in areas of particular need and interest. I take responsibility for screening the people who interact with my family”. (Parent/caregiver of a child or young person with disability, Registered Provider Survey).

“All NDIS provider’s should be well trained and understanding of different aspects and practices and procedures with people with disabilities. This is not happening and disabilities workers are not getting the support and training that they need. Let alone the families or people with disabilities.” (Parent/caregiver of a child or young person with disability, Registered Provider Survey).

Others recommend the provision of human-rights focused resources:

“...‘innovative’ human rights based and community therapy programs [...] are effective and prioritise dignity, autonomy and other things that organically promote the wellbeing and progress of disabled people”.

(Parent/caregiver of a child or young person with disability, Registered Provider Survey).

Based on these insights from our community, new resources could include:

- Templates or guidelines for provider screening, position descriptions, contracts, complaints handling.
- Guidance on finding, managing and training workers.
- Guidance and training on safety and prevention and reporting violence, abuse, neglect and exploitation.
- Guidance on creative support ideas like peer supports.
- Information on human rights approaches.
- Training modules that cover human rights, disability rights, standards of practice etc that participants can use to train their support providers.

Online discussion group as community of practice

CYDA recommends using a co-design process to create an independently moderated online discussion forum that addresses the needs of participants wanting to explore self-registration.

CYDA's previous work demonstrates that children and young people and their caregivers already rely overwhelmingly on word of mouth and peer support to navigate the NDIS ecosystem. As demonstrated by the below quote, the majority of this occurs online through social media platforms.

I'm in a lot of different chronic illness Facebook groups, or Facebook groups for my specific disabilities and so there's a particular Facebook group that I'm a part of that's called NDIS for Ehlers-Danlos syndrome, POTS and hypermobile spectrum disorder. That helped me make so many decisions around applying for the NDIS, the planning process, the types of supports I used in my plan. (Young person with disability, NDIS consultations).

Leveraging off the existing tendency for participants to find trust and support in peer groups online, NDIS should fund an online discussion group that can offer support to participants trying to navigate self-registered participation. It should allow participants to be anonymous if they choose.

A key part of the success for self-registration is for participants to have access to timely and accurate information about the process. The quote below is emblematic of the way many people in CYDA's community are struggling to find supports more generally, let alone navigating a new and potentially complex process:

“...if you have a child with certain conditions, there should be information about this is what a typical support plan looks like, and you should be asking for these things. Because the current system of no information available means if you ask for it, you get it. If you don’t even know about it, you don’t get it. And so transparency around what plans can and should be would be fantastic”. (Parent/caregiver of a child or young person with disability, NDIS consultations).

An online community of practice would provide such access to timely information from those who have current lived experience of the NDIS self-registration process.

Funding for peer support

In keeping with Recommendation 7 of the Taskforce review, the Australian Government should invest in peer supports and capacity building. CYDA recommends funding co-designed programs that facilitate the linking of peers to mentor others in managing self-registration. This should include support groups and one-on-one mentoring.

Participants in previous CYDA research have suggested that peer support or mentoring would be helpful for navigating NDIS more generally:

“We didn't really know many people within the area, so we made a few friends along the way, but they were having the exact same journey we were having. Something that we actually spoke about last night that we thought may help with that is having the ability to have some funding aside to pay someone for their time who's gone through this journey who's open and able to provide that extra support, so they know how the NDIS is worked and how to access and those areas. It would be something that we felt would have helped us immensely at the start to know where to go and put our best efforts.” (Parent/caregiver of a child or young person with disability, NDIS consultations).

Peer support would enable children and young people with disability and their families and caregivers to explore whether self-registration is the right choice for them, and if it is, to assist with managing the process and its responsibilities in a way that builds their capacity.

Demonstrating how many young people prefer peer engagement to feel supported, one young person told us how they use the support worker process to gain peer-type support to attend an art program:

“I have an unregistered support worker who does art with me and I hired her because that is what I want. It is the only way to hire disabled people

to look after me with peer connections.” (Young person with disability, Registered Provider Survey).

Peer support should/could also be considered as an important option for support with self-registration.

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