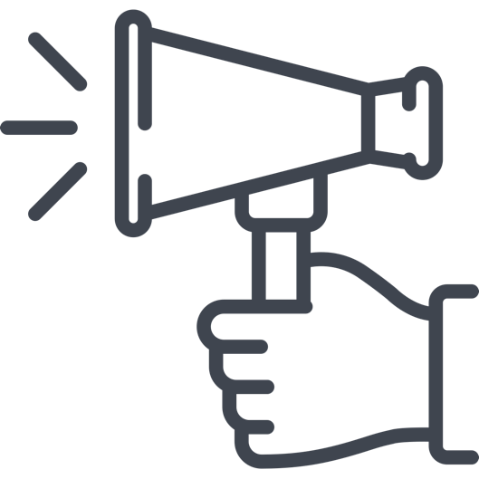
Feedback from young people with disability and the families of children and young people with disability about a risk-proportionate model for provider registration

*“Registration does not equal safety and limits choice and control”.*

Young person #21

**Submission to the NDIS Provider and Worker Registration Taskforce**

**May 2024**

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A note on terminology:

Children and young people with disability

The disability community has largely recognised and used inclusive language and terminology for decades. 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.



Content warning:

*References to ableism, violence and abuse (including sexual)*

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 First Nations land.

**Contents**

[Executive Summary 4](#_Toc166856795)

[1. CYDA’s Position on Terms of Reference 5](#_Toc166856796)

[2. Summary of recommendations 6](#_Toc166856797)

[3. Foregrounding and context 7](#_Toc166856798)

[The problem as outlined by the NDIS Review 7](#_Toc166856799)

[Disrupting ableism, shaping meaning and changing outcomes 8](#_Toc166856800)

[Language and implied meanings 9](#_Toc166856801)

[Supporting a human rights approach 9](#_Toc166856802)

[Informed by staff lived and family experience of disability 10](#_Toc166856803)

[Data considerations 10](#_Toc166856804)

[4. CYDA’s provider registration survey 12](#_Toc166856805)

[Survey results 12](#_Toc166856806)

[Respondent overview 12](#_Toc166856807)

[Question 1 12](#_Toc166856808)

[Question 2 14](#_Toc166856809)

[Question 3 15](#_Toc166856810)

[Qualitative analysis 15](#_Toc166856811)

[Summary of results 23](#_Toc166856812)

[5. Detailed recommendations 24](#_Toc166856813)

Executive Summary

In order to address various challenges to delivering the NDIS a new risk-proportionate provider registration model has been proposed and a Taskforce set up to investigate its implementation.

As means of addressing the limitations in regulatory oversight and challenges with quality and safety, recommendation 17 of the NDIS Review Report outlines a graduated model of registration and enrolment to capture everyone providing services to NDIS participants. Based on this information, CYDA conducted a survey among children and young people with disability and their families and carers, to gather views on how they thought this model might impact them.

* 161 people responded (19% young people and 81% parents/carers).
* 33% were hopeful or very hopeful about the potential changes.
* 40% were concerned or very concerned about the potential changes.
* 17% selected ‘other’ in which most detailed concerns and were not supportive of the potential changes.
* A majority of respondents selected statements with negative sentiment when asked what the Taskforce should consider. Concerningly,7.5 % revealed negative experiences (some constituting abuse) at the hands of registered providers.
* Very few qualitative statements demonstrated support for the potential changes.
* Most qualitative statements indicated concerns about the changes creating barriers for service providers, limiting their choices, exacerbating service shortages in regional and remote areas, dismantling support systems for non-registered providers, and worsening price gouging.
* Qualitative responses demonstrated existing natural safeguards like access to various non-disability services’ registration processes (e.g., working with children checks, AHPRA), protective relationships, self-management, and supported decision making.

In the context of these survey results alongside existing organisational knowledge and lived experience – over 50% of staff at CYDA have lived and/or family experience of disability – we present our submission outlined as follows;

Section 1 CYDA’s position on the relevant Taskforce Terms of Reference

Section 2 Five recommendations to the Taskforce (summary)

Section 3 Foregrounding and context

Section 4 Findings from CYDA’s provider registration survey

Section 5 Five recommendations to the Taskforce in detail

# CYDA’s Position on Terms of Reference

Should the government implement the risk-proportionate provider registration model, CYDA provides our position on the relevant NDIS Provider and Worker Registration Taskforce Terms of Reference.

**The design and implementation of the graduated risk-proportionate regulatory model**

In the design of the regulatory model, CYDA urges the Taskforce to consider the implications of effectively forcing children and young people with disability to “out” themselves as having a disability and being NDIS participants. Many young people are already struggling with their place in the world and their various identities and this would place an unfair burden on them.

Once implemented, the measurement and publication of registered provider performance might ease of the concerns of people who have had negative experiences with providers in the past and provide confidence among participants that the new registration model is leading to more transparency, safety and higher quality supports.

**A Provider Risk Framework**

To achieve accountability and oversight, at a baseline the registration model should collect only the most essential information from providers of low-risk funded supports. This information should equip the NDIS Quality and Safeguarding Commission (or other regulatory body, such as the Australian Tax Office) with the information it needs to follow-up concerns about non-compliance. To reduce concerns in our community about the impact of registration on choice and control, the level of information requested and the process to register as a provider of low-risk supports should not act as a barrier to registration.

**Arrangements for platform providers and circumstances where participants directly employ their workers**

Participants who undertake a risk assessment process and work with proposed Navigators, Support Coordinators, and decision supporters to increase safeguards should be enabled to continue to directly employ their service providers. They would still provide details of their service providers via invoices enabling NDIS to have oversight about who is participating in the system.

# Summary of recommendations

CYDA provides five recommendations for the Taskforce should the government implement the risk-proportionate provider registration model.

**Recommendation 1: Implement further reforms to improve the quality and safety of NDIS-funded services provided by registered providers\*. These reforms should include strategies to enhance protective measures, such as natural safeguards, to prevent abuse.**

* We outline other final NDIS Review Report recommendations that will increase the quality and safety of service provision.
* We discuss natural safeguards as found in CYDA’s survey data and academic literature.

Recommendation 2: Provide details about how it will ensure people with disability will not experience a reduction in access to supports and services and are not charged more by providers once the registration model is in place.

* We detail the possible restrictions to participant access in relation to the proposed registration model.
* We point out the potential impact to existing natural safeguards.

Recommendation 3: Demonstrate how the registration system will be designed so as not to require participants to declare their status as a NDIS participant in order to access services from providers offering services which are not disability related/are low risk.

* We highlight the implications to privacy that the proposed change might have.
* We propose a balanced approach to managing risk while maintaining privacy.

Recommendation 4: Consider the use of existing data (such as the names and ABNs of service providers which are collected by the NDIS when participants or plan managers lodge invoices) and the role of the proposed Navigator to track participant’s supports in the rollout of a new registration model.

* We suggest alternative methods of gaining oversight of the NDIS provider market.
* We call for a strengths-based rather than deficit model when understanding risk.

Recommendation 5: Provide participants with information about enforcement actions for service providers who breach rights and cause harm and implement a "no wrong door" approach to receiving complaints.

* We indicate ways to deal with breaches of trust among NDIS participants.
* We propose an approach to managing complaints.

# Foregrounding and context

In addressing the Terms of Reference for this taskforce and sharing the voices of children and young people with disability and their parents and carers, CYDA holds the disturbing statistics of violence, abuse, neglect and exploitation of people with disability at the forefront of our work.

Volume 3 of the Disability Royal Commission’sfinal report provides the following overarching statistics:

* 55 per cent of people with disability aged 18 to 64 have experienced physical or sexual violence, compared with 38 per cent of people without disability.
* Children and young people with disability experience higher rates of interpersonal violence than older people with disability and young people without disability.

In order to ensure children and young people with disability are being empowered to fully exercise their rights and aspirations, and a means of shifting these unacceptable statistics, CYDA critiques the presentation and framing of policy problems. In doing so, we aim to disrupt any implicit bias and highlight opportunities to reframing policy positions and thereby wider disability narratives.

## The problem as outlined by the NDIS Review

The NDIS Review report[[1]](#footnote-2) outlines the objective of recommendation 17 as being 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.”*

When detailing the problem that this recommendation is intended to address, the report states:

*“There are gaps in oversight of providers, particularly when delivering high-risk supports”.*

In particular they are concerned that unregistered providers do not need to adhere to any *“specific standards beyond the basic expectations in the NDIS Code of Conduct, which describes broad community expectations of expected behaviours for providers and workers involved in support delivery*”.

A yellow circle with hands holding a heart

Description automatically generatedUnregistered providers are described as ’flying below the radar’ with limited regulatory oversight leaving participants, especially those with complex needs, potentially exposed to risk.

The NDIS Quality and Safeguards Commission cannot monitor the market for unregisted providers or *“proactively intervene to prevent harm and promote quality improvement, and has fewer options for taking action against providers if something goes wrong”*.

The NDIS Provider and Worker Registration Taskforce has been asked to provide advice to the Minister on:

* The design and implementation of the graduated risk-proportionate regulatory model;
* A Provider Risk Framework; and
* Arrangements for platform providers and circumstances where participants directly employ their workers.

## Disrupting ableism, shaping meaning and changing outcomes

Acknowledging that the words we use shape our understanding of the world, CYDA values the opportunity to disrupt problematic narratives around disability to advance the human rights of children and young people with disability. Both intentional and unintentional use of words and phrases can perpetuate subjugation and further entrench bias and prejudice, or they can open our minds, change our thinking, and drive inclusion.

A report[[2]](#footnote-3) for the Disability Royal Commission reviewed 168 publications which examined risk and protective factors in the experience of violence, abuse, neglect and exploitation of people with disability. The authors reported four key factors that obstruct a more complete understanding of the experience of violence, abuse, neglect and exploitation and therefore opportunities for better policy making:

1. Investigations of risk and protective factors focus on the person with disability rather than the perpetrators and systems that carry out and perpetuate this abuse.
2. Risk is assigned to static factors within individuals, such as their disability and gender, which fails to guide the most effective interventions.
3. A yellow circle with hands holding a heart

   Description automatically generatedPresentations and descriptions of disability lack diversity, in particular the intersectional experiences of first nations, LGBTIAQ+, those from linguistically diverse communities.
4. Disability is described through a deficit lens using concepts such as vulnerability rather than focusing on agency and capabilities.

CYDA examines language, concepts and recommended actions that might explicitly or implicitly perpetuate ableism – attitudes and practices that devalue and discriminate against people with disability – including our own. In doing so we join a lineage of change makers who disrupt entrenched ideas and narratives and move the need for social justice and human rights – in our case, for children and young people with disability.

### Language and implied meanings

The words and phrases used in spoken and non-spoken communication can impact understandings of the problem being considered, and how we think about the agency of the people being discussed. As such we question the use of particular words and terminology, the placement of agency, the type or level of problem being considered, and any factor that obscures the actual root cause of the problem being considered.

Common narratives we disrupt by highlighting their use in our advocacy work:

* Language, tone and phrases that perpetuate a concept of a “normal” or “average” person as a non-disabled person that systems are generally built by and for.
* Language, tone and phrases that make it seem as though the conditions of risk, vulnerability and victimisation are inherent to the person with disability or to disability itself rather than the systems and cultures that perpetuate ableism.
* The assignment of agency for change to a person or group who did not create the problem and who have no control over the conditions that are actually responsible for the problem (this can sometimes be the case with objectives such as ‘building capacity and resilience’).
* Language, tone and phrases that are deficit rather than strengths-based.
* Red-herrings, or statements that claim to be addressing something they are not.

## Supporting a human rights approach

Emerging from the United Nations Convention on the Rights of Persons with Disabilities, one of nine human rights instruments developed by the United Nations, a human-rights model recognises that:

* Disability is a natural part of human diversity that must be respected and supported in all its forms
* People with disability have the same rights as everyone else in society
* A yellow circle with hands holding a heart

  Description automatically generatedImpairment must not be used as an excuse to deny or restrict people’s rights.

As per the recommendation of the Disability Royal Commission, CYDA calls for the Australian government to commit to the enactment of a Disability Rights Act that reflects and embodies the principles in the UN Convention on the Rights of Persons with Disabilities.

Following are some of the rights outlined in the NDIS Act 2013, that have particular relevance to this submission:

* People with disability should have their privacy and dignity respected.
* People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.
* People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.
* People with disability should be supported to receive supports outside the National Disability Insurance Scheme and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.
* Innovation, quality, continuous improvement, contemporary best practice, and effectiveness in the provision of supports to people with disability are to be promoted.

## Informed by staff lived and family experience of disability

As well as being a systemic advocacy organisation with a mandate for policy reform, CYDA directly employes many people with lived experience of disability, family experience of disability and sometimes both. This places us in a position to appreciate the policy process while also having a direct understanding of the impact of policy outcomes. Most of us live with the intended and unintended consequences of disability related laws, policies and practices.

## Data considerations

CYDA acknowledges that the survey was open for response prior to the initial webinar introducing the Taskforce and as such respondents potentially had a limited understanding of the Taskforce, their terms of reference and the proposed model. However, we feel it is significant that 161 members of our community chose to share their feelings about the proposed changes and as such believe the results provide an important “tone check”.

A yellow circle with hands holding a heart

Description automatically generatedOur recommendations are balanced to take account of the survey responses as well as existing organisational knowledge and lived experience within CYDA.

We would also like to note that all qualitative responses presented in this submission are documented verbatim and include words, punctuation, and phrases exactly as entered into the survey. We have done this to allow the Taskforce to derive their own interpretation of what respondents said.

# A light bulb with rays of light coming out of it Description automatically generatedCYDA’s provider registration survey

Between 20th February and 18th March 2024, CYDA collected responses via online survey from young people with disability and parents/carers of children with disability on the proposed proportional registration of NDIS providers. Following a question on demographics, the survey asked respondents how they feel about the proposed changes to registration, what aspects the taskforce should consider and how they felt about using unregistered providers (if they did so).

## Survey results

### Respondent overview

* 161 total respondents
* 30 (19%) respondents identified as young people with disability and 130 (81%) as parents or carers of a child or young person with disability. One respondent didn’t specify[[3]](#footnote-4).
* 102 respondents made one or more additional comment (19 of these were young people), which makes up a substantial body of qualitative data.

### Question 1

*How do you feel about the potential changes in how NDIS providers are registered, based on risk?*

*For example: Advanced registration for high-risk supports, such as daily living supports delivered in formal closed settings like group homes. Basic registration for lower-risk supports, such as sole traders and smaller organisations or supports involving more limited 1:1 contact.* A link to the NDIS page was included.

Table 1: Responses to question 1

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Parents/ carers (n=131) | Young people (n= 30) | Total (n=161) |  |
| Very Hopeful | 25 | 1 | 26 (16%) | 33% |
| Hopeful | 23 | 4 | 27 (17%) |
| Concerned | 11 | 5 | 16 (10%) | 40% |
| Very concerned | 40 | 9 | 49 (30%) |
| Other (please specify) | 22 | 5 | 27 (17%) |  |
| Neutral/Undecided | 10 | 6 | 16 (10%) |  |

A light bulb with rays of light coming out of it

Description automatically generatedInitially, the quantitative data[[4]](#footnote-5) appears to demonstrate mixed views on the proposed recommendation, however 17% of respondents selected ‘other’ warranting a deeper analysis of this impression. Drilling down on the quantitative responses revealed a strong sentiment of concern for this recommendation with just over half (16) of those who provided additional details (27) demonstrating that they do not support the proposed changes. Only four of the responses indicated clear support for proposed changes with the remaining seven indicating neutrality or indecision.

One parent/carer respondent said,

*“It will limit choice and control, in the 28 years of caring for my daughter it is the registered agencies that have put her most at risk.”*

PC 3

Furthermore, it is important to note that of the young people who responded quantitatively, 47% said they were concerned or very concerned and only 17% said they were hopeful or very hopeful about the proposed changes, with the remainder having selected neutral or other.

One young person who responded ‘other’ said,

*“It is a bandaid. Just like the wwc checks and ndis screening. Nothing is full proof - particularly when regulations are used to solve a society wide responsibility of protecting vulnerable people (PwD) or keep them safe within their own family home”.*

YP 90

And other shared concerns about autonomy, saying,

*“I should be able to decide the level of risk”*

YP 130

The themes from the qualitative data in this question are discussed further, alongside the other qualitative responses, in a separate section following.

### A light bulb with rays of light coming out of it Description automatically generatedQuestion 2

*In your opinion, what positive or negative aspects should the Taskforce consider during this process? Please select all that apply.*

Table 2: Responses to question 2

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Statement | Parents/ carers (n=379\*) | Young people (n=75\*) | Total (n=454\*) |  |
| Concern | Concerns about limited options and potential difficulties finding providers who truly understand your needs | 95 | 24 | 119 | 71% |
| Apprehension | Apprehension that relying solely on registered providers might restrict your ability to choose those offering innovative or non-traditional services | 82 | 20 | 102 |
| Worry | Worries about reduced flexibility in the types of support available, making it harder to adapt as your needs change | 83 | 19 | 102 |
| Belief | Belief that it could help ensure NDIS providers meet specific standards of care and professionalism | 45 | 3 | 48 | 25% |
| Optimism | Optimism that it might lead to better coordination of services and support, making it easier for you to navigate the NDIS | 39 | 2 | 41 |
| Excitement | Excitement about how this could encourage innovation and diversity among NDIS providers, offering more tailored solutions for people with disabilities | 25 | 2 | 27 |
| Neutral | Neutral feelings about proportional registration, open to learning more about its potential benefits and drawbacks | 10 | 5 | 15 | 9% |

\* Indicates the total number of selections, not the total number of respondents.

Responses to this question demonstrate vastly more negative sentiment towards the proposed change to registration compared to positive or neutral sentiment.

Of the total responses selected (454), many more were statements that indicated concern, apprehension and worry (323 or 71%) than belief, optimism or excitement (116 or 25%) or neutrality (15 or 9%).

### A light bulb with rays of light coming out of it Description automatically generatedQuestion 3

*If you currently use unregistered providers for the supports and services in your NDIS plan, what do you think?*

Responses to this question, and those who selected ‘other’ in question 1 have been broken down into four key themes, which are discussed below.

### Qualitative analysis

#### Identifying risks

Respondents identified and discussed their thoughts and feelings in relation to risk, both as an outcome of the proposed changes to the registration process and of not changing it.

A few respondents felt like it was a risk to use unregistered providers, pointing out things like lack of training and expertise in the sector.

One respondent said,

*“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.”.*

PC 8

However, many more respondents concluded that the proposed changes presented a risk for themselves and their loved ones.

Many were worried that the proposed changes might disincentivise existing service providers to continue their services, such as this young person who said,

*“This is a crap idea. No way my providers will register - they have already told me so. Registration should only be required for participants that don’t Self or Plan Manage. If you self or plan manage you should have capacity (or capacity with support) to exercise your consumer rights”*

YP 19

And this parent drew attention to potential issues of discrimination in a reduced market for services.

*“I think unregistered providers make things easier to access and realize that some people have different needs and interests. Some places would close up or not accept people with some disabilities”.*

PC 18

Among the concerns about existing unregistered providers being disincentivised to remain in the market, some respondents highlighted the potential for geographical A light bulb with rays of light coming out of it

Description automatically generatedlimitations to be compounded by the proposed change. This young person explains why they think unregistered providers are necessary,

*“I think it’s a necessary thing since in smaller cities & towns, there’s significantly less options for providers let alone registered ones. In fact it’s so bad that I’ve had an NDIS plan for nearly a year and a half and I still haven’t even gotten some supports that were listed in my plan or have just gotten them a few weeks ago”.*

YP 36

Quite a few parent/carers share this concern, such as,

*“There are no registered providers in our town. This recommendation is a disaster for regional and remote people. Providers have only 1 or 2 NDIS participants out of hundreds of clients. They will never bother with registration, and have said so. It isn’t worth the effort for only 1 or 2 clients. Which means we lose all supports. Also, therapists are already AHPRA[[5]](#footnote-6) registered!!!!!”*

PC 111

Some were worried about the ability of a narrower, registered market to meet the needs arising from their intersectional identity and disability.

*“I’m concerned about losing the people that I rely on. 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”.*

YP 128.

And parents of children and young people with complex support needs were concerned about a shrinking market for tailored supports.

*“There are so few supports that meet my child’s significant needs (Sign Language, interpret non-verbal autistic behaviours, toileting assistance, etc). Their services are in high demand OUTSIDE OF NDIS. If more barriers are created in engaging them through NDIS funding, many (most?) will choose to simply not provide services to NDIS clients like my child. The horrific abuse and deaths of NDIS participants at the hands of registered providers are always front of my mind as my teenage child is at high risk of abuse (intellectual disability and non-verbal and minimal communication ability): Alex Raichman; Anne Marie Smith; Merna Aprem; …”*

PC 12

*“I currently use unregistered providers for my son's supports. 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* A light bulb with rays of light coming out of it

Description automatically generated*supports that we will be forced to used providers with higher registration requirements and that may exclude some of his current support workers”.*

PC 41

A parent/carer noted issues with disclosure and privacy alongside the fact that they are able to make the plan budget stretch when providers aren’t aware of the participant’s NDIS status.

*“I am very concerned about the requirement to use registered providers because it will necessitate disclosing the fact that you are an NDIS participant. As a self manager, I like maximum flexibility to choose providers and use the plan to best meet my son’s support needs and allow the plan to stretch”.*

PC 75

Many indicated existing price gouging and expressed their worry about worsening its impact. For instance, this parent, who also shares the importance of ‘relatable’ services that meet the needs of their child, says,

*“I get better prices and more relatable services suiting child needs. Price gauging, raised prices occurs when organisations have to increase fees to justify have registered. There are not enough services in all areas to justify this, this is a bad move. Some Unregistered services provide cheaper prices and that's a good thing. Please rethink this decision before you make a price gauging increase of services. Supposed to be fixing issue not creating a further one”.*

PC 64

Perhaps most alarmingly, 12 respondents (across all qualitative responses) provided examples of negative experiences, as well as violence, abuse, neglect and exploitation, while using the services of registered providers.

One young person said,

*“Registration does not equal safety and limits choice and control. I was stolen from several times with registered providers and had so many support workers through my door! Registration is a step backwards. Has registration improved the nursing profession or the teaching profession?”*

YP 21

A parent shared their child’s abuse,

*“My daughter was sexually assaulted in the care of a registered service provider. Forgive me if I prefer hand picked unregistered providers for my daughter. Registration proves nothing! It does not guarantee participant safety or quality of care. Let us choose. Do not discriminate against my daughter with a disability. She has a right to choose!”*

PC 115

And another shared an experience of exploitation of their child’s NDIS service package,

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Description automatically generated

*“I like my current service providers, most of which are not registered providers. I don’t want to change as the registered providers have taken funds without providing the service”.*

PC 70

Concerns about the risk of losing choice and control amongst responses was so prevalent in the data that it is discussed separately below.

#### Concerns about choice and control

CYDA cannot state strongly enough the range and number of comments and concerns that specifically mentioned choice and control – indicating a strong desire among children and young people with disability and their parents/carers to retain autonomy and flexibility, as is their right under the original intention of the NDIS.

*“[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

This young person decisively stated their objection to the proposed change to registration, citing choice and control as critical elements of how the NDIS was envisioned to operate.

*“Removing unregistered providers under the recent decision contradicts the fundamental principles the NDIS was built upon. Rather than equipping and enabling me and my family to be in control and make choices with confidence, this decision does the opposite, instilling fear about the direction of my life. The Productivity Commission's vision for Tier 3 of the NDIS included entitlements to individually tailored supports, certainty of funding based on need, genuine choice over how needs are met, local area coordinators, disability support organizations, and a long-term approach to care with a strong incentive to fund cost-effective early interventions. The decision to eliminate unregistered providers jeopardizes these fundamental features, making the NDIS inaccessible for my needs. It undermines the genuine choice envisioned by the Productivity Commission, putting barriers in place that hinder my ability to tailor support packages to my individual needs and to choose providers who align with my preferences. While acknowledging the need to address fraudulent behaviour, I urge you to reconsider this decision and explore alternative solutions that uphold the original principles of the NDIS. And Recognize the adverse impact on the well-being of participants who depend on the unique advantages provided by independent contractors and unregistered providers*

YP 68

In keeping with other publicly available discussion on this proposed change to NDIS registration, participants respondents discussed the concept of choice and control primarily in relation to not supporting changes to the provider registration process”. Choice and control were identified clearly by some respondents as being a right, as this young person indicated,

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Description automatically generated

*“I am nervous as a young person to lose choice and control so early in my disabled life. My rights are being ripped away from me. Only me and my family know what is safe for me, not the government”.*

YP 130

One respondent, recognising the innovative aspects of the current arrangements, emphatically questioned,

*“What happened to Choice and Control? We have innovative providers who don't need more paperwork to provide their excellent services. They focus on the participants!!”*

PC 29

Another highlighted the absence of genuine choice in the proposed changes and related this to concerns about the limitations of existing supports in regional locations.

*“I don’t like the idea as mainstream registered providers do not give holistic supports and in regional areas are few and far between. It’s not choice if you have bad and then worse registered providers to choose from”.*

PC 124

Respondents also highlighted regulatory over-reach as adversely impacting choice and control, as this parent/carer exemplifies,

*“Forced registration would be a nightmare, it removes choice and control, gives too much power to careless corporations, is discriminatory and patronising to people with a disability, is an over reach and over regulating people’s lives”.*

PC 121

#### Identifying safety

Many respondents identified and discussed their ideas in relation to safety, both as an outcome of changing the registration process and not changing it. Many of the responses that discuss safety, overlap with other themes, especially risk and choice and control.

Similar to the theme of risk, a small minority of respondents pointed out the safety in using registered providers. For example, one parent/carer said,

*“I only use registered providers because I am always concerned about my daughters safety”*

PC 123

However, a clear majority of respondents argued that their use of non-registered providers is a key factor in what creates safety for them and their families. Highlighting numerous natural safeguards, they discussed the autonomy, flexibility, dignity, trust and innovation they have experienced while using non-registered providers.

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Description automatically generatedRespondents, such as this parent/carer, identified the tailored and targeted support that self-management and non-registered providers and workers offer.

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

PC 120

Another respondent, identified the specific skills sets their family is able to find in the open market and voiced their concern about narrowing opportunities for support services in rural and regional locations,

*“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, as I have always done, for years before NDIS. Being directed towards only registered supports limits our choice and control, and further restricts our options as we live rurally”.*

PC 100

Numerous respondents drew attention to the use of supports that aren’t necessarily targeted at people with disability underscoring the potential for better inclusion outcomes by allowing participants to create and manage their own teams of providers.

For instance, this young person’s comment illustrates their desire to retain autonomy and their capacity for engaging the precise supports that are right for them via service providers who might not solely work for people with disability.

*“Where I can I choose to seek supports through providers that don’t market themselves as disability service providers and would likely not go down the path of registration for NDIS if it was going to create more admin for them. In a society where we are advocating for inclusion, we should be encouraging and enabling integration. I really dislike the idea of not having that choice. Disability service providers are the biggest money grabbers and suck every dollar they can. My unregistered service providers treat me like a regular human being and often go over and above. The onus on Ndis should be on ensuring that clients are allocated the correct support budgets. How as client we use that support budget and the providers we choose should absolutely be up to us, or the people we trust to make those decisions. Requiring service providers to register is not going to address the route problem of all the money that’s being wasted. Possibly is only going to make it worse”.*

YP 44

One young person explained their use of peer-to-peer support workers as being beneficial to their sense of trust, autonomy and affirmation of their identity, saying,

*“Unregistered providers offer services I can’t get on NDIS. I have an unregistered support worker who does art with me and I hired here because that is what I want. It is the only way to hire disabled people to look after me with peer connections. Art therapy offered on the NDIS does not work for me and I’m is too expensive for me to afford and providers are unreliable, not affirming and not from the community. Removing unregistered provides* A light bulb with rays of light coming out of it

Description automatically generated*removes the ability for disabled people to hire those they choose and other disabled people who understand me”.*

YP126

A parent/carer who is a NDIS participant themselves, pointed out dignity and autonomy as being critical to the wellbeing of people with disability, suggesting that these attributes arise through innovative, human-rights based service models that may be restricted if the proposed changes are implemented.

*“I am very happy with my supports (I am over 25) and the supports for my son (aged 6). I have vetted both registered and unregistered providers extremely carefully. I am concerned that this requirement for registration will restrict amazing support workers like the ones we have found from entering the industry, as well as restrict the growth of ‘innovative’ human rights based and community therapy programs (which are effective and prioritise dignity, autonomy and other things that organically promote the wellbeing and progress of disabled people)”.*

PC 150

Some respondents pointed out existing processes that enable a sense of safety and highlight the duplication that further registration processes would create, potentially disincentivising service providers and shrinking the market.

*“I agree that advanced registration for high-risk supports requires a higher level of scrutiny. I also think that small organisations should be registered. However, for lower risk supports such as sole traders it is not necessary. They already have their Blue Card if working with children, and the yellow NDIS card. Crim history checks can be obtained before working. It is up to the client to interview and choose a support worker most suitable to their needs. EG. My child would not interact with anyone I interviewed who had “qualifications”. The only people he could work with successfully where people known to him that understood him. They were the ones I chose to be his support workers. Anyone else failed and could not interact with him. This change would leave kids like him without support workers”.*

PC 80

As previously demonstrated, many respondents indicated a level of trust in service providers who are registered with AHPRA. This parent/carer exemplifies the sense of confidence respondents felt in this choice as well as the broad cynicism about the safety that the existing registration process achieves.

*“The providers we choose are registered with AHPRA. (We don't use support workers so can't comment about registration requirements for this group) we are confident that there provision of support is just as safe and professional as any other who is registered with the NDIS . We have also heard of some very concerning practices by registered providers so a provider being registered with the NDIS does not mean that they will be any better than a non-registered provider”.*

PC 86

#### A light bulb with rays of light coming out of it Description automatically generatedDemonstrating scepticism and lack of clarity in the process

Many respondents were dubious about the impact that changing the registration process would have on their lives. Most simply didn’t believe the changes would lead to improvement.

One respondent said the proposed changes were,

*“Pointless, total beat up of how many people are abused by non-registered…”.*

PC 39.

A young person shared their cynicism, saying,

*“I think whatever is done will be worked around by dodgy providers regardless, look at nursing homes”.*

YP 24

And a parent carer similarly stated,

*“I think registration is likely irrelevant at best to the chance of abuse, neglect etc occurring. At worst it will increase the probability. Most cases of abuse, mistreatment, poor performance that I am aware of occur within registered organisations and providers (closed culture, protection of workers as priority within complaints). I have seen this fear similarly reflected in people who need high levels of care. My (and many others) observations is that the best providers of support consistently seem to be independent workers (accountable to client/guardians) and the new ‘innovative’ human rights based practise organisations”.*

PC 150

Some responses indicated lack of clarity about what was being proposed. For instance,

*“If there is to be registration of services they need to make it more streamlined and more affordable and less time consuming otherwise we will lose a lot of very helpful smaller ndis businesses”.*

PC 105

And although some respondents may not be aware of the exact detail of the proposed changes, many still had valid concerns.

*“I'm concerned about the costs of supports and when I use unregistered providers as they don't need to pay to be registered they are able to be more flexible on the amount they charge. Thus I can make my plan go further. I'm concerned that I will loose all my unregistered providers and then not be able to choose who will support me on a daily basis but be "allocated" someone by a registered provider. I'm concerned that I will end up with poor support where I will need to be constantly training a new face everyday and not have consistent support. This will make the support exhausting”.*

Nil 76

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Description automatically generated

Some also indicated existing capacity to manage and deal with risk, maintaining their lack of faith in the proposed changes to manage risk effectively.

*“I have safeguarding plan in place and feel that registration does not equate with quality or safer service”.*

PC 119

## Summary of results

Based on the analysis of survey results, CYDA concludes that the majority of respondents do not support the proposed changes. Survey participants indicated that they are concerned with the proposed changes and that the changes might represent additional burden and risk to the daily lives of children and young people (and their families/carers).

In particular:

* The loss of choice and control which currently provides autonomy and dignity, both human rights essential for wellbeing.
* Possible restrictions to the already limited workforce in regional and remote areas.
* The potential for price gouging and therefore less overall support for participants.
* Privacy and confidentiality concerns as an outcome of forced disclosure of NDIS participation and disability identity.
* The potential for further ruptures in trust among a community of participants who do not believe that current registration is improving safety or who have experienced violence, abuse, neglect and exploitation.
* The possibility of restrictions in the workforce leading to limitations for NDIS participants to tailor support to their specific needs and identities.

Many descriptions of natural safeguards in the existing set-up were compelling:

* Community embedded, tailored supports to increase inclusion and sense of identity affirmation and belonging.
* Cost savings through innovative use of supports.
* Autonomy and dignity in current choice and control model.
* Increased flexibility, especially in rural and regional areas, to find supports for very specific needs.

# A head with a brain inside Description automatically generatedDetailed recommendations

Taking into account the findings from the survey and our previous work, CYDA offers the following.

If the government proceeds with implementing a graduated risk-proportionate regulatory model of NDIS providers, the government must:

CYDA recommendation 1: *Implement further reforms to improve the quality and safety of NDIS-funded services. These reforms should include strategies to enhance protective measures, such as natural safeguards, to prevent abuse.*

The NDIS Review report contains 26 recommendations along with 139 actions to reform the delivery of the scheme. Following is a brief summary of 10 of these recommendations that CYDA believes, if adequately implemented, will introduce improved quality and safeguarding to the scheme. We end this section with an overview of natural safeguards as protective measures.

*NDIS recommendation 2:* Increase the scale and pace of change in mainstream and community inclusion and accessibility and improve the connection between mainstream services and the NDIS.

The actions in this recommendation form an overarching plan for mainstream inclusion, public education on intersectional disability identities, and reform including disability rights more broadly across public policy. These actions would create more awareness of human rights, and a higher level of inclusion for children and young people with disability in public life which the evidence tells us, increases safety and wellbeing outcomes.

*NDIS recommendation 4*: Support all people with disability to navigate mainstream, foundational and NDIS service systems.

The actions of this recommendation advocate for the introduction of the ‘Navigator’ role, a person already embedded in the community, to assist and act on behalf of and at the direction of participants. This role, if also subject to accountability, will provide safeguarding and oversight of service providers on behalf of NDIS participants.

*NDIS recommendation 5:* Provide better support for people with disability to make decisions about their lives.

The actions under this recommendation would assess each participant’s needs for assistance with decision making and provide funding for formal supports where required. They also include decision making capacity building for participants with cognitive disability and complex communication support needs. The proposed Navigators would have a role in guiding participants to access decision making supports and linking A head with a brain inside

Description automatically generateddecision supporters to information and training. If proposed Navigators also receive training in disability inclusion, anti-ableism and intersectionality, these actions would be best practice in enabling people to develop their skills while preserving choice and control.

*NDIS recommendation 8*: Fund housing and living supports that are fair and consistent, and support participants to exercise genuine choice and control over their living arrangement; and

NDIS r*ecommendation 9:* Deliver a diverse and innovative range of inclusive housing and living supports.

Although CYDA is concerned that the suggested shared support ratio of 1:3 and ‘bundled’ supports might lead to problematic group home environments, other actions within both these recommendations do support increased flexibility, inclusivity and choice for housing. These actions have the potential to increase safety in that participants could more successful embed themselves into their local community, an outcome associated with natural safeguarding.

*NDIS recommendation 10*: Invest in digital infrastructure for the NDIS to enable accessible, timely and reliable information and streamlined processes that strengthen NDIS market functioning and scheme integrity.

The actions in this recommendation might be able to capture data from service providers, such as name, ABN and contact information, partially meeting the stated intention of the lower tiers of the proposed model (light-touch registration and basic visibility).

*NDIS recommendation 12*: Embed, promote, and incentivise continuous quality improvement in the market, supported by a dedicated quality function in the new National Disability Supports Quality and Safeguards Commission.

In particular, the action regarding the measurement and publication of registered provider performance might ease of the concerns of people who have had negative experiences with providers in the past. Also increased transparency by powerful institutions will act as a natural safeguard.

*NDIS recommendation 16*: Deliver safeguarding that is empowering and tailored to individuals, their service needs, and environments.

Many of the actions in this recommendation will address the quality and safeguarding that the proposed model is also seeking to address. In particular, the individual risk assessments, Visitor Scheme, and universal safeguarding to facilitate anyone to raise safety concerns (with a national reporting phone number) will significantly increase the safety of children and young people with disability.

*NDIS recommendation 18*: Reinvigorate efforts to urgently drive reduction and elimination in the use of restrictive practices.

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Description automatically generatedImplementing the actions associated with this recommendation will increase the safety of children and young people through bans on restrictive practices, stronger compliance actions, and rights-based culture building.

*NDIS recommendation 19*: Embed effective quality and safeguarding institutions and architecture across the disability support ecosystem.

The actions from this recommendation use policy drivers to support many of the safeguarding priorities across the entire NDIS Review.

Additionally, a framework of protective factors and natural safeguards could be developed using existing evidence from the Taskforce, DRC, and literature from fields of trauma[[6]](#footnote-7) and critical disability[[7]](#footnote-8).

The survey data revealed the following factors which would likely serve as protective:

* Self-management
* Access to wide range of service providers, including non-registered, peer-to-peer, non-disability specific services
* Choice and control
* Supported decision-making
* Protective relationships
* Sense of belonging and affirmation of disability identity
* Dignity
* Flexibility
* Individualised support opportunities
* Human-rights based support organisations
* Existing processes and registration (AHPRA, Working with Children check, police check)

In a recent article[[8]](#footnote-9) on choice, control and safety among NDIS participants, researchers pointed out that choice and safety are not opposing concepts and that in fact, increasing participant choice also increases safety. *“Choice – which promotes safety –* A head with a brain inside

Description automatically generated*is best supported when participants are informed, empowered, and have a range of people to go to for help, including when things go wrong”,* the authors said.

They added,

*“Safety is about being connected and embedded within the community, where many people are looking out for you, checking in on you and noticing if you don’t show up to your usual activities. Supporting all people with disability to build and sustain these relationships should be a priority”.*

Additionally, the Disability Royal Commission Final Report (Volume 10: Disability Services[[9]](#footnote-10)) stated that denying participants choice can increase their risk of violence, abuse, neglect and exploitation.

CYDA recommendation 2: *Provide details about how it will ensure people with disability will not experience a reduction in access to supports and services and are not charged more by providers once the registration model is in place.*

Existing evidence[[10]](#footnote-11) demonstrates that majority of participants do not utilise even close to 100% of their plan budget. Participants are unable to access the support they need due to limitations in the type, availability, and number of approved providers. Media reports[[11]](#footnote-12) in late 2023 revealed that most participants use only 70-80% of their funds and in thin markets, such as regional and rural areas, utilisation rates are low as 40%. Given that existing participants are unable to receive support due to lack of access, CYDA is concerned, as revealed in the survey data, that the proposed registration model should not exacerbate this issue.

In a recorded discussion[[12]](#footnote-13) led by Dr George Taleporos, an academic expert on governance and public policy, Prof. Helen Dickinson from University of New South Wales shared her thoughts on the impact of the proposed changes to registration might have on the supply of supports for participants.

*“There’s a real danger that if providers don’t register or enrol, we’re going to see even bigger gaps in the market. We know that there’s already some substantial* A head with a brain inside

Description automatically generated*gaps there, so we’re going to see a shortage of workforce and of services, and I think we’ll particularly feel that in regional and remote areas where at the moment in a number of those areas there are no or very few registered providers. So, we could see these real gaps emerge. And there’s a bunch of people who have developed support arrangements over many, many years. They’ve given really careful thought to how to set those up. They’re really innovative and they’re often lower cost than registered providers.”*

She added her concern about the proposed changes to registration limiting the natural safeguard of being embedded within a local community.

*“[I]f we make people use just registered providers, are we going to segregate people into disability only services, and that’s going to push people further away from the communities that they should be embedded within”.*

She followed this concern with a description of her recent research into why people use unregistered providers, which is outlined in CYDA recommendation 3, below.

CYDA recommendation 3: *Demonstrate how the registration system will be designed so as not require participants to declare their status as a NDIS participant in order to access services from providers offering services which are not disability related/are low risk.*

The government need to outline how participants’ privacy will be maintained and protected in the new system, as per article 12 of the Universal Declaration of Human Rights[[13]](#footnote-14) which prevents interference in privacy and the corresponding federal and state legislation.

Privacy and forced disclosure of disability status is a significant concern. CYDA does not support a registration model that forces children and young people with disability to reveal their identity/status as being disabled or NDIS participants. Many may fear prejudice and biased treatment based on this. Others might also be concerned about price gouging once providers become aware they are NDIS participants.

Academic and lived-experience experts involved in the discussion on the Reasonable and Necessary podcast12 mentioned in CYDA recommendation 2, discussed the reluctance of some participants to disclose their disability or participant status.

Academic expert, Professor Helen Dickinson, said,

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Description automatically generated*“Thinking back to the research that we did when we asked people why they use unregistered providers, often they said it’s, “Well you know, I want to get gardening or cleaning or whatever services from the sorts of organisations that other people use.” They don’t have to know that I’m an NDIS participant or I’m a person with a disability. But in this new system, if you’re going to go and get services from those, you will have to – if they’re not already registered or enrolled, you’d have to ask those organisations to go through that process in order to use that, and in that process you’re going to have to disclose that you’re an NDIS participant as well.”*

Another podcast participant with lived experience of disability said,

*“We have to lean into this human rights piece, and that’s the bit that I guess really gets me around the enrolment of a gardener or the enrolment of a cleaner in a remote area is that the UNCRPD talks about we should be equal citizens before the law. And that means we should be able to consume products like everyone else. And so those gardeners will know that my child had a disability. Why should they know for those services where it’s better and it’s more economical to use those services that everyone uses because that’s what inclusion is. That’s what citizenship is.”*

Despite the NDIS Review being reluctant not to place additional responsibility for risk management onto participants, CYDA believes it is important to strike a balance. Participants should have autonomy and be supported to choose a higher level of risk for themselves in order to maintain their privacy, dignity or any other number of benefits, as it their right. The proposed risk assessment process in NDIS Review Recommendation 16 would support this approach.

CYDA recommendation 4: *Consider the use of existing data (such as the names and ABNs of service providers which are collected by the NDIS when participants or plan managers lodge invoices) and the role of the proposed Navigator to track participant’s supports in the rollout of a new registration model.*

Given that ABN data is publicly accessible and already provided to the NDIS when invoices are submitted, having participants register their own service providers (through the service of the proposed Navigator if needed) meets the needs of the NDIS to provide oversight of Practice Standards and full visibility of the market as outlined in the Final Review Report. This is especially achievable for provider categories C and D and would allow participants to work with their Navigator to register their service providers and manage adherence to a code of conduct and screening requirement where relevant.

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Description automatically generatedThis approach would ensure participants are not forced to disclose their disability or participant status to potential service providers, thus maintaining their right to privacy.

In determining how participants are assessed regarding the requirement to register their own providers or only use registered providers, CYDA does not support the categorisation of NDIS participants using terminology such as “vulnerable”. Such categorisation does not correctly assign agency where change is required (systems and institutions) and further entrenches a deficit approach to disability. The blanket labelling of people as vulnerable erodes individual identity, removes choice, limits independence, and legitimises doing to, not with. It also turns our attention away from addressing the attitudes and practices and policies and institutions that create and perpetuate vulnerability.

Rather, we recommend using a human-rights approach to risk assessments and safety that focuses on working with people with disability to build participants’ skills in decision-making and using support in instances where systems are not safe for people who require additional support to understand their rights and communicate their needs and preferences.

CYDA recommendation 5: Provide participants with information about enforcement actions for service providers who breach rights and cause harm and implement a "no wrong door" approach to receiving complaints.

The significant and serious breaches of trust and failures of the NDIS Quality and Safeguards Commission was evident in our survey data. We draw particular attention to the examples of violence, abuse, neglect, and exploitation provided by respondents in relation to accessing services through registered providers.

Additionally, we note that the actions contained in NDIS Review recommendation 16 (individual risk assessments, Visitor Scheme, and universal safeguarding with a national reporting phone number) have arisen from The Boland Report[[14]](#footnote-15), an independent review of the reportable incidents, complaints, restrictive and prohibited practices of a registered service provider in 2023. Alarmingly, the same recommendations were also made in an independent review conducted into the circumstances of Anne-Marie Smith’s death[[15]](#footnote-16) in 2020.

A head with a brain inside

Description automatically generatedConsequently, CYDA believes that changes to the model of provider registration will continue to be met with significant scepticism unless the changes are accompanied by tangible actions to address these misgivings.

The lack of safe and accessible reporting system for concerns and complaints of violence, abuse, neglect and exploitation has been robustly established in evidence and reporting[[16]](#footnote-17) for the Disability Royal Commission.

CYDA welcomes recommendation 16.5 of the NDIS Review which calls for, “a single national phone number for raising concerns regarding the safety of a person with disability at risk of harm and taking a ‘no wrong door[[17]](#footnote-18)’ approach on safeguarding issues”. In keeping with the Commonwealth Ombudsman’s Better Practice Complaint Handling Guide, CYDA would like to see the current NDIS complaints process improved using the ‘no wrong door’ approach.

Participants should be provided with details about new and improved safeguarding processes and enforcement actions used against providers who violate NDIS participant’s rights or cause harm.

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