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# ‘I've probably risk assessed this myself’: Choice, control and participant co-regulation in a disability individualised funding scheme

Sophie Yates<sup>1</sup>  | Helen Dickinson<sup>2</sup>  | Raelene West<sup>3</sup>

<sup>1</sup>Crawford School of Public Policy, Australian National University, Canberra, Australian Capital Territory, Australia

<sup>2</sup>Public Service Research Group, School of Business, UNSW Canberra, Canberra, Australian Capital Territory, Australia

<sup>3</sup>Melbourne Disability Institute, University of Melbourne, Melbourne, Victoria, Australia

## Correspondence

Sophie Yates, Crawford School of Public Policy, Australian National University, Canberra, ACT, Australia.

Email: [sophie.yates@anu.edu.au](mailto:sophie.yates@anu.edu.au)

## Abstract

Co-production is an intrinsic component of disability individualised funding schemes such as Australia's National Disability Insurance Scheme (NDIS). In this paper, we argue that an under-explored facet of co-production is the role that users of these services play in co-regulation. We draw on data collected in a qualitative study exploring participants' use of providers who are not registered with the NDIS regulator, the Quality and Safeguards Commission. Employing Steiner et al.'s (2023) 5Ws framework, we focus particularly on the dimensions of *what*, *why* and *where* to understand the conditions underpinning client co-regulation of quality and safety in the NDIS. We also explore the various types of activities participants engage in to co-produce their NDIS services, highlighting activities designed to improve the quality and safety of services delivered by unregistered providers.

## KEYWORDS

co-production, co-regulation, disability services, individualised funding schemes, NDIS

## 1 | INTRODUCTION

In individualised funding schemes for disability services, regulation is necessary to ensure the quality and safety of services purchased from the market. In Australia, the National Disability Insurance Scheme (NDIS) provides

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individualised funding packages to over half a million people with disability. A founding principle of the NDIS is to 'enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports' (NDIS Act 2013). The rationale is that giving more choice and control to participants will improve outcomes, following international trends that promote improved service outcomes through increased personalisation. The Quality and Safeguards Commission (QSC) is a regulatory agency established to work with NDIS participants and providers to improve the quality and safety of services and supports. Service providers can choose to undergo an audit and registration process with the QSC to be designated a 'registered provider' in the market. As the NDIS has evolved, many studies have explored how and whether principles of choice and control have been achieved in the scheme (e.g., Gavidia-Payne, 2020; Perry et al., 2019; Warr et al., 2017). However, an area that has received less attention is individualised funding participants' role in the regulation of services.

There are various ways that NDIS participants can manage their funds. Some of these require more labour from participants in exchange for more control over provider selection and service delivery. One way participants do this is through engaging service providers that are not registered with the QSC, known as 'unregistered' or 'non-registered' providers. These participants arguably take on a more significant risk and quality management role in the selection, vetting, onboarding and management of providers, for reasons explored below. While no evidence exists to suggest that participants purchasing services from unregistered providers are more at risk, the current national Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has focused attention on the safety and quality of disability services. In this context, some commentators have raised concerns about the use of unregistered providers and suggested that this may be contributing to cost 'blowouts' and mistreatment of 'vulnerable' clients (Burton, 2022; Per Capita, 2022). Several studies have explored issues of quality and safety from a workforce perspective (MacDonald, 2021; van Toorn & Cortis, 2022), noting the potential for worker exploitation in situations where no traditional oversight or compliance process is in place. However, there has been no research exploring NDIS participants' use of unregistered providers, and significantly, the voices of people with disability have been missing from this debate.

In this article, we seek to understand why clients choose to use unregistered providers, and what actions they take to improve the quality and safety of services purchased in this way. We draw on interviews with 30 people who purchase services and supports from unregistered providers. Employing a co-production lens, we argue that these clients are *co-regulators* of their services, in that they are willing to play a role in assessing risk and contributing to smooth and safe delivery of services, in line with the QSC's policy goals. We employ Steiner et al.'s (2023) 5Ws framework to analyse co-regulation of NDIS services by participants and their family members, focusing particularly on the dimensions of *why* and *where* (context) to understand the conditions underpinning this co-regulation. We also explore the various types of activities participants engage in to co-produce their NDIS services, highlighting activities designed to improve the quality and safety of services delivered by unregistered providers.

Although the NDIS was founded on principles that emphasise client choice and control over the design and delivery of their services (and therefore co-production), no research has been conducted that takes an explicit co-production lens to understand NDIS service delivery. The co-regulation lens also remains unexplored. This article therefore contributes to the co-production literature by introducing the notion of client co-regulation, and to the NDIS regulation and implementation literature by exploring the use of unregistered providers from the perspective of people with disability. Viewing NDIS participants as co-regulators of their services implies the necessity for a series of regulatory activities that recognise and support this role, which would improve choice and control for users of all NDIS services.

## 2 | BACKGROUND

More than half a million Australians with significant and permanent disability have individualised funding packages through the NDIS, representing just over 12% of Australians with disability (NDIS, 2022b). The scheme is administered by the National Disability Insurance Agency (NDIA). The NDIS was developed in recognition that the prior state-based system was underfunded, inflexible and built around the needs of the system, rather than those of the

individual (National People with Disabilities and Carer Council, 2009). The scheme aims to provide people with disability more choice and control over the services they receive, using an investment approach, which should ultimately be more efficient for whole of government spending on disability services (Needham & Dickinson, 2018). The expectation is that participants will self-direct support, however those who require assistance to manage their funds or coordinate services (such as children under 18 or those with diminished decision-making capacity) are appointed plan nominees. Nominees have a duty to ensure that participants have every opportunity to participate in the decision-making process for their plans (NDIS, n.d.), consistent with the UN Convention on the Rights of Persons with Disabilities, which recognises the right of people with disability to have control over their own lives.

In seeking to achieve flexibility, choice and control for participants, the NDIS offers three options for managing individual budgets (David & West, 2017):

- ‘Agency-managed’: where clients choose services and the NDIA makes payments directly to service providers. There is no option to negotiate the cost of services. This option requires the least administrative work from clients.
- ‘Plan-managed’: where participants employ a third-party financial intermediary. Plan managers pay invoices on behalf of participants and provide accountability through NDIS plan budget reports and budget oversight. This relieves some of the administrative burden for the participant, while allowing for more flexibility (such as the use of unregistered providers). Plan-managed participants have the option to negotiate lower rates than set out in the NDIS Price Guide,<sup>1</sup> but cannot pay higher rates (NDIS, 2022c).
- ‘Self-managed’: allows NDIS participants, or their plan nominee, to manage their individual funding package and directly choose, control and purchase support services, equipment and consumables within the constraints of their funding package (Fisher et al., 2023). This includes the option to pay higher rates than the Price Guide. The participant is responsible for arranging invoice payments. Participants can directly employ support workers under this option, which involves the administrative work of running a business, including paying wages, superannuation and insurance.

Participants may also choose a combination of options, for example some of their funding can be plan-managed and some self-managed.

The different types of funding management have implications for the kinds of providers participants can use. Agency-managed participants may only purchase services from registered providers (NDIS, 2022c). NDIS registration requires organisations to go through significant quality compliance processes, undertake auditing reviews, implement incident reporting structures to the QSC, support workers with training relevant to the NDIS Practice Standards, and support and screen workers in line with the NDIS Code of Conduct. The QSC takes a responsive approach to enforcement, drawing on Ayres and Braithwaite's (1992) regulatory pyramid to rely mainly on persuasive options and reserve the most punitive options for serious issues and breaches (NDIS QSC, 2022a). Registration can be costly, as audit processes are undertaken by private providers. There are scaled costs for registration depending on the size of the organisation and the complexity of services being provided (NDIS QSC, 2022b). Registered providers tend to be larger agencies who receive high amounts of NDIS funding. For example, NDIA figures indicate that 9% of providers paid through plan managers are NDIS registered, but they represent 59% of total payments in the relevant quarter (NDIS, 2022b, p. 96). Registered providers are bound by the maximum rates set out in the Price Guide.

Some providers choose not to undergo NDIS registration. They may be smaller in size and therefore less able to spend the resources necessary for registration and ongoing audits, or their main source of business may not be disability specific (e.g., cleaning companies or gardening services). Participants who are plan-managed or self-managed may purchase services from these ‘unregistered’ providers. Unregistered providers are still regulated by the QSC in that they are required to comply with the NDIS Code of Conduct and can be sanctioned and banned from providing NDIS services, although the mechanisms for monitoring and enforcement are more limited (Hough, 2021). The QSC can also receive and investigate complaints regarding unregistered providers and may support NDIS participants to make complaints directly to unregistered providers (NDIS QSC, 2022b).

Where NDIS participants use unregistered providers (particularly sole traders and direct employment), they can take on a number of the activities that would traditionally be the responsibility of a service provider. For example, they may interview prospective workers, check references and qualifications, negotiate wages, train staff, and deal with workplace incidents. Direct employment also involves all the responsibilities of running a small business, as described above. For this reason, NDIS participants employing unregistered providers often assume more responsibility for co-producing the safety and quality of NDIS services than those employing registered providers.

## 2.1 | Co-production and co-regulation

Co-production can be defined as clients' or citizens' contribution of time or effort to the delivery of public services (Alford, 2016). This can either occur in concert with 'regular' (or professional) producers, or 'indirectly through independent yet related efforts of regular producers and [co-]producers' (Parks et al., 1981, p. 1002). With its particular focus on who does the work (Alford, 2016), co-production is a useful lens through which to view the contribution of NDIS participants to the delivery of their services. While all clients arguably co-create value with service providers (Osborne, 2018; Parks et al., 1981), individual funding schemes are especially predicated on principles of co-design and co-production, with the intention that clients take an active role in the design and delivery of their services. However, no research has been conducted using an explicit co-production lens to understand NDIS service delivery. Indeed, while 'co-design' is increasingly recognised as crucial in NDIS policy documents and reform initiatives (e.g., through recent amendments to the NDIS legislation [NDIS, 2022a]), the term co-production does not feature in these documents.

Applying a similar principle to the regulation of NDIS services, we argue that NDIS participants act as co-regulators of their services. Alford and O'Flynn (2012), in discussing the contribution of regulatees to regulatory outcomes, describe regulatory compliance as 'people or organizations acting in a manner consistent with the public purposes the regulatory agency serves' (p. 156). To the extent that NDIS participants further the purposes of the regulator by undertaking activities to improve the quality and safety of their services, they can be seen as co-regulators. In the case of NDIS participants purchasing services from unregistered providers, this co-regulatory role is arguably more significant as providers and purchasers operate outside the oversight and compliance framework provided by the QSC's registration scheme.

van Toorn and Cortis (2022) investigated the regulatory role of frontline disability workers, arguing that work they undertake to mitigate potential risks and threats to service quality (in addition to the usual client-focused components of care work) amounts to 'regulatory labour'. This occurs as a consequence of devolution of responsibilities, where the regulatory agency sets the broad parameters of the scheme, and the regulatees (in this case the service providers) are responsible for translating them into specific actions. In fact, the contribution of regulatees to outcomes through the devolution of regulatory activity to the local level is what is usually meant by the term 'co-regulation' (Alford & O'Flynn, 2012). However, there has been no work exploring the regulatory contribution of disability *clients* in the NDIS.

We employ Steiner et al.'s (2023) 5Ws framework (who, when, what, why, and where) to analyse co-regulation of NDIS services by participants and their family members. This framework was developed to enable the systematic comparison of a variety of co-production cases. In particular, the framework recognises that context (i.e., where?) should be an integral part of co-production analyses, because 'specific socio-political, geographical, and service setting conditions have an impact on the processes and outcomes of co-production', and that the reasons (i.e., why?) behind co-production help to determine who is involved in co-production and when (p. 517). Therefore, a comprehensive analysis of 5Ws can assist in better articulation of co-production success factors beyond the more familiar 'who, what, when' of co-production. We explore the activities clients engage in to co-produce their NDIS services (the 'what' dimension), focusing particularly on activities designed to improve the quality and safety of services delivered by unregistered providers—in other words, activities that can be described as co-regulation. We then explore the dimensions of 'where' and 'why' to understand the conditions underpinning client co-regulation of quality and safety in the NDIS.

### 3 | METHODS

This project used a semi-structured interview design with purposive sampling. We recruited 30 adult NDIS participants or plan nominees through social media advertising on Twitter and Facebook in September and October 2022, with the help of disability advocates and disability community organisations. A disability advocate reviewed the advertisement and provided advice on visual and cognitive accessibility. Inclusion criteria were that participants be aged 18 or over, NDIS participants or plan nominees, and purchase one or more unregistered supports at the time of interview. Interviews were conducted using Microsoft Teams, with other options (e.g., phone) offered for reasons of accessibility. We also asked participants beforehand whether other adjustments would be required, such as provision of interview questions in advance, a shorter interview, or breaks during the interview. Participants provided consent either through a written consent form (available in standard and easy read formats) or through a verbal consent script. This project received approval from the UNSW Human Research Ethics Committee (HC220514). Questions covered topics such as why people used unregistered providers, negative experiences with unregistered providers and how those had been resolved, details of finding, hiring and managing unregistered providers, advice for people thinking about using unregistered providers for the first time, and how they would feel about being required to use only registered providers (full interview schedule provided at Appendix A). Participants received a \$50 pre-paid Mastercard to thank them for their contribution.

#### 3.1 | Analysis

We audio recorded the interviews and produced 'intelligent verbatim' transcripts (McMullin, 2021), replacing participants' names with pseudonyms. We thematically analysed transcripts using NVivo. The 5Ws framework formed our overarching analytical approach, particularly for exploring participants' comments regarding *what* co-productive activities they undertook and the types of services involved, and *why* they did so. With the goal of understanding participants' motivations in detail, we separated the *why* dimension into 'push' factors (what participants disliked about using registered providers) and 'pull' factors (what qualities drew participants toward unregistered providers). To facilitate discussion of participants' *co-regulation*, we remained sensitive to comments regarding (a) service quality and (b) risk/safety, as quality and safety are the focus of the relevant regulatory agency. In line with Braun and Clarke's 'codebook' thematic analysis (see Braun & Clarke, 2021), we used a high-level structured coding framework based around the 5Ws, but refining our coding as we went and remaining open to unexpected themes. For example, exploring the *why* dimension enabled us to draw out broader themes to understand the *where* dimension of location and context, such as participants' previous experiences of disability policy settings, their understanding of the scheme's overarching goals, and the maturity and functioning of the disability services market.

#### 3.2 | Interview sample

We summarise the demographic characteristics of interviewees in Table 1. Twenty-two interviewees were adult NDIS participants, while 6 were plan nominees and 2 were both participants and plan nominees. The 8 plan nominees were all women or non-binary people, which means our overall interview sample has greater representation of women than the NDIS itself (participants are 2/3 male). This is not surprising, as carers of people with disability are disproportionately women (Yates et al., 2022). While a significant proportion of NDIS participants are children under 18, we did not seek to speak to this cohort directly as under-18s are represented by a plan nominee or NDIS representative. The plan nominees represented a range of family members, including siblings, spouses, adult children, and children under 18.

As the focus was on participant choice across a range of disabilities, we did not systematically collect information about impairments. However, in describing their disability service experiences, participants often described their

**TABLE 1** Participant demographics.

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

impairments. Interviewees (or the NDIS participants they represented) had a wide range of disabilities, including physical, psychosocial, neurological, intellectual/cognitive, sensory, and energy impairments.

## 4 | FINDINGS

In this section, we set out the findings of our study according to the dimensions of the 5Ws framework (see Table 2). Following a brief consideration of ‘who’ and ‘when’, we focus primarily on three of the dimensions in this discussion (‘what’, ‘why’ and ‘where’), as these are crucial to understanding the conditions underpinning client co-regulation of quality and safety in the NDIS. We then explore interviewees’ suggestions for improving their experiences navigating the use of unregistered providers.

### 4.1 | Who

A range of professional co-producers are involved in co-producing the quality and safety of NDIS services, including the QSC, the NDIA, and service providers (who may be sole traders, businesses or companies). Providers come from both the for-profit and not-for-profit sectors.

The lay co-producers in this co-production example are clients (and family members) of a national disability funding scheme. This article focuses on their perspectives. Only clients who are plan-managed or self-managed may purchase services and supports from unregistered providers, so this requirement may be a proxy for a particular level of functional capacity. Some participants noted that using unregistered providers is not for everyone, contrasting their own sense of being alert, engaged and capable of assessing risk with the situation of others (e.g., those with high and complex support needs and a lack of family assistance).

**TABLE 2** 5Ws of co-production applied to client co-regulation of NDIS services.

Dimension	Details
Who	<i>Lay co-producers</i>
	Clients (and family members) of a national disability funding scheme. Clients must be self-managed or plan-managed
	<i>Professional co-producers</i>
	Disability service providers
	NDIS Quality and Safeguards Commission
When	National Disability Insurance Agency
	Delivery/implementation of services
What	Co-regulation behaviours during selection, onboarding, and ongoing management of providers
	Behaviours aimed at increasing quality and safety of disability services
	Individual co-production
	Mostly individual value
	Non-complementary (i.e. core service)
Why	Mostly voluntary, sometimes involuntary
	Regulatory failure
	Necessity (due to market failure)
	Cost and financial transparency
	Service quality
Where	Flexibility
	Dislike of large organisations
	Recent transition from inflexible block-funded disability services
	Move toward choice and control in disability services
	<i>Thin markets</i>
	Shortage of support workers
	Shortage of certain types of allied health professionals
	Insufficient providers outside major cities

4.2 | When

Steiner et al. (2023) note that co-production can occur during design/planning, delivery/implementation, or evaluation of services. In this case we are focusing on client contributions to the delivery of services, although the success and sustainability of the NDIS depends on co-production at all stages of the public service cycle.

4.3 | What

In this research, clients are co-producing market-based services purchased using an individually assessed budget of government funding. Interviewees purchased four main types of services from unregistered providers: *consumables* such as access equipment and sanitary supplies, *household services* such as cleaning and gardening, *allied health and various therapies*, and *support services*. Support workers can be employed through unregistered agencies, as sole contractors (often via gig-economy platforms), or through direct employment. This category of supports is arguably the most controversial in discussions about registration given it often involves personal care delivered in domestic contexts.

Steiner et al. (2023) identify several types of factors relating to what is co-produced. In this case, client co-producers contribute *behaviours* aimed at increasing service quality and safety. Interviewees reported engaging in a

variety of management activities, many of them particularly relevant for using unregistered support workers. While we do not have scope to go into detail regarding specific co-regulation activities, we provide a summary in Table 3. At all stages, participants recommended tapping into wider disability support networks for advice, through channels such as social media. Facebook groups were frequently mentioned as being a useful resource for finding providers, receiving warnings about providers to avoid, and navigating the NDIS more generally.

It is important to note that clients may also undertake some of these activities in relation to employing *registered* providers, so there is not a clear distinction between the co-regulation work required of those using each type of provider. For example, clients using the online support worker platform Hireup, which is a registered provider, may interview, train and terminate support workers much in the same way as those using independent contractors. However, in general more of these types of activities are required of those using unregistered providers.

Steiner et al. (2023) outline several other potentially relevant factors about *what* is being co-produced. One refers to whether the value produced is individually or collectively consumed (i.e., whether it is largely private value or public value) (Alford & Yates, 2016). In this example, the value created by client co-regulation is consumed largely on an individual rather than collective level—in other words, participants improve the quality and safety of their own individual services. However, this nonetheless contributes to the wider policy goals of the agency, so in some sense

**TABLE 3** Co-regulation activities undertaken by NDIS participants using unregistered providers.

Stage of service delivery	Co-regulation activities
Hiring	<ul style="list-style-type: none"> <li>• Recruiting through known networks</li> <li>• Recruiting for rapport and skills rather than qualifications</li> <li>• Conducting meet-and-greets and interviews               <ul style="list-style-type: none"> <li>◦ Saying no if there are red flags</li> <li>◦ Conducting two rounds of interviews (one off-site and one in the home)</li> <li>◦ Observing how the candidate interacts with the potential client</li> </ul> </li> <li>• Checking references</li> <li>• Checking insurance and qualifications</li> <li>• Negotiating rates (having regard to award rates, skills, training, experience and tasks required)</li> </ul>
Training and onboarding	<ul style="list-style-type: none"> <li>• Arranging written service agreements</li> <li>• Communicating expectations of support interaction early and clearly</li> <li>• Supporting sole contractors to get an Australian Business Number, create invoices, and organise insurance and superannuation</li> <li>• Training workers using:               <ul style="list-style-type: none"> <li>◦ Documentation</li> <li>◦ Videos</li> <li>◦ Buddy shifts</li> <li>◦ NDIS funding for upskilling workers</li> </ul> </li> <li>• Having trial periods</li> </ul>
Ongoing arrangements	<ul style="list-style-type: none"> <li>• Using software and apps for scheduling, communication and record-keeping</li> <li>• Having support workers text upon arrival and departure, to ensure clarity of hours worked</li> <li>• Checking all invoices (even if plan-managed)</li> <li>• Having a back-up plan in case of support worker cancellation</li> <li>• Communicating clearly and often about how things are going</li> <li>• Deciding when and if to increase rates</li> </ul> <p><i>Resolving problems</i></p> <ul style="list-style-type: none"> <li>• Having ‘tough’ conversations (e.g., if there is an incident, asking support workers to write down what they did wrong and what they would do to prevent this in the future)</li> <li>• Terminating providers or workers               <ul style="list-style-type: none"> <li>◦ Not being afraid to let providers or support workers go if something does not feel right (i.e., not waiting for quantifiably bad behaviour, but trusting intuition)</li> </ul> </li> <li>• Reporting serious incidents to the QSC</li> </ul>

the value created is also collective/public. Further, the services being co-produced are not complementary to the purpose of the scheme—they are core, in that participants are co-regulating the very services that form the heart of the scheme (Steiner et al., 2023). Lastly, the framework prompts consideration of whether the co-productive contribution is voluntary or involuntary. As we will explore further below, NDIS participants' use of unregistered providers is often voluntary in that they choose to boost their co-regulation in exchange for an improvement in service quality and safety. However, for some clients this is not voluntary, as there are few or no registered providers in their geographical area or who provide the services they require.

## 4.4 | Why

Interviewees provided many reasons for using or even preferring unregistered providers. These can be summarised as not feeling any safer with registered providers; feeling unregistered providers offered better quality and more flexibility; and finding unregistered providers to be cheaper and more financially transparent.

### 4.4.1 | Registration is not any safer

Half the interviewees made comments amounting to feeling that registration is irrelevant or does not make providers any safer. In fact, some reported feeling safer with unregistered providers, or having experienced more safety and quality issues with registered providers. Others pointed out that abuse and neglect happens in registered providers, which had recently been highlighted through high-profile scandals and a national public inquiry.

Kayla: I have no care whether or not a provider is registered or unregistered. All I care about is the quality of care that my daughter receives, and I think with registered providers people can be given a false sense of security thinking that they're going to get a better level of care. Where, in my experience, that's not the case at all.

When asked to expand on what contributed to feelings of safety (if provider registration did not do so), interviewees described being able to feel in control of who delivered their services and how they were delivered. This included choosing the right person for the job (and not just whichever provider happened to be registered and available), people with the right attitudes and skills, and people who were embedded in the local community or the disability community. Often relationships and continuity were the most important considerations.

Kim: Safety for me means being able to work with people that I know have relevant qualifications and people that are embedded in my community.

For allied health workers, a sense of safety came from the fact that workers typically hold registration or accreditation with their appropriate professional bodies. Participants did not see what NDIS registration could add to their professional standards.

Participants often reflected that no service could be risk free and that it was important to be able to assess and choose their own risks. Many emphasised their sense of self-efficacy: although this may not be the case for all clients, they personally felt able to train workers, to assess risk, and to deal with workplace incidents.

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

#### 4.4.2 | Better quality and more flexibility

While a minority were agnostic about differences in service quality, many strongly preferred unregistered providers for at least some of their services. For those using non-disability specific unregistered providers such as cleaning, gardening and maintenance providers, they often felt there was no elevated risk, and they were more reliable and flexible and better at their jobs. Further, clients appreciated the sense of inclusion afforded by being able to hire local small businesses rather than feeling segregated by using disability-specific providers.

Khin ...my experience so far is support workers don't really clean very well. So, it's easier to get a standard cleaner and I feel like that's probably more value for money anyway, because they do a better job because that's what they do rather than, like, an add on task.

For therapists and support workers, interviewees were sometimes drawn toward unregistered providers for reasons of innovation and expertise. For example, there might not be any registered providers with the right skillset, or participants might be seeking a different kind of therapy, delivered outside of business hours, or at a different location (such as in the community or in nature).

Organisational size frequently featured in discussions of service quality. The costs associated with registration mean that in general these organisations are quite large, although registration and ongoing auditing costs are scaled. Participants often saw larger organisations as less desirable due to depersonalisation of services, a more rigid codification of rules, inflexible cancellation policies, poor treatment of staff, and turnover and lack of choice in staffing. Several noted that with larger companies they felt like 'just a number'.

Claire: I didn't want to use one of the bigger providers, because they tend to stick a lot of restriction—as soon as they know that you're blind, the ways in which a support worker is allowed to move around with a blind and vision impaired client are significantly curtailed. And there's lots and lots of rules because we're apparently a falls risk.

Claire felt these rules and restrictions to be infantilising: 'my eyes just don't work, like ... you know it's okay, I've probably risk assessed this myself'. Participants also explained they found working with larger organisations unpleasant due to the inflexibility and communication difficulties associated with the extra layers of management.

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

Conversely, many participants appreciated the direct and continuous relationships they could form with unregistered providers, which contributed to feelings of safety, quality and empowerment.

Andy: I just want to have an agreement where you minimise the bureaucracy between me and the person that's wiping my bum I guess.

Interviewees also found flexibility in timing to be better with smaller organisations, sole traders and directly employed workers. While this sometimes required more work from the clients in the form of scheduling and communication, they appreciated being able to organise services to fit around their lives rather than conforming to the set shifts offered by larger registered providers. As Lyra said, 'the hours that I need support are kind of unusual':

I think the flexibility of being able to hire people who are really local and really close means you've got people who attend 15 minutes, 5 minutes. I've got a couple of people who just walk across the road.

#### 4.4.3 | Cost and profit-seeking

Despite public commentary about the risk of unregistered providers over-charging for services, most interviewees appreciated unregistered providers for their cost effectiveness. Many felt they could save money through using unregistered providers, or make the same funding go further. Some felt a dual responsibility to save money for the sake of their individual funding, and to support scheme sustainability and be a responsible taxpayer. In this way, the value created by co-regulation can encompass public as well as private value.

Organisational size again featured in interviewees' explanations for profit seeking behaviour. Many large, registered providers charge the maximum NDIS price as standard, which they are entitled to do given the additional costs associated with registration and audit. However, although interviewees understood that the higher prices of registered providers often stemmed from these kinds of overheads, many did not see the point in paying these higher prices given they perceived unregistered providers as offering equal or better service. Ben told us of his experience with a registered provider, '*I was paying top dollar and getting crap service*'. Further, some felt that the extra cost of using registered providers was profit-seeking rather than due to genuinely incurred overheads. Interviewees spoke of providers charging for services that had not been delivered, charging extra fees wherever they could, taking a long time to pay their staff, harassing potential clients about signing on with them, cherry picking easier or more lucrative clients, and repeatedly asking to see the details of clients' plans so they could determine how much to charge. Some were concerned about large companies referring clients from one part of their business to another, or having an income stream that was entirely based on the NDIS.

Jill: ...a lot of these big companies that are NDIS registered providers, they really are based on profit, and a lot of them- for example the [occupational therapy] company, they then try and refer you to their speechies, or their physios—they're trying to upsell.

#### 4.5 | Where

The context and history of disability service funding in Australia is important in understanding some interviewees' motivations for co-producing. Several participants who had used disability services for a long time reflected on what their experiences had been like prior to the NDIS. They felt the promise of choice and control offered by the NDIS had not been realised through the services of registered providers, who often behaved exactly like the inflexible block-funded providers of the 'bad old days' (and sometimes were exactly the same organisations).

Harriet: I've been disabled a long time. I've got an illness that is degenerative and until the NDIS, the providers told you what you could have, when you can have it, if you can have it, no, you can't have it now. ...The NDIS came along and the first thing I realised was that I was going to have choice. I could decide when I wanted something. And then the registered providers did the same thing. 'No, you can't, you have to fit in with us, we know what's best for you'. And I was so angry.

Once Harriet realised she could use unregistered providers, she started arranging her services in a way that suited her for the first time. In this context, it makes sense that clients would want to contribute their own time and effort in exchange for service flexibility they had never had access to before. Even those who had not received

disability services before the NDIS had often experienced the grassroots advocacy campaigns that led to its implementation, which emphasised the need for people with disability to have more choice and control over their services and supports. Participants frequently spoke of the overall aims and purpose of the scheme when reflecting on why they found it so important to use unregistered providers.

Another important piece of context is the relative immaturity of the disability provider market. When adequate services are not available due to a lack of providers offering the kinds of services required, this is known as 'thin markets'. Importantly, thin markets can be due to a lack of market *sufficiency* (i.e., not enough providers) or market *diversity* (providers may exist but they are not tailored to the needs of the client) (Reeders et al., 2019). Despite efforts at market stewardship since the relatively recent implementation of the NDIS (NDIS, 2016), increased demand due to a large injection of funding has not yet been met by sufficient supply. Over half of participants spoke of issues that amounted to thin markets. This was not just an issue for regional and rural participants—even city-based interviewees noted insufficient providers, especially those in outer suburban areas. Supply issues were particularly acute for support workers in the context of COVID-19 market turbulence and a loss of workers to the aged care sector, but were also noted for allied health workers—particularly occupational therapists, speech therapists and psychologists. Some interviewees noted that if they were required to use registered providers, they would not be able to receive services at all. This was a particularly worrying proposition for those who required significant support for tasks of daily living.

## 4.6 | What would assist NDIS participants with co-regulation

While many interviewees felt no inherently greater risks in working with unregistered providers, some did identify potential risks. These included NDIS participants not understanding their legal and tax obligations with respect to hiring sole traders, and support worker supply issues prompting a glut of inexperienced support workers to sign up with gig economy platforms. Neil felt that in some cases clients could be putting themselves at risk by engaging providers who did not have insurance, reasoning that registered providers were at least more likely to have the requisite insurance.

To ameliorate some of these issues, interviewees suggested capacity development for NDIS participants. For example, Claire suggested '*empowering participants and the support networks around participants to have more idea of their rights but also making it clearer cut and making it easier*'. Lyra suggested it would be useful for the NDIA to provide training for participants on practical elements of support worker organisation such as rostering and calendar maintenance. She also suggested resources empowering people with disability to respond when support workers are behaving in abusive or controlling ways. Another idea was a basic guide for hiring sole traders, written in plain English, with links to documentation with more detailed information where necessary. As Caleb commented:

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

## 5 | DISCUSSION

At present, the regulatory system of the NDIS focuses on providers and largely disregards the involvement of participants, apart from supporting them to complain if something goes wrong. In general, the policy architecture and context of the NDIS often works to constrain participants' agency and self-direction of services. However, it is clear from our findings that some NDIS participants find it valuable and sometimes essential to take on an enhanced co-regulation role through the use of unregistered providers. Clients described undertaking many co-regulation

activities, including during selection, onboarding, and ongoing management of providers. Some reported awareness of the potential risks involved in using unregistered providers, but many felt there was no difference in risk between the two types of providers, and some felt less safe with registered providers. Feelings of safety were instead underpinned by such factors as the ability to choose from a wide range of providers, hiring people embedded in communities or with the right expertise irrespective of registration status, and direct relationships formed with workers and providers in the absence of company 'bureaucracies'.

Clients described many reasons for choosing to co-produce, including regulatory failure (i.e., perceiving registered providers as no safer or even less safe than unregistered providers), improved cost and financial transparency, better service and flexibility, and a preference for smaller or local organisations and sole traders. Underpinning these decisions were two major themes: choice and control, and dignity of risk. The NDIS was established to increase choice and control in the context of previous experiences of poor quality, block funded services. Therefore, many clients desired as much control as possible over the delivery of their services, especially when they perceived services from registered providers to be inflexible and inadequate. In other words, these clients felt their services were safer and better quality when they had *more* freedom to co-regulate. Second, clients felt that no service could be free of risk, and that it was important to be afforded the dignity of choosing and assessing their own safety and level of risk in service delivery. This was especially important in the context of the NDIS' statutory purpose to maximise participants' independence, social and economic participation, and inclusion in the community. We argue that the context of recent transition from inflexible block-funded services, a move toward choice and control in disability services, and an underdeveloped market is crucial for understanding client co-regulation of NDIS services. In some cases, use of unregistered providers was unavoidable due to the thin market of service providers (a) in their geographical area or (b) for the type of service they required. This accords with Steiner et al.'s (2023, p. 518) observation that 'rural geographical context with lack of other service-providers can act as a push factor for co-production'.

The implications of these findings are twofold. First, in discussing the design of the NDIS regulatory system, Hough (2021, p. 107) notes 'the importance of research into the effectiveness of regulatory processes', in service of more evidence-informed policymaking and practice. One source of such evidence is exploring the lived experience of service users and whether this matches the policy goals of the regulatory agency. Accordingly, understanding why some participants choose to assume this more significant co-regulatory role points to improvements required in the delivery and regulation of *registered* services. Focusing on the 'why' of the 5Ws framework has uncovered failures in regulation and market stewardship that may prompt some people to perform more co-regulation than they would ideally prefer. If clients perceived registered service providers as readily available, cost-effective, reliable and safe options, some may choose not to take on the additional responsibility described in this research. As Neil reflected, '*my preference would be making it better, making it more desirable to use a registered provider. And at the moment that's not what's happening.*' Ideally, active forms of client co-production should be undertaken to improve the delivery of services rather than remedy service failure (Steiner et al., 2023). This points to interventions to assure clients that provider registration can have real implications for the quality and safety of services. These interventions would also benefit the cohort of NDIS participants who mostly or exclusively use registered providers (such as those whose funding is agency-managed).

Second, even if issues with the quality of registered service provision are addressed, it is clear that due to factors such as flexibility, choice of local workers and ability to negotiate cost, some clients will always prefer to have full choice over who delivers their service, regardless of registration status. Therefore, clients require more support and capacity development to effectively navigate service provision in the unregistered space. Fisher et al. (2023) have made similar observations regarding the need for capacity development in their exploration of what assists NDIS participants to self-manage (another service design option offering opportunities for increased client co-production). As Alford and Yates (2016) argue, one way for government agencies to encourage co-production is to make it as easy as possible for citizens and clients to participate (see also Palumbo and Manna [2018] on organisational health literacy as an enabler of co-production). However, NDIS information provision has been consistently criticised as adding

to the difficulties of scheme participation (Purcal et al., 2018; Wilson et al., 2022; Yates et al., 2022). This is one reason interviewees relied so much on peer support through social media to navigate the use of unregistered providers. Plain English, accessible how-to guides would assist clients in hiring unregistered sole traders. Support should also be provided for small unregistered providers, to enable them to better understand and fulfil their obligations.

However, some participants will not have the capacity to increase their co-productive contribution through information provision alone. Ideally, support should also be provided in the form of individualised NDIS navigation assistance from government-funded workers or advocates. As our interviewees told us, too often NDIS participants are not provided with any such assistance to learn how to use their plans. Building the capacity of participants and plan nominees so they are clear what should be expected of services and what to do in situations of bad practice or misconduct would be a good way to help with quality and safeguarding issues across both registered and unregistered providers. Further, empowering participants to better operate choice and control over their services would have broader benefits for the overall effectiveness of the scheme.

While this research represents an important step toward understanding participant co-regulation in the NDIS (and in individualised funding schemes more broadly), we need more information on how best to support NDIS participants in their co-production of services. The purpose of this project was to explore why and how NDIS participants use unregistered providers through their NDIS plans, because there has not been any published research on this issue. For this reason, we limited our sample to people who used unregistered providers at the time of interview. We did not interview those who avoided unregistered providers or had previously used unregistered providers and ceased doing so. Therefore, we were likely to speak largely to people who had positive views of unregistered providers and less likely to speak to people who had neutral or negative views or experiences. This means we are limited to exploring why some NDIS participants choose (or need) to take on this increased co-regulatory role, and what co-regulatory activities they undertake.

Future research exploring the views of those who prefer to use registered providers would provide a fuller picture of NDIS participants' experiences and decision-making in this area. There is also a need for quantitative research to understand the parameters of unregistered provider usage, for example what percentage of NDIS participants use this option and whether this is increasing over time. Another crucial element is research to explore what exactly about registered providers might underpin the characteristics that drive clients such as those we spoke to away from these providers, and how much the QSC's registration process does or does not affect these characteristics. This may assist with efforts to ameliorate perceived failures in the regulatory scheme so that registration does not, in the words of Kayla, amount to 'a false sense of security'.

## 6 | CONCLUSION

The NDIS is founded on principles of co-production. In this article we have introduced the notion of client co-regulation, using Steiner et al.'s (2023) 5Ws framework to help us explore how NDIS participants co-regulate their services. Focusing particularly on the dimensions of *what*, *why* and *where* has helped us to understand the vital role clients play in co-regulating both quality and safety, especially in the context of participants' experiences of market and regulatory shortcomings. Ironically, our findings show that for some NDIS participants, what was intended as a marker of quality and safety has in fact become the opposite. In contrast, many interviewees spoke of how much they appreciated and valued their unregistered services, including the increased autonomy and opportunity to co-produce that these arrangements afforded. Interviewees demonstrated extensive use of various risk assessment mechanisms and showed capacity to evaluate and reduce risk in service delivery. They argued that no service provision arrangements could be risk free, and it was important for inclusion and citizenship to be allowed the 'dignity of risk' in choosing between registered and unregistered providers. Along with interventions to the registration process aimed at improving the quality and safety benefits of provider registration, we recommend capacity development of NDIS participants to understand their options, rights and obligations with regard to scheme operation. Supporting

choice and control in this way is likely to have positive implications far beyond the unregistered provider space and promote better outcomes with regard to the scheme as a whole.

## CONFLICT OF INTEREST STATEMENT

The authors report there are no competing interests to declare.

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## DATA AVAILABILITY STATEMENT

Data cannot be shared due to privacy or ethical restrictions.

## ORCID

Sophie Yates  <https://orcid.org/0000-0003-1912-8509>

Helen Dickinson  <https://orcid.org/0000-0003-3852-8815>

## ENDNOTE

<sup>1</sup> The Price Guide 'set[s] out the pricing arrangements and price limits that the NDIA has determined will apply to the provision of supports for participants in the NDIS' (NDIS, 2022c, p. 8).

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## APPENDIX A: INTERVIEW SCHEDULE

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