

When care becomes captivity: Does the NDIA capably support National Disability Insurance Scheme participants who reside in Private Congregate Care (PCC) settings??

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The PCC Alliance is comprised of a group of organisations working towards the goal of systemic recognition of the unmet needs of people with disability who live in PCC settings, including Support Residential Services (SRS) in Victoria. The PCC Alliance welcomes the opportunity to contribute to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry – *Capability and culture of the National Disability Insurance Agency (NDIA)*.

This Submission provides evidence that the NDIA does not capably or adequately support and safeguard many participants residing in PCC settings. Increased preventative safeguarding are required. Preventative safeguards optimally focus on service design to prevent abuse and neglect, and actively address risks for individuals [1]. Currently, significant deficiencies in the NDIA process for administration of supports create unacceptable risks for PCC residents. These individuals comprise of an exceptionally vulnerable group who continue to experience challenges in having their disability and daily life support-needs met.

KEY RECOMMENDATIONS

Policy reform required to ensure effective provision of safeguarding and support for at-risk groups including PCC residents

1. A co-designed, person-centred NDIS risk-assessment framework aiming to ensure participant safeguards underpin allocation of disability supports through NDIS participant plans
2. A clear framework for ensuring optimal decision-making support. This will reduce the risk of exploitation, violence, abuse and neglect and maximise participant's choice and control in their daily lives. Current strategies do not afford sufficient protections to PCC residents (See Appendix 1 and 2).
3. A mandated separation of housing provision, and provision of daily living supports, for NDIS participants.
4. Review of existing 'Typical Support Package (TSP)' allocation process, as the current TSP reduces access to tailored, individualised daily living supports and has questionable capacity to allocate equitable, individualised daily living support packages with consideration of risk-factors.

INSUFFICIENT PREVENTATIVE SAFEGUARDS CAN RENDER THE NDIS FUNDING OF DAILY LIVING SUPPORTS INEFFECTIVE

PCC residences are privately operated businesses that provide accommodation and support with daily living, predominantly utilising a ‘group-home’ model which retain many features of institutional care [2]. They exist Australia-wide and include Supported Residential Services (SRS) in Victoria, psychiatric hostels in WA, Licenced Boarding Houses in NSW, Supported Residential Facilities in SA and Boarding Houses and Hostels in Queensland. Collectively, it is estimated that they accommodate over 4000 Australians with disability and those who cannot live independently – including approximately 3000 people residing in SRS in Victoria[2]. A significant proportion of PCC residents experience complex disability. Many do not have contact with family members, independent advocacy or the support of a legal guardian. Substantial evidence indicates that PCC residents are at heightened risk of exploitation, violence, abuse and neglect [2][3].

This Submission provides evidence that insufficient preventative safeguards render NDIS -funded daily living supports ineffective, for many NDIS participants living in PCC. The gaps in preventative safeguarding in NDIA administration of daily life supports, place the intended benefits of the NDIS, out of reach for this group. This Submission demonstrates these administrative flaws through a case study, **Luke’s Story** (Appendix 1, below), alongside contextual explanation and recommendations for changes necessary to manage risk in allocation of NDIS supports for vulnerable groups, including PCC residents. In addition, a summary of evidence of the misappropriation of NDIS participant plan funding due to insufficient preventative safeguards, is included below (Appendix 2).

This PCC Alliance expresses gratitude for the opportunity to contribute to Inquiry – *Capability and culture of the National Disability Insurance Agency*. This submission does not intend to represent individual organisations within the PCC alliance, but rather represents the views of this collective group.

Written by Muriel Cummins on behalf of the Private Congregate Care Alliance, which includes representatives from the following organisations:

Eastern Health
Mental Health Legal Centre
Mind Australia
St Vincent’s Mental Health Service, Melbourne
Victorian Mental Illness Awareness Council
Victorian Office of the Public Advocate
Wintringham

REFERENCES

1. Kendrick, (2005) Self direction in services and the emerging safeguarding and advocacy challenges that may arise. [“Self Direction” In Services And The Emerging Safeguarding and Advocacy Challenges That May Arise \(squarespace.com\)](#)
2. Dearn, E., Ramcharan, P., Weller, P., Brophy, L. & Johnson, K. (2022) Supported residential services as a type of “total institution”: Implications for the National Disability Insurance Scheme (NDIS). Australian Journal of Social Issues, 00, 1–17. Available from: <https://doi.org/10.1002/ajs4.233>
3. [Public hearing 26: Homelessness, including experience in boarding houses, hostels and other arrangements | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)

Appendix 1

Case Study – Luke’s Story

This case study presents the story of Luke, an SRS resident and NDIS participant*. It aims to identify the specific shortcomings in NDIS policy and administration of daily life supports that placed him at risk of exploitation, abuse and neglect.

Background: Luke was 30 years old when he was granted access to the NDIS, due to his disability, long term schizophrenia and an acquired brain injury. Shortly afterwards, he was discharged from the public mental health service that had assisted him to apply. He did not have a guardian or family with capacity to assist him in decision-making. He became homeless as the family member who he shared a house in rural Victoria with, experienced her own mental health decline. She lived with a significant disability herself, subsequently reducing her capacity to support his decision making or assist with daily support needs. Luke travelled to Melbourne and a community health social worker linked him with a Support Coordinator, and found him accommodation in a pension-level SRS. This is what happened next. *Not his real name, details are deidentified

Participant story*	Risk due to NDIA process in administration of daily life supports	Changes necessary to manage risk in allocation of NDIS daily living supports
<p>1. “I have no one to talk to, all the other residents are elderly. I can’t make a hot drink or snack for myself. There is no privacy, people walk into my room which doesn’t have a lock” . Luke’s Support Coordinator identified that the SRS environment was unsuited to meeting his daily living needs. She organised supports including an occupational therapist, and a neuropsychological assessment. Consensus allied health reports identified that Luke experiences the following challenges and risk-factors:</p> <ul style="list-style-type: none"> - Significant cognitive impairment - Reduced capacity for independent decision making & need for support in this area - Low literacy & self-advocacy skills 	<ul style="list-style-type: none"> Recent changes to the NDIS Act (Section 43,44) highlight that NDIS risk assessment must occur for both self-managed and plan managed groups, aiming to provide “consistency and protections for participants who use a registered plan management provider to purchase services from unregistered providers” [1].However there has not been transparency around this risk assessment process, and if/how planners or LACs complete the risk-assessment process and use this information to inform allocation of daily living supports, and supported decision making resources. In addition, there is no clear process for the consideration of participant 	<ul style="list-style-type: none"> A co-designed, person-centred NDIS risk-assessment process aiming to ensure participant safeguards are established. A clear framework for ensuring optimal decision-making support. This will reduce the risk of exploitation, violence, abuse and neglect and maximise participant choice and control in daily living.

Joint Standing Committee on the National Disability Insurance Scheme Inquiry – Capability and culture of the NDIA

<ul style="list-style-type: none"> - Risk of acute mental health decline - High risk of homelessness; urgent recommendation for housing solution i.e. Supported Independent Living (SIL). <p>An NDIS Plan review was requested, this review:</p> <ul style="list-style-type: none"> - Took place by phone, Luke was unseen by the planner - The Planner re-issued the WHODAS, an assessment already completed by Luke's OT - The planner indicated she did not believe SIL was merited. - Luke's plan remained unchanged; SIL funding was declined. There was no enabling strategy for supported decision making included. His plan continued to be plan-managed meaning unregistered providers can provide care without direct oversight by the NDIA. 	<p>risk-related evidence from existing providers at the plan review process (In Luke's situation, substantial allied health reports).</p> <ul style="list-style-type: none"> • There is no formal process for identifying when an NDIS planning meeting should involve direct person-to-person meeting with. Or sighting of, the participant. Phone-based NDIS plan review does not support preventative safeguarding of vulnerable participants who have reduced capacity to articulate their needs, or self-advocate. Phone-based plan review was highlighted as a risk factor in previous cases of exploitation, abuse and neglect [2]. • The allocation of a Typical Support Package based on a planner-completed assessment and determination of 'functional level', has been critiqued for lack of evidence supporting its validity [3]; and for lacking the required tailoring of individual support packages to meet daily living support needs. • When NDIS declines to fund a housing solution for a participant, is there a process by which the NDIS ensures participant safety, safeguarding, and adequate daily living supports, in their current housing situation? This process is not clear from NDIS guidelines. 	<ul style="list-style-type: none"> • An end to phone-based planning meetings for participants who experience reduced decision making capacity, or other identified risk factors. • Review the existing 'Typical Support Package (TSP)' and examine the validity of the TSP in allocating tailored, individualised, daily living support packages. • Tailored 'pathway' prioritising PCC residents e.g. planners skilled in complex disability; specialist support coordinators. • Clear process for ensuring preventative safeguarding of participants in the event of NDIS declining a request for a housing solution (SIL, SDA, ILO). Appropriate housing is an essential platform upon which to build daily living support.
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2. “They said if I didn’t sign it, I’d be kicked out and homeless on the streets again” Immediately following plan review, Luke was approached by the SRS proprietor and requested to sign a Service Agreement, making the proprietor’s company the sole NDIS provider of NDIS -funded supports. He was told that he would be evicted if he didn’t sign. Luke has limited literacy and did not understand what was written on the form. Once signed, the SRS staff actively prevented existing providers from contacting Luke. They were prevented from entering the SRS premises. He did not have access to a phone or email, and messages left at reception were not passed to him. He was effectively cut off from existing NDIS supports following the signing of the new Service Agreement, and a ‘closed system’ of care and housing provision established, under a sole provider. The SRS proprietors company began billing to Luke’s plan, for services that he later said he never received, or were already included in his tenancy agreement (room cleaning, community outings) and his \$185 weekly rent. For example, they billed him for community outings to the gym; the ‘gym’ was an exercise bike located in a corridor in the SRS which he never used. Over a three-month period**, thousands of dollars were billed by this proprietor, to Luke’s NDIS plan.

Meanwhile, Luke’s original provider team grew very concerned as they could not contact him. They finally made contact by waiting on the street outside the SRS until he went out for a walk – Luke asked why they had not visited, he did not understand the implications of signing the Service Agreement with the SRS, or that his funds were being channelled to the SRS proprietor.

- There are no regulations in place preventing an SRS or PCC proprietor billing for services under an NDIS plan, despite the clear conflict of interest, and evidence of the impact of ‘double dipping’ on residents. This practice frequently renders the NDIS plan ineffectual in providing much needed daily living supports, and creates barriers to participants working towards their goals.
- Recent commentary from the NDIS Quality and Safeguards Commission at the Disability Royal Commission Public Hearing no.26, indicated there is no evidence for systemic neglect of NDIS participants living in PCC due to a low number of complaints. Clearly Luke’s situation illustrates the barriers to making a complaint for this vulnerable group [4]
- When NDIS LAC or planner is made aware of red flag around participant well-being or misuse of daily living support funding, what is their duty of care to respond? This process is not clear from NDIS guidelines.
- There are severe shortages and lengthy waitlists for independent advocacy organisations who could provide decision making support for PCC residents.

- **A mandated separation of housing provision, and care provision (including the provision of daily living supports).** This principle of separation is a basic safeguard. According to the Summer Foundation, *“Separating housing from support puts people with disabilities in control, by giving us the freedom to choose where we live and who supports us”*. [5]
- A transparent feedback loop between ‘upstream’ preventative safeguarding in implementing NDIS daily living supports, and ‘downstream’ corrective safeguarding undertaken by the NDIS Quality and Safeguards Commission.

Joint Standing Committee on the National Disability Insurance Scheme Inquiry – Capability and culture of the NDIA

<p>The Support Coordinator asked if he would like to make a complaint to the Quality and Safeguards Commission, he declined as he was fearful of the consequences from the SRS proprietor. She proceeded to make a complaint on his behalf, but never received any follow-up or contact from the Commission. The LAC was also informed, who stated she could not liaise with any provider not currently providing care to Luke.</p> <p>A short time later, the situation at the SRS became untenable for Luke as he was forced to room-share. He felt extremely unsafe in the SRS environment. He left and became homeless, disengaged from all NDIS supports and stopped taking medication. He became acutely unwell and was subsequently admitted involuntarily to a psychiatric hospital in rural Victoria. He is likely to be sent to another SRS upon discharge as he has nowhere else to go.</p>	<p>**Many SRS proprietors continue to inappropriately bill to participants plans for years, or indefinitely, largely within a ‘closed’ system of support– impacting the funds available for authentic daily living support and working towards participants goals[6]. The provision of supports under an institutionalised model (e.g. food prep, cleaning, ADL’s) is inconsistent with the principle of choice and control. The PCC environment is counter to capacity building, even with capacity-building funds contained in the participant plan.</p> <p>Many PCC and SRS employ or engage their own Support Coordinator. There is emerging evidence that some SRS proprietors are instrumental in moving vulnerable NDIS participants from the licensed SRS to a separate unlicensed residence where they continue to bill substantially from NDIS funds [7]; retuning the participant to the licensed SRS once funds are exhausted.</p>	<ul style="list-style-type: none"> • Greater transparency around NDIS (planners, LAC’s) duty to respond when risk -related red flags are raised by providers, by family, as well as by the person living with disability, around effective daily living supports.
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References

1. [2022 NDIS legislation amendments – July update | NDIS](#))
2. [Independent review into circumstances relating to the death of Ann-Marie Smith | NDIS Quality and Safeguards Commission \(ndiscommission.gov.au\)](#)
3. [Submission 77: Occupational Therapy Australia Submissions – Parliament of Australia \(aph.gov.au\)](#)
4. [Public hearing 26: Homelessness, including experience in boarding houses, hostels and other arrangements | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)
5. [separating-housing-and-support-toolkit.pdf \(summerfoundation.org.au\)](#)
6. [Community Visitors Annual Report 2020-2021 - Office of the Public Advocate](#)
7. [Evidence to Disability Royal Commission's hearing on homelessness - Office of the Public Advocate](#)

APPENDIX 2: A SUMMARY OF EVIDENCE INDICATING MISAPPROPRIATION OF NDIS DAILY LIVING SUPPORT FUNDING IN PCC SETTINGS

1. Victorian Office of the Public Advocate

September 2022 [Evidence to Disability Royal Commission's hearing on homelessness - Office of the Public Advocate](#)
[Community Visitors Annual Report 2020-2021 - Office of the Public Advocate](#)

2. Disability Royal Commission Hearing September 2022

[Public hearing 26: Homelessness, including experience in boarding houses, hostels and other arrangements | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)

Media Summary

[Royal Commission investigates arrangements for participants living in Victorian Supported Residential Services \(nds.org.au\)](#)
[Disability royal commission hears of abuse, neglect and fraud in supported residential system | Australia news | The Guardian](#)
[Disability royal commission examines conditions inside Supported Residential Services - ABC News](#)
[Royal commission told disability homes spent \\$2 per person a day on food \(theage.com.au\)](#)
[Hearing to inquire into experiences of poverty and homelessness | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)
[Disability royal commission shown images of filthy facilities as woman testifies on her mother's death | The West Australian](#)
[People with disability living in poor co... | Disability Support Guide](#)

3. Fairfax media investigation 2021-2022

[Disability care home Sydenham Grace closed amid allegations of bullying, abuse and poor food \(theage.com.au\)](#)
[How Melbourne's Hambleton House became a squalid residence for some of the most vulnerable \(theage.com.au\)](#)
[Sydenham Grace and Gracemanor \(formerly Meadowbrook\): Victorian government seizes control of supported care homes over abuse, 'uninhabitable conditions' \(theage.com.au\)](#)

Joint Standing Committee on the National Disability Insurance Scheme Inquiry – Capability and culture of the NDIA