

WHEN CARE BECOMES CAPTIVITY: STRATEGIES TO ADDRESS THE EXPLOITATION OF NDIS PARTICIPANTS LIVING IN PRIVATE CONGREGATE CARE SETTINGS

The case of Victoria's Supported Residential Services – SRS

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
Star Health
St Vincent's Mental Health Service, Melbourne
Victorian Mental Illness Awareness Council
Victorian Office of the Public Advocate
Wintringham Supports.

This submission does not intend to represent individual organisations within the PCC alliance, but rather represents the views of this collective group.

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1. ABOUT THE PCC ALLIANCE

Established at the 2018 National Mental Health Conference following concerns raised about what was occurring as the NDIS full roll-out commenced, the PCC Alliance is a group of organisations working towards the goal of systemic recognition of the unmet needs of people with disability who live in PCC settings. While these facilities exist in other states, the current focus of the Alliance is on Support Residential Services (SRS) in Victoria. The PCC Alliance is comprised of a diverse membership including legal, advocacy, disability representative, mental health, allied health, housing and welfare organisations.

2. STRUCTURE OF THIS SUBMISSION

The PCC Alliance thanks the NDIS review panel for the opportunity to submit to the NDIS Review 2023. Our submission builds on the body of work the Alliance has been building over the past three years documenting its concerns regarding the increased risk of violence, abuse neglect and exploitation to people living in PCC settings (attached). This body of work is comprised of submissions to the:

- *Victorian Mental Health Royal Commission (July 2019)* (not included, available on request)
- *Royal Commission to Violence, Abuse, Neglect and Exploitation of people with disability* (December 2022) [See Submission 1 attached].
- The Joint Standing Committee on the National Disability Insurance Scheme Inquiry – *Capability and culture of the National Disability Insurance Agency* (October 2022) [See Submission 2 attached].
- *Australian National Audit Office Performance Audit Effectiveness of the NDIA's management of assistance with daily life supports* (October 2022) (not included, available on request)

This submission makes specific, evidence-based recommendations based on these earlier submissions and on our reading of recent policy developments and inquiries. However, we ask that the NDIS Review panel consider this body of work as a whole (see attachments – Submission 1 and 2).

Our key argument is that while the NDIS has brought new and unprecedented opportunities for people with disabilities nationally, significant deficiencies in the NDIA process for administration of supports, alongside glaring safeguarding deficiencies, create unacceptable risks for NDIS participants who reside in PCC settings.

3. ABOUT PCC SETTINGS

Private congregate care (PCC) facilities are for-profit accommodation and support facilities that house large numbers of people with psychosocial disability and other disability. These are titled 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. For the purposes of this submission, we focus specifically on concerns and recommendations relating to SRS in Victoria, and acknowledge that these concerns and recommendations extend to other forms of PCC settings including those named across respective states; and also, to a proportion of relatively recently established Supported Independent Living (SIL) settings.

4. COMMENTS ON RECENT POLICY DEVELOPMENT AND RESEARCH

Whilst our recommendations are informed by our previous submissions (see point above), we also draw on our analysis of some recent policy and research developments, as seen here in brief.

Comments on the Australian Government response to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) report: General Issues 2021 (February 2023)

The PCC Alliance expresses disappointment that the government response to the NDIS Joint Standing Committee recommendations (page 4-5) did not support the recommendations related to homeless persons. Both these recommendations hold merit in increasing the safety of people at risk of homelessness living in PCC. They were to develop an NDIS strategy to engage people homeless community and to introduce NDIS specialist homeless liaison officers.

Comments on the NDIS Supported Independent Living Guideline (December 2021, updated July 2022, available at [National Disability Insurance Scheme \(NDIS\)](#))

The PCC alliance would like to draw the Review Panel's attention to the change in Supported Independent Living policy which occurred in late 2021 as outlined in *NDIS Supported Independent Living Guideline (July 2022)*. While the NDIA maintained there was no change to policy, simply 'clarification', the evident subsequent reduction in approval SIL funding has increased the likelihood that people with disability have no option but to live in PCC or SRS. Moreover, this change in policy in some instances led to an increase in flexible core support funding in lieu of a formal NDIS housing solution. The provision of 'flexible core funding' combined with insufficient safeguards as outlined in Submission 2 (attached), has meant this cohort has become the target of unscrupulous providers. As one advocate described 'this policy change placed a target on the backs on people with disability, particularly where they do not have independent decision-making support, they are pursued aggressively by unscrupulous providers.' Alongside revision of home and living policy, the NDIS needs to work effectively with the NDIS Quality and Safeguards Commission in relation to monitoring and mitigating disability-provider related risk [ANAO, 2023].

Comments on the NDIS Commission Compliance Strategy: Supported Residential Services in Victoria (July 2022)

In July 2022, the NDIS Quality and Safeguards Commission produced a document titled *NDIS Commission Compliance Strategy: Supported Residential Services in Victoria*. This document highlights the high level of awareness held by the Commission, with regards to the risks faced by PCC residents. The PCC Alliance position is that this document must be made publicly available in the interest of transparency, and an action plan and accountability framework developed to address the extremely concerning and known risks identified. (See recommendations)

Comments on the report, Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings: Accommodation and community living, employment and education" March 2023

This research report, published by the Disability Royal Commission has recommended that private congregate care settings must be closed. The PCC Alliance recommends that the shared governance stakeholders of Supported Residential Services and the NDIA work towards implementing this recommendation.

5. EVIDENCE BASED RECOMMENDATIONS

The PCC Alliance recommendations are outlined in the summary table below. These recommendations are based on collective learnings, anecdotal reports, lived experience reports, alongside published research, policy documents, and media summaries as referenced. The rationale for recommendations 4-8 is outlined through a case study 'Luke's story', in Submission 2, Appendix 1 (page 13), below.

RECOMMENDATIONS: THE ROLE OF THE NDIS QUALITY AND SAFEGUARDS COMMISSION

1. The Commission produce a **detailed, publicly-available action plan and framework** to address the safeguarding concerns they outline in the *NDIS Commission Compliance Strategy: Supported Residential Services in Victoria*.

RECOMMENDATIONS: SHARED GOVERNANCE

2. The Commission immediately **establish a taskforce** in partnership with the Human Services Regulator Unit in the Victorian Department of Families, Fairness and Housing (DFFH) and Homes Victoria in the (DFFH) to investigate the systemic nature of opportunism and exploitation of SRS residents who receive NDIS funding, including to examine NDIS data relating to SRS (e.g. number of proprietors who are plan managers or NDIS service providers; number of residents with NDIS plans). This partnership would aim to fulfil the recommendation of the Disability Royal Commission research report^{**}:

“Congregated accommodation settings (e.g., institutions, hostels, and boarding house-like facilities) need to be closed. They are unsafe and unable to deliver on the expectations of (and obligations imposed by) the UNCRPD and the objectives of the National Disability Insurance Scheme (NDIS) Act.”**

^{**}McVilly, K., Ainsworth, S., Graham, L., Harrison, M., Sojo, V., Spivakovsky, C., Gale, L., Genat, A., Zirnsak, T. (2022). Outcomes associated with ‘inclusive’, ‘segregated’ and ‘integrated’ settings: Accommodation and community living, employment and education. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. P.50, published March 07 2023

3. The scope of the **Victorian Community Visitors Program** be expanded to hold a national safeguarding remit for implementation in all private congregate care, and supported accommodation, settings.

RECOMMENDATIONS: NDIS POLICY REFORM

4. A co-designed, person-centred **NDIS risk-assessment framework** aiming to ensure participant safeguards underpin allocation of disability supports through NDIS participant plans
5. **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
6. A mandated **separation of housing provision, and provision of daily living supports,** for NDIS participants.
7. **Review of existing ‘Typical Support Package (TSP)’ allocation process,** as the current TSP reduces access to tailored, individualised daily living supports with consideration of optimal safe-guarding.
8. The NDIA review their **Home and Living policy** to align with recommendation 2 above.

Submission 1: PCC Alliance submission to Royal Commission to Violence, Abuse, Neglect and Exploitation of people with disability (December 2022)

A PCC Alliance response to evidence provided to the Disability Royal Commission Public Hearing 26: Homelessness, including experience in boarding houses, hostels and other arrangements.

19 December 2022

The PCC Alliance is 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 is comprised of a diverse membership including legal, advocacy, disability representative, mental health, allied health, housing and welfare organisations.

The Private Congregate Care (PCC) Alliance membership has felt compelled to provide a written response to the evidence provided at Public Hearing 26, and to contribute additional evidence based on the themes arising (appendix 1). THE PCC Alliance is grateful for the opportunity to make this Submission. We are grateful to the witnesses who attended Hearing 26 and presented their experiences, particularly those sharing lived experiences, and family and carer perspectives. As one of the participant's shared:

"What does that paint, what picture does that paint when we as a society put our trust in these people to do the right thing, that's their job, and they don't do it. And my mother dies as a result of that neglect?... My mother's disability did not make her lesser. And she should have been treated as a valuable human being, as all people with disability are. I feel that the SRS treated my mother as a number and a pay cheque. Based on my experience, I feel the Australian disability system treats people with disability without dignity, respect and humanity, and the government departments which are supposed to be there to investigate and prevent such mistreatment cannot be trusted to do their jobs correctly. This is not right. We need to do better."

Georgia Wilson, DRC Public Hearing 26, 02 September 2022, Transcript p.364 & 365

The evidence provided to the DRC at Hearing 26 clearly underscores concerns for the safety and unmet disability needs of people living in PCC settings, specifically those residing in Supported Residential Services in Victoria. The evidence highlights the inadequacies of current regulatory and safeguarding systems. The PCC Alliance supports urgent substantial reform to enable pathways out of SRS. As the Honourable John Ryan, Disability Royal Commissioner, stated in Hearing 26 when speaking about SRS:

"Because it looks to me this is a broken model which needs to either be significantly reformed or abolished all together."

Commissioner Ryan, DRC Public Hearing 26, 02 September 2022, Transcript p.404

As the DRC is aware, PCC residences are privately operated businesses that provide accommodation and support with daily living, predominantly utilising an institutional model care [1]. They exist Australia-wide and include Supported Residential Services (SRS) in Victoria. Evidence provided at Hearing 26 confirmed that SRS accommodate up to 4000 people, 79% of whom live with disability. 30% or approximately 1000 are NDIS participants. The SRS census 2018 says 69% of people in SAVVI-level SRS have a mental health/psychiatric disability (figure 53, p 75). There are currently 117 SRS in Victoria; SRS accommodate up to 80 people at a single residence.

The evidence provided at Hearing 26 described that the NDIS Quality and Safeguards Commission (QSC) has been developing an internal document titled *NDIS Commission Compliance Strategy - Supported Residential Services in Victoria*. The existence of this document confirms that the NDIS QSC is aware of the issues facing SRS residents.

"The NDIS Commission is aware of and responding to the following types of issues impacting NDIS participants living in SRSs."

1. *"Financial exploitation, where the SRS operator uses NDIS funds as well as the payment already made by the resident from their pension to pay for the same supports or provides no services after depleting the person's NDIS plan."*
2. *"Trading of residents between SRSs or entities associated with SRSs where the value of their NDIS plan makes these residents lucrative for unscrupulous operators. And that includes relocating residents to private accommodation which does not have the oversight of the Victorian regulator."*
3. *"...complex business networks established by SRS operators to operate collectively providing a range of supports and services and duplicating costs already met by a participant where the relationship between these businesses is not transparent to a resident."*
4. *"Poor or non-existent record keeping by SRS operators. And that results in a lack of transparency. It also limits the information available to regulators."*
5. *"Residents being limited in their choice of other providers and the ability of other providers to deliver supports in SRSs, or significant conflicts of interest between SRS operators and other providers involved in the person's support."*
6. *"Coercion of residents, particularly those at greater risk of such practices due to cognitive impairment."*
7. *"The lack of skills and competency of the SRS workforce to deliver NDIS supports and services to the level required by residents."*

Hearing 26 Transcript 02/09/2022 p. 409-414

Both the NDIS Commission and Victorian Human Services Regulator stated at the hearing that they could not say to what extent this issue was widespread or systemic. Indeed, it appears neither the Commission nor the Regulator have established the means by which they might collect this data. This is urgent and research into the extent to which exploitation, particularly in the NDIS context, is occurring, needs to be funded.

Agencies and services who work directly with people on the ground including nurse outreach workers, mental health workers, occupational therapists support coordinators, community visitors, describe witnessing examples of abuse over many years. We have come together as an alliance in an attempt to raise the issues we have been seeing and to alert relevant authorities to the critical nature of the problem.¹

What the agencies and services working within the PCC alliance have seen is indeed a situation of systemic and widespread exploitation and abuse in these settings, particularly in the NDIS context. Whilst we have not had the funding or research capacity to document this in detail, we are attempting to document what we are seeing on the ground, compiling case studies on what is occurring. The case studies listed below illustrate the tip of the iceberg of what is occurring.

***Deidentified, not their real name**

1. Nick's* story

Nick, who has a cognitive disability, spent two years living in an SRS, and recently moved out with the assistance of an advocate. On the Disability Support Pension, he describes paying \$880 fortnight to share a room, plus signed over some of his NDIS funded for care he did not receive. If he missed a meal, he often went hungry as he had to wait until the next formal mealtime for food. "It felt like living on a psyc ward or in prison", he said.

He also had an experience where an SRS proprietor had him sign a form he didn't understand, a service agreement that gave them permission to manage his NDIS plan. This meant his existing disability support workers were effectively locked out of the SRS, and his care for a period of time. Nick's occupational therapist, recalls being stopped at the door of the SRS by a staff member, and told not to come back.

"I didn't know why they stopped coming to see me, now I know I was tricked into signing away my NDIS funding", said Nick, who at the time didn't have a mobile phone and messages left for him at the SRS were not passed on. His OT engaged an independent advocacy service, who assisted with resolving the issue.

Nick's occupational therapist describes the impact of living in an SRS for extended periods of time. "Due to the institutional environment, residents can't use their living skills and often lose these skills, along with confidence and the ability to make decisions for themselves". She describes how Nick got to make himself a cup of tea for the first time in two years, during an OT session. "He literally hadn't had any opportunity to do that simple task for himself, in almost two years".

Most SRS residents are not given opportunity to plan, prepare or cook their own meals, do their own laundry or cleaning. Their daily routine is imposed by the SRS. "This makes transitioning out of the SRS to an independent living environment even more unattainable."

Nick recently moved out of the SRS as the conditions became increasingly untenable. He moved in with his mother, an arrangement that is not sustainable, as she also lives with a disability. "I'm just relieved he is out of there, I constantly worried about him and it was so hard just to get in touch with him to ask if he was ok" his mother describes. Nick applied for an NDIS-supplemented accommodation, called Supported Independent Living (SIL), however this was declined.

¹ See Appendix 1 - PCC alliance submission to the NDIS Joint Standing Committee on Culture and Capability of the NDIA, highlighting NDIS policy reform required to ensure effective provision of safeguarding and support for PCC residents

2. Ban's* story

Ban lives with both physical and mental health issues, and lived in an SRS at a time when he had nowhere else to go. He describes the daily intrusions on his privacy and personhood that took a toll. For example, a cleaner would come into his room unannounced, often early in the morning, and commence cleaning the room while he lay in bed, without even acknowledging he was there. He remembers a friend visiting him, and the SRS staff telling her that she "should be paid by the NDIS" to visit him. He feels the only reason he was successful in sourcing alternative accommodation was because he had a physical disability alongside mental health difficulties, and had access to a strong external NDIS provider team. "I'd still be living there if I wasn't a wheelchair user" he said.

3. Clare's* story

Clare* moved into an SRS following discharge from an inpatient psychiatric unit. It wasn't practical for her to live with family, and she had nowhere else to go. She describes sleepless nights and fear of being assaulted. She witnessed violence and aggression between co-residents, and an incident where a male resident dragged a female resident down a corridor by her hair. "It was terrifying" she said "and the staff either didn't believe me and thought I was exaggerating when I told them." She has now moved into her own home, but still feels distressed at recalling those events and feels helpless for others who lack the capacity to find a route to a better place to live. "It was really bad for my mental health. I can't see how anyone could recover while living there".

4. Clinical mental health housing worker

"The reason we refer people with psychosocial disability to SRS is because we have no choice – it's an SRS or sleeping rough"

"The NDIS declining housing solutions for participants and instead placing large sums of money in their core supports, makes those participants a target. For example, I worked with a plan-managed participant whose accommodation provider [a 'pop up' SRS] billed for \$47,000 for board and support work over a period of a few months."

"There doesn't appear to be any risk assessment. This is very concerning as participants can't receive the support they need without an understanding of clinical history and risk factors for relapse. Most support workers and support coordinators are unaware of past history, risks, and actual support needs."

5. Independent advocate

"We worked with a man with a psychosocial disability who lived in a closed system SRS, and the staffing level was 30:1. They couldn't manage his behaviours, for example smashing furniture. They said he was "always angry". Still, they were reluctant to allow the independent advocacy service get involved. Once we did, we were able to support him through a plan review, and though it took almost 2 years, he is now living in Supported Independent Living and has a support worker ratio of 1:3. His anger issues have completely resolved due to having the optimal supports".

6. Occupational therapist

“ There is little to no opportunity for people to build their capacity around living skills while living in an SRS. Yet, I’ve had NDIS planners decline housing solutions because they request that the NDIS resident work on “building their capacity” prior to considering an NDIS-funded housing solution. There needs to be more skill and awareness shown by planners in working with psychosocial disability. They need to understand the complexities facing SRS residents. I’ve recently had a planner inappropriately recommend an SRS for an at-risk homeless person following NDIS decline of home and living supports”.

7. Welfare worker concerns

“A concerned family member called me last week, a parent had recently passed away and the care of her brother with a disability has now fallen to her. He has a \$200k NDIS package. A sole provider provides all care, including accommodation. A huge concern for her is that they can't contact him (brother), he doesn't use a phone and is being moved around between 'lodges' around Melbourne and Geelong, at least four times this year so far. Family have no formal record of how his funds are used, and he doesn't have an NDIS funded housing option (i.e. not SIL, mostly core funds). I gave them info on the NDIS Commission and advocacy services, and explained that they could consider filing a missing person’s report if they can’t locate him within another day or two...”

RECOMMENDATIONS

The PCC Alliance calls for urgent action in addressing the known and evidenced systemic challenges facing SRS residents.

1. Review of existing systemic safeguarding which has not proven effective at preventing violence, abuse, neglect and exploitation of people with disabilities living in SRS. The review will need to include a strategy to bridge the gap between Commonwealth and State regulatory systems, to ensure a comprehensive safeguarding framework.
2. Funding for research to explore the nature and extent of exploitation of PCC residents
3. Systemic reform with clear, independent advocacy; and housing and support pathways out of SRS
4. [Please refer to Submission 2 for additional recommendations regarding NDIS].

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

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Victorian Office of the Public Advocate
Wintringham Supports.

This submission does not intend to represent individual organisations within the PCC alliance, but rather represents the views of this collective group.

Submission 2: *PCC alliance submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry – Capability and culture of the National Disability Insurance Agency (Year month)*

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

07 October 2022

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.

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** (case study 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 (Submission 2, Appendix 2).

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 .
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.

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 \(squarespace.com\)](https://www.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](#)

Case Study 1 – 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

<p>Luke’s NDIS experience: “I have no one to talk to...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” .</p>		
Scenario	NDIS Act and processes	Solutions
<p>Luke’s Support Coordinator identified that the SRS environment was unsuited to meeting his daily living needs. His goal was to live independently with supports 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 - 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 	<p>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 risk-related evidence from existing providers at the plan review process (In Luke’s situation, substantial allied health reports).</p> <p>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].</p>	<p>A co-designed, person-centred NDIS risk-assessment process aiming to ensure participant safeguards are established.</p> <p>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.</p> <p>An end to phone-based planning meetings for participants who experience reduced decision making capacity, or other identified risk factors.</p> <p>Review the existing ‘Typical Support Package (TSP)’ and examine the validity of the TSP in allocating tailored, individualised, daily living support packages.</p>

<ul style="list-style-type: none"> - 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>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.</p> <p>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.</p>	<p>Tailored ‘pathway’ prioritising PCC residents e.g. planners skilled in complex disability; specialist support coordinators.</p> <p>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.</p>
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Resistance from proprietor: “They said if I didn’t sign it, I’d be kicked out and homeless on the streets again”		
Scenario	NDIS act and processes	Solutions
<p>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.</p> <p>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</p>	<p>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.</p> <p>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]</p> <ul style="list-style-type: none"> • 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 	<p>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, <i>“Separating housing from support puts people with disabilities in control, by giving us the freedom to choose where we live and who supports us”</i>. [5]</p> <p>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.</p>

<p>understand the implications of signing the Service Agreement with the SRS, or that his funds were being channelled to the SRS proprietor.</p> <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>organisations who could provide decision making support for PCC residents.</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](#)

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

Please find below a summary of evidence of the misappropriation of NDIS participant plan funding due to insufficient preventative safeguards. This includes formal reports and media summaries.

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](#)

3. 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](#)

4. 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' \(theage.com.au\)](#)