People with psychosocial disability living in Supported Residential Services (SRS)

Submission to Mental Health Royal Commission

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Private Congregate Care (PCC) Alliance

Contact
Liz Dearn

████████████████████
██████████

or

Neil Turton-Lane

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About the Private Congregate Care Alliance

The Private Congregate Care Alliance is a group that was formed following the 2018 National NDIS Mental Health Conference in Melbourne. Presenters from six organisations came together to discuss issues around people living in private congregate care (PCC) in a session called 'Hard to reach?: people living in private congregate care facilities – learnings from the NDIS experience in WA, NSW and Victoria'.

The organisations were the Future Social Services Institute (FSSI), Victorian Mental Illness Awareness Council (VMIAC), EACH, SalvoCare, the Victorian Office of the Public Advocate (OPA) and the National Disability Insurance Agency (NDIA).

The conference session addressed concerns that had been raised in the sector about what would happen if people in this very marginalised group, did not get access to the NDIS. Particularly as the advent of the NDIS gave rise to the withdrawal of already scarce support service provided to these settings.

The PCC alliance includes FSSI, VMIAC, EACH, SalvoCare and OPA with the NDIA as a supporting member. We were recently joined by Mind Australia and the Victorian Council of Social Services (VCOSS).

It is the explicit goal of the PCC Alliance to provide the necessary research, analysis and advocacy to ensure recognition of the needs of this vulnerable and poorly represented group, who are living in private congregate care facilities within the public policy agenda. This submission addresses Victorian PCCs, known as supported residential services (SRS).

Contributors to this submission

Liz Dearn	PhD candidate and FSSI scholar, RMIT University
Neil Turton-Lane	NDIS Manager, Victorian Mental Illness Awareness Council
Rosemary Barker	Manager Safeguarding, Inclusion and Volunteer Programs, Office of the Public Advocate
Michelle Egan	Manager Strategic Development Disabilities, Participation and Choice, EACH
Mark Heeney	National Manager Innovation and Growth, Subacute and SIL operations, Mind Australia
Peter McGrath	Manager Homelessness and Support Services, SalvoCare Eastern

People with psychosocial disability living in supported residential services: submission to Mental Health Royal Commission from the Private Congregate Care (PCC) Alliance

The PCC Alliance seeks to bring the attention of the Commissioners to the experience and related needs of people with psychosocial disability living in supported residential services (SRS. These individuals comprise an exceptionally high need group who have very limited levels of support and engagement with the broader system and related poor visibility.

People with psychosocial disability living in SRS fit under 4.2 of the Royal Commission terms of reference. They are discreet group of people 'living with a mental illness and other co-occurring illnesses, disabilities, multiple diagnoses or dual disabilities'. They are at greater risk of not having their mental health or health needs met. This submission is about how to improve mental health outcomes for this group, taking into account the structural or contextual determinants of their currently poor health outcomes.

Summary of main points

This submission will demonstrate that given the historical and institutionalised nature of these environments and the unacceptable impact on the health and wellbeing of those who live in them, a dedicated and concerted effort will be required by government to respond to the rights and optimise the life opportunities of the people that live in these settings. Recognition of this model as a residual institution in is long overdue. People in SRS need intensive support and opportunities to regain choice and control over their lives, including to choose where they live and with whom.

- Supported residential services (SRS) are a private accommodation and support model that emerged out of deinstitutionalisation to provide for people who were not able to gain community accommodation and support.
- SRS accommodate as many as 80 people per residence, many living in shared rooms
- Around 2000 people in Victoria live in pension only SRS, most of whom have psychosocial disability and complex needs (approximately 1652 residents)
- Residents in SRS are highly marginalised and around half do not have independent funding or outside support
- The SRS model does not provide 'active', recovery or rehabilitation or specialist mental health support
- SRS have many of the hallmarks of institutions
- SRS are an unacceptable housing and support option for people with psychosocial disability
- SRS do not comply with Article 19 of the *Convention on the Rights of Persons with Disabilities 2008* 'the right to live independently and be included in the life of the community'
- There is an urgent need to build alternative accommodation and support models

Recommendations

Recommendation 1. Acknowledgement of SRS residents as a priority group for policy action (e.g. NDIA complex support needs work)

Recommendation 2. Establishment of a cross sectoral taskforce to develop alternative accommodation and support models and an action plan with the goal of relocating 1600 people with psychosocial disability currently in SRS

Recommendation 3. Development of sustainable housing options for future populations of people with psychosocial disability requiring community housing and support

Recommendation 4. Provision of independent advocacy for every resident with psychosocial disability currently residing in SRS

Recommendation 5. Provision of Intensive and tailored support, including peer support, for every resident with psychosocial disability currently residing in SRS

Recommendation 6. Research into non-institutional alternative models to support people with psychosocial disability to live in the community

The terms of reference

People with psychosocial disability living in SRS are clearly within scope of reference 4.2 of the Royal Commission terms of reference. They are discreet group of people 'living with a mental illness and other co-occurring illnesses, disabilities, multiple diagnoses or dual disabilities'. The environment they are living in has a significant impact on their mental and physical health. This submission is about how to improve mental health outcomes for this group, taking into account the structural or contextual determinants of their currently poor health outcomes, their low levels of service system engagement and community participation.

Background

What are SRS?

Supported residential services (SRS) in Victoria are privately operated facilities that provide accommodation and support for people who require assistance in daily living. They are regulated under the *Supported Residential Services (Private Proprietors) Act 2010* and the *Supported Residential Services (Private Proprietors) Regulations 2012*. They provide accommodation and support to up to 80 residents. Other states have similarly legislated facilities. In NSW, they are Licenced Boarding Houses, in WA, psychiatric hostels, in SA, they are Supported Residential Facilities, and in Queensland, they are called Boarding Houses and Hostels.

Supported Residential Services were originally established as Special Accommodation Houses (SAH) in the 1970s to provide 'accommodation and low level supervision and care to frail, elderly, pensioner residents'.[1] During deinstitutionalisation in Victoria in the 1990s, the model was retrofitted to accommodate people with mental illness being discharged from mental health facilities. Between 1985 to 2000 the SRS demographics shifted from predominately older people and those with psychosocial disabilities became the highest proportion of residents. Former Public Advocate, David Green said this about the shift of people from institutions to SRS:

> 'There is no doubt, however, that significant numbers of adults with mental illness who were previously cared for in long term mental hospitals are now residents in SRSs. Some facilities were first registered during this period as a direct response to de-institutionalisation, and "dumping" did occur into new and existing SRSs (as well as rooming houses), particularly in the early 1990s.'[2]

As private businesses, SRS vary in the services they provide, the people they accommodate and the fees they charge. SRS can be divided into two categories:

- above-pension SRS, which cater predominately for frail older people paying more than current pension plus Commonwealth rent assistance for their accommodation and support
- pension-level SRS, which are defined as SRS that charge fees at no more than the current pension plus Commonwealth rent assistance for at least 80 per cent of their registered beds.[3]

While overall numbers of SRS beds have been on the decline, according to the 2014 SRS census, 156 registered SRS in Victoria remain, with a total of 5400 beds. Eighty-two (53%) of these SRS are 'pension-only' SRS (around 2,800 beds) and seventy-four are above-pension SRS (around 2,590 beds).[4] People with psychosocial disability remain the highest proportion of residents in pension-only SRS, comprising 59% of all residents (or 1652 residents).[5]

Pension-only SRS

This submission relates primarily to pension-only SRS as they house the largest proportion of people with psychosocial disabilities. A system of private congregate care facilities, SRS house people with disability alongside a minority of frail aged residents. They are akin to small to medium-sized institutions in their size and function, but they differ in that they are privately run, and residents pay most of their pension to live in them. Their residual income is ordinarily too small to fund either saving or high levels of engagement in activities or community engagement outside.While many residents would like to leave the SRS to live somewhere else, they usually have very little choice as most residents do not have independent financial resources. Many residents with psychosocial disability have been discharged from mental health facilities direct to the SRS and 25% of residents in pension-only SRS have psychosis.[6]

Pension only SRS are the focus of the DHHS Supported Accommodation for Vulnerable Victorians Initiatives (SAVVI) and Pension Level Projects (PLP) programs. These programs provide top-up money to SRS to maintain their viability as an accommodation option of last resort. SAVVI guidelines provide direction to those involved in the delivery of SAVVI, including proprietors of participating SRS, community service organisations contracted to deliver SAVVI services and Department of Health staff. The guidelines outline the aims of SAVVI and the activities and outcomes expected to flow from the use of SAVVI funds. They include purchasing rules that explain how SAVVI funds should be used and describe the roles, responsibilities, accountability and reporting requirements of those involved.[7]

Pension-only SRS are also the focus of the Resident Opportunities After Reform (ROAR) project in the DHHS Eastern Region, a partnership project of community service organisations which aims to provide support to 18 pension-only SRS to enable eligible residents to obtain access to NDIS.[8] These facilities are also the focus of a PhD study drawn on in this submission.[9] Pension-only SRS receive more focus due to the relative disadvantage of residents compared to pension-plus SRS and the large numbers of residents with psychosocial disability.

Cost of living in an SRS

According to the 2013 census, people in pension-only SRS pay $437 per week or below for their accommodation and support, which is approximately 90-95% of the disability pension. Currently, residents pay between $800 and $880 per fortnight to live in the SRS, most of their disability support pension and Commonwealth rent assistance.[10] The lower cost is for a shared room, shared bathroom, with a single room and bathroom costing $880 per fortnight. This leaves residents with between $20 to $60 per week spending money. Often residents are on administration orders, leaving them only with a small amount of discretionary spending money to meet their personal needs.

SRS legislative framework

Legislation providing the framework for the operation of SRS has been amended through the decades to introduce approvals and registration processes, minimum qualifications, privacy, overcrowding and safety standards relating to fire and food handling standards. The first act governing this sector was the *Health (Special Accommodation Houses) Act 1973*. After this, they were regulated under the *Health Services Act 1988*. Since 2010, they have been regulated under the *Special Accommodation Services (Private Proprietors) Act 2010* (SRS Act) and *Special Accommodation Services (Private Proprietors) Regulations 2012*. The SRS Act governs registration, operation, residents' money and property, notice to vacate, monitoring and enforcement and Community Visitors. The regulations govern standards around personal support, privacy, independence, food and nutrition and health and wellbeing.

Human Rights

Human rights provide a universal framework for examining the everyday reality of people with disability against the principles and expectations set by international covenants. Human rights have been at the foundation of advocacy around mental illness since the 1993 the National Inquiry into the Human Rights of People with Mental Illness, the Burdekin Report. Australia's ratification of the *United Nations Convention on the Rights of Persons with Disabilities in 2008* (the Convention) means Australia is bound by the principles and obligations outlined in the Convention and has a duty to take positive measures to enable people with psychosocial disability to facilitate full inclusion and participation of persons with disabilities

Article 19 enshrines the right of all people with disabilities to live independently and be included in the life of the community as well as the 'opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement' (Article 19, (a)).

Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

In 2013, the UN Committee's concluding observations on its report on Australia on article 19 said:

> 'The Committee is concerned that despite the policy to close large residential centres, new initiatives replicate institutional living arrangements, and many persons with disabilities are still compelled to live in residential institutions in order to receive disability support.' (point 41)

> 'The Committee encourages the State party to develop and implement a national framework for the closure of residential institutions and allocate the resources necessary for support services that would enable persons with disabilities to live in their communities. The Committee

recommends that the state party takes immediate action to make sure that persons with disabilities are given a free choice of where they want to live and with whom and be able to receive the necessary support regardless of the place of residence. The State party should therefore conduct a mapping of the various forms of living accommodation based on the needs of various kinds of persons with disabilities.' (point 42)[11]

We argue that the existence of transinstitutional models like SRS is a clear indication that deinstitutionalisation in Victoria is not yet complete. People in SRS are not living independently and being included in the life of the community. As the next section shows, residents experience high rates of service disconnection, isolation and segregation from family and community. They are not able to choose where they live and with whom.

Current situation

Many reports have been written about the inadequacy of SRSs including their impoverished conditions, low staff ratios, poorly qualified staff and the social isolation of residents.[12] In 2009, a Parliamentary Inquiry confirmed the currency of the view that even though people are often discharged from acute mental health settings to SRSs, that they are not an option that can adequately address the needs of people with mental illness.[13] SRS have a number of material and social features that combine to produce an institutional setting:

- Large numbers of people living together - facilities may house between 20-80 people
- Lack of choice about co-residents
- Lack of privacy - people commonly share adjoining bathrooms and rooms
- Routinised lives
- No opportunity to participate in activities of daily living (meals preparation, cleaning and washing)
- Severely limited discretionary spending (between $30-$60 per week)
- Low participation - residents frequently have no social engagement and/or outside activities
- Isolation/segregation from the community

SRS are an example of 'transinstitutional' settings and people with psychosocial disability in SRS remain effectively 'institutionalised'.[14] Given contemporary policy directions which seek to optimise wellbeing and enable choice there is both an imperative and opportunity to rethink this forty year old model. Notwithstanding the lack of visibility of this group, better housing and support solutions, which enable people to grow and live better lives need to be planned and provided.

> **Box 1. Anecdotal description of an SRS**
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> The first thing a visitor to a supported residential service might observe is a sign at the gate signalling that this seemingly normal large house is called " ███████████████ or some similar name. They would see several cars in the driveway and people hanging around at the entrance to the house smoking or waiting for something, giving the sense that this is a public/private space. What might ordinarily be observed once inside the door is that the house opens up into a series of single or double rooms along a corridor. Not dissimilar to a cheap hotel or a small private nursing home, doors have numbers (sometimes names) on them and there is an office of sorts at the entrance. There would be between 30 to 80 rooms. Ordinarily in the mornings, there might be a manager helping waiting residents who line up for cash or cigarette supplies for the day or talking to residents about disturbances that might have occurred the night before.
>
> Further into the house, a visitor would notice that residents are seated together on old couches watching television, like in a group home environment or sitting at tables waiting for morning tea like they would in a nursing home or sitting in courtyards smoking as they would have once done in the outdoor areas of a mental health facility. Some residents might be wearing dressing gowns, others track suits or other casual clothes. if you came on one of the few mornings when there is some planned activity, you might observe residents involved in an art activity or colouring in. You might notice that at morning tea time, tea and coffee are served in plastic cups and one or two biscuits are handed out to individual residents with tongs.
>
> [█████ 2019]

Who lives in SRS?

In Victoria, around 59% of residents of pension only SRS have a mental illness, most have complex health needs and around half have no case management support or disability funding.[15] Residents living in SRS have little opportunity to exercise choice and self-determination over their lives and are their everyday choices are very restricted. There is little privacy or freedom to choose what you do, where you go and what life is like day to day in an SRS. People don't choose to live here and around 30% are discharged from mental health facilities into SRS.[16] Residents don't choose who they live with and rely on staff to manage the inevitable conflicts that emerge between residents. Daily routines are structured and there are few opportunities to participate in activities outside the SRS. With little discretionary spending money once the SRS payment is made, there is little opportunity for residents to change their everyday reality or to create goals for the future.

Box 2. ███████ – 'too sick' to live anywhere else

██████ is █ and has lived in two different SRS over the past two years. She shares a room with another resident, with a curtain between them for privacy. They are both very mentally unwell and did not choose to live together. Her roommate does not sleep and this impacts on ████████ mental health. Over the first twelve months of the study, ████████ was admitted to an acute mental health setting twice. She works very hard to manage her own mental health, using art and techniques she learnt from the comfort room in hospital. However, the pressure of living with 50 other residents, extremely limited opportunities to participate in the life of the community and the isolation and the bullying she experiences in the SRS all mitigate against good mental health. When ██████ is shown a series of images of houses, she chooses the image with 'bars' to represent the SRS, describing it as 'like a prison'. She says she can't live anywhere else because she is 'too sick'.

[██████ 2019]

Complex needs

Pension only SRS residents are likely to have psychiatric disability (59%), intellectual disability (29%) and drug and alcohol problems (14%). Three quarters of all SRS residents were reported to have a health condition or support need including chronic health conditions and depression. Pension level residents were more likely to have depression (29%), psychotic episodes (25%) and diabetes (15%). Fifty-three percent of pension only residents engage in unhealthy eating habits and over half of pension-only residents smoked.[17]

Mental health training of SRS staff

Community Visitors report one persistent issue is the lack of information provided by mental health services about the people they discharge to SRS, noting that around 30% of SRS residents have been discharged from mental health facilities. The situation is exacerbated by a widespread misperception in the mental health sector that clinical staff are employed in SRS. An SRS proprietor needs enough mental health information to make an informed decision about whether to accept or reject a potential resident. Factors that need to be considered in this process include a person's suitability to live in a congregate care setting with a very low staff to resident ratio of 1:30. The absence of such an assessment can have dire consequences for the individual, the SRS and other residents.

> **Box 3. ▮▮▮▮ – Chronic mental and physical illness**
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> ▮▮▮▮ at ▮ years of age, has lived in seven SRS and a community care unit (CCU) over the past five years and has been homeless five times in her life. She is chronically mentally and physically unwell and shares a bathroom with another resident. ▮▮▮▮ struggled with relationships in the SRS and while she sometimes made close friends, these tended to be short-lived because of conflicts emerging people moving. ▮▮▮▮ was admitted to acute hospitals, both mental health and general four times over the first twelve months of the study. She is obese, a chronic smoker, has chronic obstructive airways disease and has had pneumonia several times. She went to a CCU to learn independent living skills for six months and said she was 'sicker at the CCU than the SRS' so she returned to the SRS. She had regular planned visits to prevention and recovery care unit (PARC) to try and manage her mental health. She was in three different SRS over the course of the study, each time being evicted due to conflict with other residents. She is an example of a type of resident that the proprietor described as 'too unwell' for SRS as staff did not have the skills to support her.
>
> [▮▮▮▮ 2019]

Isolation

Around half of residents in all SRS had weekly contact with family and friends, with pension-level SRS residents significantly likely never have contact with family and friends. Many residents do not participate in organised activities with 78% were never involved in community-based programs, 87% were never involved in organised disability programs and 72% were never involved in social and recreational programs.[18]

The SRS census reported on interviews with practitioners supporting people living in SRS. When asked which additional services would help most with meeting resident needs, at least half of practitioners suggested transport assistance (71%). Current research suggests that transport is a major obstacle to residents' participating in the life of the community.[19] The location of some SRS from shops and public transport means that residents can only leave the SRS if they have a taxi voucher or someone to go with them. Access to a taxi voucher or public transport however, is not enough on its own as many residents do not feel safe travelling alone. Accordingly, residents need assistance or supported transport in order to get anywhere. The lack of supported transport militates against residents maintaining connections with family and friends.

Safety

While the object of the SRS Act is to protect the safety and wellbeing of residents living in private supported residential services, Community Visitor reports attest to SRS being an unsafe environment, particularly for women. The 2012 report from the Office of the Public Advocate on sexual assault against women in SRS shows how vulnerable women are to assault in this environment. The report shows that inappropriate resident mix and inadequate services and

support frequently put women's safety at risk. It shows that risks to residents are often not adequately managed and victims not appropriately supported.[20]

Box 4. ██████████████ – bullying and harassment

For a period over about three months during the study, four women residents regularly talked about their feeling of a lack of safety. They reported being bullied by other residents, being picked on and feeling scared to come out of their rooms. They reported that through the night, an unwell resident was knocking on people's doors. A high level of conflict between residents was observed during this time. A hierarchy between residents had emerged resulting from a change in residents and the house had become unsettled. Residents at the bottom of the hierarchy experienced bullying and harassment on a daily basis. There was a feeling of tension in the house. The fact that residents have very little to do during the day and negligible discretionary spending money means that, despite this conflict, residents were in close proximity for much of the day.

[████ 2019]

Violence and abuse

Community Visitors have over many years reported on the severity and impact of aggression between fellow residents as well as between staff and residents in Supported Residential Services (SRS). These acts combined with verbal altercations regularly escalate to violence. Community Visitor have documented physical and sexual assaults, property damage, threats and intimidation. Many of these instances result in the police being summoned. The prevalence of mental illness combined with drug and alcohol use in SRS often heighten tensions between residents. In many instances, violent episodes lead to resident evictions, pressure on people to move to another SRS or even homelessness.

Box 5. Coronial inquiry into death of SRS resident

A 2015 coronial inquiry into the death of an SRS resident by their roommate during a psychotic episode in 2012 led to a recommendation that all SRS staff undertake mental health training. DHHS accepted this recommendation but its implementation has been very slow. The continued reporting by Community Visitors of high numbers of mental health issues and their seriousness demands a renewed focus on the rollout of this training across the SRS sector.

[Office of the Public Advocate case study]

Institutionalised identity - powerlessness

Housing within an SRS serves to reinforce and perpetuate the powerless and marginalised identities of people with histories of compulsory treatment for mental illness, disability, trauma and abuse. The institutionalised nature of life in SRS is compounded by the disempowerment associated with having little economic capital that could help residents to change their lives. This situation creates low expectations and there is not a lot residents can do to increase the choice and control they have over their lives.

In this sense, the identity that is created through these set of circumstances is a disempowered identity, an illness identity, one that is limited by structures and limited resources. It is as every aspect of residents' lives is controlled by other people who make decisions about them and in that sense there is no part of who they are in terms of exerting influence over choices about their lives. One of the consequence of not being able to make choices means that it becomes almost impossible to take carriage of who you are.

> **Box 6. ██ – Unable to realise her dreams**
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> ██ ██ has lived in ████████████ for three years. She lived in independent accommodation with a community based mental health provider for ten years and then in an independent unit before moving into the SRS after conflict with her neighbours led to an inpatient hospital stay. She was discharged into ████████████ because her sister did not want her returning to independent living. However, while she feels like she has recovered and ready for community living again, she says that her sister and the proprietor tell her that she is 'not ready yet'. Her dream is to return to live in independent living but during the 18 months of the study she did not make any progress on this. She would also like to return to work. After three years in SRS, ██ has almost given up on her dreams as the current resources and relationships aren't in place to support her to make them a reality.
>
> [██████ 2019]

The case study of ██ shows how her resignation is as much a product of the system as it is of individual choice. This is what might be called 'institutionalisation' in the sense that the experiences that ██ has continue to confine her within a system that is controlling. In the NDIS context, it will be important that residents like ██ have independent advocates to support them to achieve their personal goals.

Does the NDIS provide a solution?

The NDIA describes SRS residents as 'hard to reach' but there has been little national focus on these settings in the NDIS context. Given the residences are known and people are largely 'captive', it is not clear what 'hard to reach' means in this context. The new NDIA 'complex support needs team'[21] will be providing intensive focus to three groups: people from out of home care; young people in nursing homes and, in Victoria, to 400 people who have been identified as 'vulnerable'. While some of the 'vulnerable' group, defined as people with disabilities, experience of homelessness and connection with multiple service systems including justice, may be SRS residents, there are many more residents in SRS who are not included in the 'complex support needs' group.

Several jurisdictions have been doing work to try and support SRS residents to make contact with the NDIS. The ROAR project in the eastern region is a partnership project of community service organisations which aims to provide support to 18 pension-only SRS to enable eligible residents to obtain access to NDIS. The Victorian Government has funded a version of this

program in other regions. However, the program is not resourced well enough to provide the intensive support that residents will need.

Community Visitors have been collecting data on NDIS issues for SRS residents and have documented three key issues to date. The first is access to the NDIS for SRS residents as many have no family or friends to support them in this lengthy and often difficult process so they are then reliant on staff. The understanding of the NDIS by SRS staff is variable. In addition, proprietors and SRS staff do not have the time to adequately support the NDIS application process and associated implementation on behalf of multiple residents. As a result, Community Visitors report that access to the NDIS for SRS residents is patchy, particularly for those with undiagnosed mental health issues.

Evidence is emerging that people with psychosocial disability have low uptake rates of the NDIS relative to people with other disabilities. Evidence from the ROAR project shows that, while the NDIS can greatly benefit people living in SRS, that intensive support is needed to facilitate people's access to the scheme as well as the implementation and monitoring of their plans. It is also becoming increasingly clear, that not all SRS residents will be eligible for NDIS. Significant service gaps are expected to emerge for residents who are not eligible.

There are serious concerns about how marginalised communities will fare in the NDIS context which have not be addressed. The section below is a discussion of some of those issues.

Choice and control

The NDIS is based on the object of enabling people with disability to exercise choice and control over their goals and the services and supports they need to meet those goals, and the premise that greater choice and control will result in better life outcomes for people with disabilities. Concerns have been raised in Australia that people with complex needs and inadequate advocacy support and resources, like residents in supported residential services (SRS), may become further marginalised in the NDIS context. Rational choice theory, on which the NDIS is premised, conceptualises the individual as an active agent in decision-making, free of structural constraints. Yet, people living in SRS experience many limitations or constraints on making decisions about their lives.

One of the presumptions in a competitive market is that all consumers will be equally be able to exercise their right to choose (ACOSS 2016). But this approach fails to recognise the structural barriers impacting on individual's capacity to make informed choices. The application of principles such as competition, contestability and choice may not benefit consumers who are not empowered to make choices (Brotherhood of St Laurence 2016). In an article under review, Gemma Carey discusses the important role of the government in the shift from government provided services to marketised services in the NDIS context. She points to research that suggests marginalised citizens are least likely to benefit from competition-based market reforms; (Jilke 2015 cited by Carey 2016) and that shows that socio economic position is a significant determinant of the quality of services people will receive and their ability to move between providers (Williams 1992, cited by Carey 2016).

People with high and complex needs will generally need an array of supports to enable participation in the scheme as envisaged by the NDIA (Madden et al 2014). They are likely to be disadvantaged at all points along the NDIS trajectory including contact, assessment, planning, choice of supports and implementation (Dowse et al 2016). Experience shows that supporting people with complex needs requires collaboration between services; continuity of workers; specialist understanding of the needs; supervision of support staff; specialist supports including behaviour and trauma, training and mentoring of staff, none of which are guaranteed in the NDIS environment (Dowse et al 2016, Collings et al 2016, Fisher 2016, Soldatic 2014).

In the UK, intensive support has been shown to be needed to establish and maintain services in an individualised funding environment for people with disabilities and complex needs (Gridley 2014). Their needs are likely to extend beyond mental health services to housing, health, education, employment, participation and connection to financial. However, concerns have been raised about the impact of the NDIS on specialist disability support agencies and whether mainstream services will have the capacity to people with complex needs (Green 2014, Dowse et al 2016, Stephens et al 2014, Ramcharan 2016). [22]

Supported Independent Living funding

NDS reported in 2018 that supported independent living (SIL) funding makes up approximately one third of the NDIS operating budget at full Scheme.[23] It is a reasonable assumption NDIS participants with a psychosocial disability will be eligible for SIL if it can be demonstrated they meet the reasonable and necessary requirements. Individuals who are currently receiving SIL, according to Mind Australia have come from varying settings, including CU, SRS, living at home with aging parents, caravan parks, boarding houses and homelessness. SIL can be provided in varying types of accommodation settings.

In Victoria a proportion of SIL packages delivered is within state government legacy stock properties. This creates an inequity between legacy stock residents and people living in SRS, who are effectively funding the support component of living in an SRS from their disability support pension, leaving them effectively living in poverty.

Accommodation provided by Community Housing Provider, The Haven Foundation is a growing type of accommodation option across Victoria (discussed below). There are also opportunities to utilise the private rental market or other Community housing Providers to rehouse people with a SIL component in their NDIS plan. However NDIS will not solve all housing related issues for people with a psycho-social disability, as it is understood a high proportion of people with significant mental illness will not be eligible for the NDIS.

Alternative approaches

The continued acceptance of congregate care facilities like SRS as legitimate support options must be questioned. In the new policy environment, the NDIA (Specialist Disability Accommodation) Rules 2016 prescribe limits on the number of residents for both new and existing housing stock. These rules limit housing size of new builds and legacy stock to 'five or fewer long-term residents' (SDA rules section 6.10).[24]

As the policy related to mental health, dual disability and support continues to evolve and improve, consideration must be given to the need of SRS residents, for active support, recovery and rehabilitation-oriented care. SRS are not an appropriate response to these support needs. New options should be predicated on an understanding of the support requirements but also encourage and develop autonomy, independence and social engagement, consistent with human rights and clinical needs. Examples of alternative approaches for accommodation and support that could be expanded and built on include the WA Perth Hills project, the Doorways Project and the Haven Foundation.

Building New Lives: Bringing the NDIS to people living in psychiatric hostels

This Western Australian project (see Appendix 1is often spoken about as a good practice model of supporting the independence goals of people living in private congregate care, in this case Perth Hills Psychiatric Hostels. The cross sectoral project provided residents with intensive individualized support to facilitate their NDIS planning. It demonstrated that, with intensive advocacy, support and funding, many residents could leave psychiatric hostels to live independently in the community. The components that were needed for residents to leave included medical care, clinical support and monitoring of medication, stable accommodation in own home, rental or share house and support to build capacity). [25]

[Stopher and Hughes 2017]

The Haven Foundation

The Haven Foundation provides permanent accommodation in multiple unit buildings for people with psychosocial disabilities in Victoria. It has residences in South Yarra, Frankston and is about to begin construction of a new residence in Geelong. The Haven Foundation is a community housing provider and Mind, a community mental health support service provides the support funded by the NDIS. The support model is an enhanced version of the adult residential rehabilitation model, although with a stronger sense of family, carer, natural support participation with a mission to reduce formal supports. This is an example of much needed sector redevelopment occurring within the NDIS context. NDIS provides the driver for this reconfiguration of residential options for people with psychosocial disability and has the potential for greater expansion but it does rely on residents being eligible for NDIS supported independent living (SIL) funding.[26]

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Doorway program

The doorway program has a high success rate in supporting people with psychosocial disability, who previously considered themselves unable to live independently, to do so. Doorway is an 'innovative and evidence-based housing and recovery program that supports people experiencing mental health issues who are homeless, or at risk of homelessness, in securing and sustaining a home within the private rental market'. The Victorian State Government funded Wellways, a community mental health support service, to deliver the program to 100 people between 2014 and 2018. An independent evaluation of the Doorway three-year Demonstration Project, highlighted one-third of participant's mental health improved to the point that they no longer required case management with clinical services and after entering Doorway 'the majority of participants achieved stable and secure private rental accommodation for the first time in their lives'. [27]

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Tailored response and priority action

The existence of transinstitutional settings like SRS is a clear indication that deinstitutionalisation in Victoria is not yet complete. People in SRS do not have the opportunity to live independently and are excluded from the life of the community. They experience high rates of service disconnection and isolation and segregation. This is inconsistent with article 19 of the Disabilities Convention which states that people with disabilities have:

> 'the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement' (Article 19, (a)).

The PCC Alliance members have worked extensively with people living in SRS over a long period of time. Together we have been responsible for developing assertive in reach initiatives, specific care planning arrangements, monitoring, safe guarding programs and legislative responses, research and advocacy.

It is clear that priority effort is required to effectively address the needs of people living in these settings. These problems have demonstrated themselves to be resistant to general policy trends and broader efforts, and a concerted and specific suite of actions are necessary to effectively engage with and to halt the continued deterioration of the circumstances of these residents. The required responses fall into four main areas:

Priority group and establishment of a taskforce

In the first instance SRS residents with psychosocial disability should be acknowledged as a priority group for policy action and a taskforce established to address issues raised in this submission.

Recommendation 1. Acknowledgement of SRS residents as a priority group for policy action (e.g. NDIA complex support needs work)

Recommendation 2. Establishment of a cross sectoral taskforce to develop alternative accommodation and support models and an action plan with the goal of relocating 1600 people with psychosocial disability currently in SRS

Alternative models of accommodation and support

Building on recommendation one, the development of models of accommodation and support to divert new residents from SRS. These models would comprise independent and supported housing, individualised and suitably skilled support and be underpinned by recognition of both clinical needs and human rights.

Recommendation 3. Development of sustainable housing options for future populations of people with psychosocial disability requiring community housing and support

Intensive support

Intensive support, including peer support and advocacy are needed for residents currently living in SRS to enable them to regain choice and control over their lives (see Appendix 1)

Recommendation 4. Provision of independent advocacy for every resident with psychosocial disability currently residing in SRS

Recommendation 5. Provision of Intensive and tailored support, including peer support, for every resident with psychosocial disability currently residing in SRS

Policy and research

Further research is needed combined with a strong recommendation to policy makers (both DHHS and NDIA) to ensure SRS residents are a priority group for new policy development

Recommendation 6. Research into non-institutional alternative models to support people with psychosocial disability to live in the community

Appendix 1.

Figure 1: Typical life journey for a person who lives in a psychiatric hostel

Onset of mental illness
- Illness is severe and persistent
- Often starts in late teens or early 20s
- More recently, may be due to drug-induced psychosis

Progression
- Admissions to hospital mental health units
- May not have informal support upon leaving hospital - a time when the person is especially vulnerable and not making good decisions
- May experience a traumatic event
- May not be following prescribed medication
- Guardian or trustee may be appointed

Move into psychiatric hostel
- Person is generally aged in 30s or older and has had psycho social disability for 15 years or more
- Lack of other accommodation options due to no family support or family is exhausted or due to domestic violence or very poor coping behaviours
- Note a person may choose to live in a hostel due to perceived independence

Barriers to leaving hostel
- Older people who joined hostels decades ago are institutionalised
- Residents are quickly deskilled and dependent due to provision of laundry, meals, cleaning and money management(Centrepay)
- Fears of leaving hostel as staff and residents regarded as family
- Mental illness may have occurred early in life, before a person developed their interests, direction, work ethic and daily care skills
- Disconnection to community as hostels are not funded to help residents access community activities

What people need to leave
- Medical care and clinical support in place
- Monitor medication dosages and manage side effects (eg: lethargy)
- Accommodation is stable in own home, rental or share house
- Support to build capacity and progress goals at home and in community, including tenancy support, support to access community, connect to family and friends, establish volunteer or paid work or take up further education.

Stopher K and Hughes D 2017

[1] Green D 2001, Advice to the Department of Human Services on Supported Residential Services, Melbourne. Department of Human Services, p9.

[2] Green 2001 p17

[3] Department of Health 2012, 'Supporting Vulnerable Victorians Initiatives Guidelines', Victorian Government.

[4] Market Solutions 2013, 'Census of Supported Residential Services (SRS) in Victoria, commissioned by the Victorian Department of Health and Human Services.

[5] In pension plus and pension-level SRS as a whole, 39% of all SRS residents have psychosocial disability

[6] Market Solutions 2013

[7] Department of Health 2012

[8] https://www.ehn.org.au/uploads/images/115/Eastern_SRS_ROAR_Project_NDIS_Practice_Advice_Final_16022018.pdf

[9] Dearn 2019 'Choice and control: The experience of choice and control for people with psychosocial disability in the NDIS context: A critical ethnographic study in two supported residential services in Victoria. Unpublished paper, National NDIS Mental Health Conference. RMIT University/Future Social Services Institute. Contact the author ███████████████████

[10] Dearn 2019

[11] UN Committee on the Rights of Persons with Disabilities 2013, 'Concluding observations on the initial report of Australia', adopted by the Committee at its tenth session' (2–13 September 2013).

[12] Green 2001; Office of the Public Advocate 2002, 'Community Visitors Annual Report to Parliament' (Health Services).

[13] Parliament of Victoria 2009, Inquiry into supported accommodation for Victorians with a disability and/or mental illness, Family and Community Development Committee.

[14] Dearn 2019; Drake G 2014, 'The Transinstitutionalisation of People Living in Licensed Boarding Houses in Sydney', *Australian Social Work*, 67-2, pp.240-255; Jewell, P, Dent, M, Crocker, R 2016 'Measuring Ethical and Empirical Consequences of De-institutionalisation', *Contemporary Issues in Applied and Professional Ethics*: *Research in Ethical Issues in Organisations*, Volume 15, pp.149-167

[15] Market Solutions 2013

[16] Market Solutions 2013

[17] Market Solutions 2013

[18] Market Solutions 2013

[19] Dearn 2019

[20] Bedson, L 2012, 'Sexual assault in supported residential services: Four case studies, Office of the Public Advocate, Victoria.

[21] https://www.ndis.gov.au/news/1002-improved-ndis-planning-people-complex-support-needs

[22] This is an excerpt from Dearn 2017 PhD proposal. Please contact the author for references. ███████████████████

[23] National Disability Services Supported 2018 Independent Living (SIL) practice guide

[24] https://www.legislation.gov.au/Details/F2017L00209/Html/Text#_Toc256000055

[25] Stopher K and Hughes D 2017 'Building New Lives: Bringing NDIS to people living in psychiatric hostels – Perth Hills Site WA: Overview and stakeholder reflections'. NDIA. Located at https://valuedlives.org.au/wp-content/uploads/2017/09/Bringing-the-NDIS-to-people-living-in-psychiatric-hostels-Final-002.pdf

[26] http://www.havenfoundation.org.au/contact-us

[27] https://www.wellways.org/our-services/doorway

This submission has been read and supported by the following organisations