Submission to

National Disability Insurance Agency
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Home and Living Policy consultation

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The NDIS CMH Interface group

The Victorian Statewide Clinical Mental Health (CMH) NDIS Interface group consists of NDIS Program Leads who are specialist clinicians based at tertiary Mental Health services across the state of Victoria. These NDIS Program Leads provide the interface between the NDIS and tertiary MH treatment providers. These clinicians do not provide NDIS services, but rather work with clinical staff groups as they support and treat people with mental ill-health and associated psychosocial disabilities.
The following is the CMH NDIS interface group submission to the National Disability Insurance Agency's consultation regarding its proposed Home and Living policy. This submission does not intend to represent the organisations with which the NDIS Program Leads are engaged, but rather represents the views of this collective group.

Introduction

In 2011 the Productivity Commission determined "any people with significant and enduring psychiatric disabilities have the same day-to-day or weekly support needs as people with an intellectual disability or acquired brain injury." This determination does not reflect the experience and outcomes for people with psychosocial disability, particularly when it comes to housing. In 2020 the Productivity Commission enquiry revealed that just 1.6% of NDIS participants with PSD received Specialist Disability Accommodation (SDA), which is much less than the predicted 6% across all disabilities (pp. 992-993).

The NDIA's data report on participant outcomes released in June 2020 indicates that participants with Psychosocial Disabilities (PSD) had a tendency for poorer baseline outcomes when compared with participants with intellectual disabilities, and other disabilities overall (p.147). Of all cohorts, these people were the least likely to live in a private home (owned or rented) and much less likely to be in paid employment. Participants with PSD were significantly less likely to have informal supports, or even connections with family and friends. Overall, we know that health outcomes for people with PSD are much poorer than the general population, and that these poorer outcomes can be linked to a range of health and social support disparities (AIHW 2020). These findings are consistent with the experience of our staff who are working every day with NDIS participants and non-participants living with Psychosocial Disabilities across our program.

Home and Living Survey

The NDIA's draft of a new Home and Living policy should be seen as an opportunity to address the inequities experienced by NDIS participants with PSD. The following response is aligned to the various elements of the online survey and pertains to people with a psychosocial disability.

Response aligned to:

a. Changing the conversation.

We are supportive of a change in the conversation regarding a person's home and living situation. Home and Living supports should be individually tailored to a participant's needs. Flexibility in design and a willing market are required to achieve this.

Currently, NDIS participants with Psychosocial Disabilities (PSD) with high and complex support needs are denied NDIS funded home and living supports more often than participants with other disabilities (Productivity Commission 2020, pp 992-993). Instead, they are frequently forced to live in Supported Residential Services (SRS) that are ill-equipped to manage complex support needs, boarding houses rife with illegal activities, or become homeless. Private rental is commonly inaccessible for many of these participants due to cost, and also due to barriers related to their Psychiatric condition and associated behaviours of concern (NDIA 2020, p.147). Having a conversation about home and living options with NDIS participants who have PSD needs to lead to some concrete and attainable solutions. Current options are very limited.

In relation to Individual Living Options (ILO) where the focus is on a private arrangement between the provider and the participant, it leaves the participant more vulnerable to exploitation. There needs to be a conversation about how we can strengthen safeguards for NDIS participants. Having dedicated consumer advocates, independent Support Coordinators, and Recovery Coaches may provide some monitoring of these relationships.

Recommendation: If the NDIA is to have a conversation with NDIS participants who have PSD, they need to be prepared to support suitable solutions.

b. Supporting you to be an informed and empowered consumer;

Improving communication with NDIS participants about their home and living options is a sound idea. However, many people with significant psychosocial disabilities find they need someone to work through the options with them. Support Coordinators and Recovery Coaches have provided vital support for these NDIS participants up to now. Many people with PSD lack the informal supports to guide them along the journey to explore their home and living options. They have become separated from family because of their Psychiatric conditions.

Another issue for NDIS participants with PSD is that they experience fluctuations in their mental state that often see them hospitalised for several weeks to months at a time. In general, maintaining their accommodation can be challenging under these circumstances. An Individual Living Option (ILO) arrangement will foreseeably be more difficult to maintain, due to the dependence on another party to manage such uncertainty. The challenging behaviours experienced due to fluctuations in the mental state of the participant, is known to fatigue and ultimately sever the relationship with their house mates.

Recommendations: Funded NDIS supports including Support Coordination and Recovery Coaches are a reasonable and necessary way to support NDIS participants with PSD to navigate home and living options and maintain their accommodation.

c. Expanding support for decision making;

Supported Decision Making is a necessary form of support for NDIS participants with PSDs. It should be noted that people experiencing mental illness across their lifetime will have fluctuating ability to make informed decisions about their care, support, and housing needs. A flexible approach is required and may mean that these participants have periods under legal guardianship and administration orders.

d. Reforming the funding model;

Many NDIS participants with PSD have been denied funding that would enable them to live in supported housing options such as Specialist Disability Accommodation (SDA) or SIL homes. Additionally, the SIL and SDA application processes are “unduly lengthy and complex” as outlined by the Joint Standing Committee (JSC 2020, p 71). This is causing considerable suffering to individual participants, and places unnecessary strain on the public hospital system.

It would appear that the NDIA has a decreasing appetite for SIL accommodation approvals and are building the case for ILO. There are a range of reasons that ILO will be unsuitable for most of these participants with PSD. We are concerned that ILO is an even more unstable option than SIL for most participants with PSD. Additionally, it appears that ILO options will be less regulated than the current SIL and SDA market.

Independent Living Options (ILO)

We raise the following concerns in relation to ILO type home and living options for NDIS participants with Psychosocial Disabilities and complex support needs.
These participants are likely to:

1. Find it difficult to identify a suitable host.

   Reasons may include: limited capacity/skill to engage with others; likelihood of being exploited by others; behaviours of concern causing safety issues for themselves and/or others; paranoia associated with their mental illness; lack of informal supports.

2. Be vulnerable to exploitation by potential hosts

   Reasons may include: Lack of boundaries in social interactions; previous institutionalization and blind acceptance; having prescribed medications that are sought after by others such as Benzodiazepines; lack of safeguards in private arrangements; lack of oversight and monitoring of private hosts; financial incentives offered by NDIA to host someone who may be a less desirable choice as a living companion; lack of informal supports. Conflict of interest is more likely to arise in ILO arrangements, where the other organizational safeguards are not in place.

3. Experience instability in their home and living arrangements

Reasons may include: Challenges with their personal decision making around suitable hosts; Host fatigue due to incapacity to manage behaviours of concern and/or lack of awareness of what they signed up to; Lack of regulation and oversight provided by NDIA in relation to hosts; landlords not obligated to continue arrangements; lack of informal supports; frequent hospitalisations.

SRS appears to remain the only option for a significant number of NDIS participants with PSD (Andrews 2016). Many SRS providers have been observed to take advantage of NDIS participants by spending their core support funding, without providing an appropriate level of care in return. NDIS participants with PSD will continue to be vulnerable to the SRS proprietors if their home and living options are so limited under the NDIS.

SIL home providers are also taking advantage of NDIS participants with PSD, by inviting them to stay at their homes and exhausting their core NDIS budget to fund their supports, even in the absence of an SIL team endorsed Roster of Care. These participants are being told to find other accommodation when the funds in their NDIS budget run out, and the NDIA are often not willing to further fund the participant. This leaves the participant with no home and no NDIS funded supports, until a plan review is conducted, which can be weeks to months. Even when the plan is reviewed, many participants are not approved for SIL type supports and are at risk of physical and mental deterioration, and subsequent hospitalisation.

Consumer O was relinquished by their NDIS support workers to the emergency department of the local public hospital. The Support Coordinator had advised that this should occur as this participant had no further funding in their plan to pay providers for the level of care required for this participant. The NDIA did not review the plan in sufficient time to enable continuity of care. Additionally, the SIL team did not approve the SIL type supports required for this participant and they had a lengthy stay in hospital whilst the SIL decision was reviewed. A new provider was then required.

The Joint Standing Committee (JSC) has recommended clarification of the access to SIL for people with PSD to improve their experience with the NDIS (JSC 2020, p. 33).

Recommendations:

We provide the following recommendations in relation to home and living options for NDIS participants with Psychosocial Disabilities (PSD) and complex support needs.

1. Stable long-term home and living options that include disability supports that adequately address the specialist needs of people with PSD and associated behaviours of concern.

2. Individual (single occupant) living options with high level supports for some. A significant number of people with PSD cannot live with others.

3. Shorter term capacity building support in transitional housing to meet the gap between inpatient settings, including hospitals and short-term bed-based Community Care Units (CCUs) delivered by Tertiary Mental Health services and SIL homes.

4. Clear regulation of providers, and potent oversight processes to reduce and eventually eliminate current exploitation of people with PSD.

5. Co commitment and co investment in a solid housing market response for people with psychosocial disabilities.

6. Sustainable home and living options that do not leave people vulnerable to exploitation.

7. Options to be created for Lived experience co-designed supported living.

e. Improving choice and control through flexible budgets;

Improving choice and control with more flexible budgets appears to be theoretically sound. However, we recommend caution regarding the length of time between plan reviews, and the risk of budgets being exhausted before they can be reviewed. Careful budget monitoring is required and increased responsiveness of the NDIA to requests for unscheduled plan reviews. Support Coordinators and Recovery Coaches are well placed to assist with the monitoring of NDIS budgets. It is concerning to note that many participants with PSD are having their support coordination hours reduced or removed entirely from their NDIS plans. This leaves people with no one to ensure they are utilising their plan effectively.

Case example: Consumer J was hospitalised recently, and the ward Social Worker raised alarm that this NDIS participant had their Support Coordination funding removed from their plan in the preceding months. Despite an appeal via the Local Area Coordinator, the decision was upheld. This participant had not been able to utilise their funded supports effectively in the absence of a Support Coordinator. This had led to their deteriorating mental health, due to lack of disability supports. When this situation was escalated to the NDIA, the response was that they had already reviewed their decision. No further evidence was considered. This person continues with a lack of disability supports.

Recommendation: Where plans are extended, it is essential that utilisation of supports is assisted and monitored. Support Coordinators are best placed to manage the monitoring of NDIS participant plans where people have Psychosocial Disabilities. This is a reasonable and necessary support for the vast majority of NDIS participants with PSD.

f. Engaging the market and driving innovation;

It is well known that many SRS and SIL home providers are exploiting NDIS participants who reside at their facilities. This has been raised numerous times with the NDIS Q &S commission, with no consequence to the offending providers. Meanwhile NDIS participants in SRS and SIL accommodation are left vulnerable. There is a continuing risk of providers gauging NDIS plans unless the regulation of providers is more effective.

Consumer F was residing at an SRS. When they became an NDIS participant, the SRS provider told them they would need to use their NDIS funding to pay for the supports that they already had in place as a resident at the SRS. This meant the participant had no choice or control over how they engaged their disability supports. The Mental Health Case manager observed that the SRS provider was not engaging the participant in capacity building activities but rather continuing to do everything for the participant. This was not in alignment with the participant's goals. The participant did not make a complaint for fear of losing their accommodation.

Participant G was residing at an SRS. Once they became an NDIS participant, they went ahead to select suitable providers of support. The SRS proprietor asked this participant to leave the SRS as they stated that the participant had not selected the SRS as the provider of their core daily supports.

Recommendations: We recommend and support the tightening of regulations around NDIS provider conflicts of interest; and strengthening the NDIA Quality and Safeguards response to complaints about NDIS providers, even when those complaints are made by non-NDIS provider advocates on behalf of participants.

Robust Housing

There is a notable lack of robust housing availability to meet current needs. SDA providers appear reluctant to build homes for participants with PSD and complex behavioural support needs. It is also apparent that SDA providers with existing stock are denying applications from people with PSD and complex behavioural support needs, as they are not their preferred clients. Much of the existing stock is also not in areas of choice for participants. There are extensive wait times for SDA housing, and SIL homes as an interim option are too insecure and inappropriate for people with high levels of complexity.

Provider of last resort

Where an NDIS participant is unable to locate a suitable support, the NDIA is responsible to arrange for a provider of last resort to meet the participants support needs (NDIA 2016). This does not seem to be occurring.

Consumer R has approval from the NDIA for SDA. However, all efforts to locate a suitable SDA provider have not eventuated in any accommodation. As a result of this market failure, the Tertiary Mental Health inpatient service is compelled to keep this Consumer in their care, even though they are medically cleared for discharge. Consumer R's Support Coordinator was able to locate a SIL home as an interim solution, however the NDIA's SIL team did not approve the SIL quote, and the participant was forced back to the inpatient ward. SDA providers have declined all applications.

There is a noticeable absence of the provider of last resort, as described in the NDIS Market Approach (2016). It would appear to us that the NDIA views the tertiary Mental Health inpatient unit as this provider of last resort. Due to the restrictive and acute nature of the inpatient environment, this is grossly inappropriate and constitutes a breach of the participant's human rights.

Summary

We are glad that the NDIA are seeking our advice regarding their new Home and Living policy proposal. However, we believe the proposal fails to address the specialist needs of the NDIS participants with Psychosocial Disabilities (PSD).

NDIS participants with Psychosocial Disabilities (PSD) and complex behavioural support needs are particularly disadvantaged by a lack of agreement regarding who is responsible for the provision of disability related home and living supports. From the available literature, it seems clear that the National Disability Insurance Agency has a responsibility to fund these supports where there are no more cost effective and existing supports available. For many participants, this is not currently occurring. Even when funded these participants are challenged by market reluctance.

We suggest the new Home and Living policy focus on improving the processes and timeliness of SIL and SDA decisions; strengthening and expanding the powers of the NDIS Quality and Safeguards commission; and cease the removal of Support Coordination from participant's NDIS plans.

References

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