ermha 365 | Complex Mental Health and Disability Services

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# Response to NDIS
# Home and Living consultation paper

# Contact

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# Acknowledgements

**ermha**365 acknowledges the contribution of staff from the organisation's mental health and complex client teams, as well as Executive Management in the preparation of this submission. **ermha**365 also acknowledges the importance of maintaining privacy and client confidentiality. To that end, the organisation seeks the opportunity to be consulted prior to the reproduction or publication of any content arising from case studies featured in this submission.

# About ermha365

**ermha**365 is a company limited by guarantee, operating across Victoria and the Northern Territory, providing a range of mental health programs and services, in addition to NDIS support.

We are known for our work with people who have significant mental health and cognitive disabilities and who may have additional complex needs, including behaviours of concern. Our participants' backgrounds are likely to include trauma and at times lengthy institutional care, high contact with the service system (with little success), and a range of complex needs and diagnoses.

We are one of a very small number of specialist services working with complex participants who have co-occurring mental health needs who present with dual disability, autism spectrum disorder, alcohol and drug issues, and contact with the forensic/criminal justice system. As a result, **ermha**365 is a lifeline for people who often feel like "a square peg in a round hole". Many of our clients have experienced stigma and discrimination, often ostracised or excluded from the simple things that most of us take for granted.

At **ermha**365, we believe it is a fundamental human right to live in the community – not in prison, or a locked hospital ward, just because there is nowhere else for you to go. We are experienced in successfully transitioning high-risk, high-needs participants from Secure Extended Care Units (SECUs), in-patient units, prisons and forensic facilities to community living and we are a go-to source for the State government and the National Disability Agency (NDIA) when the system has failed people with extreme behaviours of concern and high support needs.

Our purpose is to be a unifying voice for people with mental disability, giving them the voice, choice and support to thrive in a vibrant supportive community.

**Our vision** is for progressive reform, advocating for all people living with a mental disability to be able to reach their personal potential.

**Our mission** is to work side by side with the people we work with, providing them with the compassion, care, advocacy and support they need to live the lives they want within a supportive community.

# Case studies

To illustrate key themes, ermha365 highlights the challenges our clients face though the use of case studies. Pseudonyms have been used throughout this report, to protect the identity of individuals and maintain client confidentiality in accordance with the NDIS Code of Conduct for Service Providers and statutory privacy obligations. The case studies in this submission have been de-identified. However, ermha365 would appreciate the opportunity to be consulted prior to the reproduction or publication of any content arising from such case studies.

# Contents

# 1. Executive Summary

This submission outlines our recommendations relating to the small cohort of NDIS participants that we work with ('Complex Care needs clients').

Complex Care needs clients include people living with complex mental disorders, cognitive disabilities and challenging behaviours who often have extended histories of self-harm, property damage and violence, placing at risk staff, family members and the wider community. These clients with multiple, complex and challenging needs are at significant disadvantage due to a combination of the nature and severity of their mental illnesses, disability status, persistent criminal offending behaviour, traumatic backgrounds and social isolation and require multi-agency support.

Whilst we welcome many of the Home & Living paper's recommendations for the vast majority of NDIS participants, we are acutely aware that the needs of Complex Care needs clients are not being met now, and are not adequately addressed within the discussion paper for Home & Living as it currently stands.

In 2020 **ermha**365 responded to two NDIS papers in respect of Supported Independent Living:

- SIL Pricing Controls (September 2020), and
- Improving outcomes for participants who require SIL (November 2020)

**ermha**365 remains extremely concerned that the narrative of the NDIS continues to push towards Individualised Living Options as a replacement for SIL.

To apply a blanket policy that Individualised Living Options, as they currently stand, are the only options available to NDIS participants – regardless of their complexity – will expose participants, our staff, and the community to increasingly high and unacceptable risks.

Removal of 24/7 services like SIL, and replacement with ILO, will eventually result in catastrophic service failures for complex participants, as the very few quality providers like **ermha**365 that are willing to work with this cohort are faced with no other option but to exit supports.

This is the inevitable result when individual plan budgets come back completely unviable to deliver on the ground. Ultimately, if the Agency pursues this strategy, it will result in total market failure at the complex end of the market, leaving no service options for extremely vulnerable people.

Therefore, our submission in respect of the Home & Living paper addresses specifically housing and living options for people with complex care needs. We draw upon our extensive experience and expertise in providing supports for Complex Care needs clients in Australia for almost four decades.

**We make five (5) specific recommendations to the Agency:**

1. **Individualised Living Options will not be appropriate for every Complex Care need client, and a new stepped care approach needs to be designed and funded by the agency.** Without this stepped care approach, the NDIS risks significant market failure across the country for people with complex needs – these failures are already occurring, with few

providers willing to accept the risk and cost associated with this cohort, and this risk and cost will grow significantly under the current proposal.

2. **ermha365 recommends the Agency establish eligibility criteria related to accessing flexible funding through ILO and the use of the existing SIL structure.** This eligibility criteria needs to be clearly communicated to support providers, support coordinators and SDA providers as it will underpin long-term decisions about the appropriate models for individual care.

3. **There is a need to develop policy settings that create and encourage additional group models of mixed accommodation** that can include SDA and private rental options in congregate settings, which can deliver cost savings over current standalone arrangements.

4. **Incentives could be introduced to enhance complex care needs clients' ability to access Social/ Affordable housing and homes in the private rental market**, promoting choice and control while reducing current unfunded burdens on providers to manage tenancies and property risks.

5. **Flexible Home & Living transition funding arrangements (housing and support) that extend for more than 90 days should be made available for complex participants**, to enable proper assessment of the person's needs in a community setting where many are currently living in hospitals or forensic settings.

# 2. The case for change: Complex Care needs clients

**Complex Care needs clients** often have extended histories of self-harm, property damage and violence, placing at risk; staff, family members and the wider community. Clients with multiple, complex and challenging needs ('Complex Care needs clients'), are at significant disadvantage due to a combination of the nature and severity of their mental illnesses, disability status, persistent criminal offending behaviour, traumatic backgrounds and social isolation. They require multi-agency support to assist with their health, housing, social participation and personal function. This cohort have been found to be likely to use alcohol and other drugs and be homeless or marginally housed in insecure or inappropriate arrangements.

Appropriate housing choices for people living with Complex Care needs are currently very limited - even more so for NDIS participants[1]. When housing is provided that is not fit for purpose, there is often significant property damage and an increased safety risk to the individual and community. It is not unusual, therefore, for delayed or inappropriate provision of support to lead to long-term hospitalisations or incarcerations, which present severe infringements on an individual's human rights and significantly compromise their ability to achieve life goals. These prolonged admissions and detentions are often not clinically or legally justified, but are a result of these clients having "nowhere else to go". Once trapped in these circumstances, clients with complex and challenging support needs can enter a vicious criminal justice cycle, putting significant pressure on emergency services, prisons and hospitals[2]. The costs to the person, their family, and the agencies who provide services to these groups are estimated to be very high.[3]

According to the Office of the Public Advocate's Report (2018)[4] there are a range of factors that characterise clients with Complex Care needs. They usually:

- have multiple and/or severe disabilities requiring various forms of support, often compounded by experiences of trauma
- experience issues with interpersonal engagement, such that they have limited family support and/or are unable to live with others
- engage in challenging behaviours that can put themselves or others at risk of harm
- are or have been engaged in multiple government service systems
- have exhausted (or are at risk of exhausting) service providers and workers
- have a history (or are at risk) of unstable accommodation, homelessness and/or periods in detention in the criminal justice and/or mental health systems and, as a consequence of the above. Fit for purpose, stable housing plays a critical role in the prevention of exacerbating existing conditions.

[1] Office of the Public Advocate (2018), 'The illusion of 'choice and control'' available at: https://www.publicadvocate.vic.gov.au/ourservices/publications-forms/research-reports/ndis/519-the-illusion-of-choice-and-control (accessed 29 April 2019).

[2] Baldry et al (2006), 'Ex-Prisoners, Homelessness and the State in Australia' Available at: https://journals.sagepub.com/doi/abs/10.1375/acri.39.1.20 (accessed 19 April 2019).

[3] Burt 2003; Edwards et al 2009; Flatau et al 2008; Gulcur et al 2003; Mental Health Coordinating Council 2008.

[4] NDIS (2018), 'Improving the NDIS participant and provider experience' available at https://www.ndis.gov.au/media/1068/download (accessed 15 April 2019).

## Limited housing options for clients with Complex Care needs

At present, there is no single point of coordination for housing assistance for Complex Care clients. Housing solutions vary depending on the client needs, severity of behaviours and availability of housing.

The NDIS' Specialist Disability Accommodation ('SDA') program has proven difficult to access for many Complex Care clients that qualify for NDIS funding. This is reinforced by the Office of the Public Advocate's Report (2018), which highlights difficulties for people with complex and challenging needs in obtaining adequate support, in particular with regards to accessing and retaining suitable accommodation under the NDIS. Consequently, temporary accommodation needs to be sourced for many clients during negotiations with the NDIS, resulting in additional costs for Supported Independent Living ('SIL') providers and major disruptions for clients.

SIL providers currently deal with multiple agencies to identify available accommodation for their clients. This process is time consuming and invariably results in outcomes which do not provide a permanent solution for the client.

There is a mix of alternative, but limited housing options in place for Complex Care clients. These include:

- Public housing available from the pool provided by the State Governments Departments of Housing, facilitated and overseen by the Department and managed by SIL providers such as **ermha**365
- Housing accommodation provided by independent housing providers, such as Community Housing and others
- Private rental accommodation sourced by the client's service provider and funded by either the NDIS, State Governments or the client
- Short term hotel accommodation sourced and managed a service provider such as **ermha**365.

Private rental is often not a viable option, as there is a significant degree of tenancy uncertainty as landlords retain the right to evict tenants. Complex Care clients often have poor rental histories and an increased likelihood of behaviour which leads to property damage and nuisance to neighbours, thereby deterring landlords from approving applications for these clients.[5] Given the lack of alternatives, clients are often being allocated inappropriate, short-term contingency placements, including motels and caravan parks or are living in other forms of unstable accommodation.[6]

[5] See Roberts story - Office of the Public Advocate (2018), 'The illusion of 'choice and control'' available at: https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/ndis/519-the-illusion-of-choice-and-control (accessed 29 April 2019)

[6] Public Advocate (2018), 'The illusion of 'choice and control'' available at: https://www.publicadvocate.vic.gov.au/ourservices/publications-forms/research-reports/ndis/519-the-illusion-of-choice-and-control (accessed 29 April 2019).

In addition to the lack of available long-term housing options, Recommendation 13 of the Office of the Public Advocate's Report (2018)[7] identifies the 'need for the NDIA to commission the provision of crisis and respite accommodation for participants who need accommodation at short notice' given the current lack of respite placements. Many Complex Care clients would be at risk of homelessness if it were not for the support of family members. While it is difficult to quantify, many families care for their relatives due to a lack of affordable alternatives.

Caring for complex care needs patients can be demanding, traumatic and stressful, significantly impacting the quality of life of carers. Many people with disabilities and their families, friends and carers describe their lives as a constant struggle for resources and support.

## Limited providers delivering supports to clients with Complex Care needs

The Productivity Commission's Report recently found the NDIS utilisation rate in 2016-2017 was approximately 70%. This underutilisation results from several factors, including insufficient market supply. The Productivity Commission's Report further states that Thin Markets will persist for participants 'with complex, specialised or high intensity needs, or very challenging behaviour' in the absence of government intervention and will ultimately result in poorer participant outcomes.[8]

For too many people with disabilities, quality of life is dependent on the commitment of families. The crisis in accommodation means that few are able to plan effectively, and transitions out of the family home are often traumatic experiences. When accommodation cannot be found, sometimes extended family members are pressed into service. Alternatives to group homes are few and far between and for some clients this can lead to a restricted lifestyle and poor quality of life with limited opportunities for independence.[9]

The 'Shut Out' report published in 2009 proposed an injection of funds to increase the availability of accommodation options, in particular on the development of more creative models that were more responsive to individual need and lifestyle.

At present, ermha365 is one of only a very small handful of SIL service providers in Australia specifically catering for the multiple and complex needs of the Complex Care client cohort. Most providers operating in this space operate distinct models, e.g. either provide a mix of aged care and disability services or focus on different cohorts (e.g. lower levels of mental illness/care).

[7] NDIS (2018), 'Improving the NDIS participant and provider experience' available at https://www.ndis.gov.au/media/1068/download (accessed 15 April 2019).

[8] Productivity Commission (2017), 'National Disability Insurance Scheme (NDIS) Costs' available at ttps://www.pc.gov.au/inquiries/completed/ndis-costs/report (29 April 2019).

[9] National People with Disabilities and Carer Council (2009), 'Shut Out: The Experience of People with Disabilities and their Families in Australia' available at: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-outthe-experience-of-people-with-disabilities-and-their-families-in-australia?HTML (accessed 8 May 2019).

## Unsuitable housing options exacerbate negative client circumstances

One of the biggest problems for people with complex needs is the absence of adequate, affordable and secure accommodation. In ermha365's experience it is the single most important factor in the success or failure of those who live with chronic mental illness. In the past, clients who have been provided public housing are vulnerable due to neighbours' complaints or demands on emergency services, for example, clients with multiple fire service callouts.[10]

They are unable to live sustainably with others because of their behavioural presentation and low thresholds for frustration and distress. As a result, many of these clients have been bounced back and forth between the mental health system and disability system over many years with neither system wanting to accept responsibility for their support.[11]

The Multiple And Complex Needs Initiative ('MACNI') run by the Department of Health and Human Services identified that Complex Care needs clients are often unable to sustain fit for purpose accommodation because they require a level of and type of support that 'the contemporary service system structure, with its usual emphasis on targeted, time-limited, specialist interventions, does not readily allow'.[12]

Only a very small number of specialist disability accommodation (SDA) recipients will receive sufficient funding for a single resident dwelling that may be able to cater to these specific needs.[13]

## The impact for complex care needs clients

Many clients with Complex Care needs are caught in the justice or forensic mental health system or may be homeless; leading to negative impact on peoples' lives, potential breaches of their civil and human rights and high costs to Government.

The lack of suitable housing for Complex Care needs clients leads to:

- suboptimal therapeutic outcomes for individuals, despite the best endeavours of all stakeholders
- poor quality of life (or at worst suffer inadvertent human rights abuse) as people get caught in a cycle they cannot break
- community concern and pushback around housing these individuals – the 'nimby' effect

[10] Hamilton (2009), 'The report on the Five Years of the Multiple and Complex Needs Panel' available at: https://dhhs.vic.gov.au/publications/multiple-and-complex-needs-review-reports (accessed 16 April 2019)

[11] Office of the Public Advocate (2018), 'The illusion of 'choice and control'', available at: https://www.publicadvocate.vic.gov.au/ourservices/publications-forms/research-reports/ndis/519-the-illusion-of-choice-and-control (accessed: 29 April 2019). 16 Hamilton (2009), 'The report on the Five Years of the Multiple and Complex

[12] 'Multiple and Complex Needs Panel' review available at: https://dhhs.vic.gov.au/publications/multiple-and-complex-needs-review-reports (accessed 16 April 2019);The Office of the Public Advocate (2018), 'The illusion of 'choice and control'', available at: https://www.publicadvocate.vic.gov.au/ourservices/publications-forms/research-reports/ndis/519-the-illusion-of-choice-and-control (accessed: 29 April 2019).

[13] NDIA (2018), 'Specialist Disability Accommodation Provider and Investor Brief' available at: https://www.ndis.gov.au/providers/essentials-providers-working-ndia/specialist-disability-accommodation#sda-provider-and-investorbrief (accessed 29 April 2019).

- additional costs being incurred across services systems that may be avoidable, including property damage, incarceration, lengthy hospital stays and other forced detention costs
- Additional strain on emergency services, police, ambulance and emergency departments
- Potential political implications in the event of incidents that may attract negative press
- Increased costs of SIL.

In many instances, delayed or inappropriate provision of support leads to avoidable detention under the Mental Health Act 2014 as well as other infringements on an individual's human rights and significantly compromises their ability to achieve life goals. The Mental Health Council of Australia stated the over-representation of people with mental illness in the criminal justice system is due to a failure of the health system to provide adequate support for those at risk of incarceration.[14]

The denial of treatment of mental health patient in prison often leads to further offending, longer incarceration (at greater cost) and aggravation of mental health conditions. It is vital for the successful community reintegration of people with a mental illness on being released from prison that they have access to stable accommodation.

Prisons and mental health services are increasingly being treated as accommodation options for people with challenging presentations[15] and often include harmful and restrictive practices.[16] Complex Care needs clients may also be admitted to seclusion ('SECU' - the confinement of a patient in a room from which free exit is prevented) merely due to a lack of appropriate supports. While seclusion can be used to provide safety to protect the patient, staff and others, it can also be a source of distress for the patient, fellow patients, staff, family and visitors.

Such prolonged admissions are rarely clinically or legally justified. The consequences of prolonged detention and the entailing trauma can contribute further to challenging behaviour patterns and compromise the ability of a person to engage with and benefit from support upon release. When they are released, Complex Care clients are often restricted to isolative arrangements in the community. Such circumstances significantly compromise a client's ability to achieve life goals as well as leads to infringements on an individual's human rights.

The cost on health and justice systems for emergency services and extended confinement (both State and Federal Government) is very high. Delays in accessing appropriate accommodation may result in people entering or remaining in detention or the forensic mental health system due to the risks arising from unmet support needs leaving them cycling through unstable and inappropriate forms of accommodation at tremendous human cost.

[14] Parliament of Australia Senate Estimates (2006), 'Mental Health and the Criminal Justice system' available at: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Former_Committees/mentalhealth/report/c13 (accessed 26 April 2019).

[15] Office of the Public Advocate (2018), The illusion of 'choice and control', available at: https://www.publicadvocate.vic.gov.au/ourservices/publications-forms/research-reports/ndis/519-the-illusion-of-choice-and-control (accessed 29 April 2019).

[16] Human Rights Watch (2018), 'I needed help, instead I was punished': Abuse and neglect or Prisoners with disabilities in Australia. Available at: https://www.hrw.org/report/2018/02/06/i-needed-help-instead-i-was-punished/abuse-and-neglect-prisoners-disabilities (accessed 29 April 2019).

## Conclusion

We are fast approaching the point where if the needs of Complex Care clients do not receive serious and dedicated attention, extremely vulnerable people's dignity and human rights will be significantly compromised. This is an untenable situation in a country like Australia.

If the NDIS cannot or will not step in to provide leadership on this issue, in partnership with States, Government must urgently create and fund a "third system" that safely and humanely provides for the needs of people with complex needs. This can sit outside of both the NDIS and state-funded mental health systems in order for those systems to focus on the 95% majorities that their policies and funding streams are currently aligned to.

This "third system" is especially essential for people exiting the forensic system, where current structures simply cannot accommodate the number of people with mental illness and disability who are being unfairly kept in prison and who do not have the right mechanisms in place to enable them to transition safely into the community.

# 3. Case studies: Complex care needs clients and the NDIS experience

The following case studies illustrate a range of **Complex Care needs clients** who we support at **ermha**365 to convey the challenges outlined in in this submission. They have been de-identified to protect individuals' privacy. All case studies represent people with significant mental health and cognitive disabilities and additional complex needs including behaviours of concern, presenting their journey through lengthy institutional care, and the significant support they have required to access a reasonable level of community-based supports. **ermha**365 would appreciate the opportunity to be consulted prior to the reproduction or publication of any content arising from such case studies.

## Case Study "John"

John, male and in his early 40s, has been trying to get access to a level of NDIS supports to help him live in the community for just over two years after transitioning from a State Funded individual support package. At that time, John was assessed for a very small package of NDIS support.

John has a number of clinical diagnoses, including schizophrenia and intellectual disability, as well as a high level of physical and mobility issues. He recently had a hip replacement and requires a walking frame. John's functional needs now are almost exactly the same now as when he was first assessed for this small NDIS package. However, at that time his physical health (including his hip) was slightly better.

Over the past decade John has experienced insecure housing. The only place John could find to live was in Supported Residential Accommodation (SRS), where he struggled to maintain tenancies due to aggression towards other residents. This aggression arose from behaviour-related incidents stemming from John's auditory and visual hallucinations. This pattern of aggression and subsequent eviction resulted in John cycling through almost 20 SRS placements.

Over the past few years, extensive care team meetings have taken place to try to secure an increase in support funding for John, including behavioural support assessments and SDA housing. This involved at least eight people in each meeting including the NDIA. In the second half of 2020, John voluntarily admitted himself to hospital after his latest SRS placement broke down. With John's long history of homelessness, and lack of formal supports, John relied on funded supports to exit hospital back into the community.

This was the latest in a frustrating 'revolving door' of inpatient admissions where John was unable to obtain support funding without a housing model in place, and unable to obtain housing without support. Since John's latest admission to hospital, the care team has worked around the clock to secure six months of 24/7 2:1 transition support, and now 1:1 support funding for John, which is about to be reviewed.

## Case Study
## "Nigel"

Nigel is a young man in his mid-20s. He was originally referred to ermha365 as a Victorian DHHS Disability client with an individual support package. Because of the complexity of his needs he was also identified as a Multiple and Complex Needs Initiative (MACNI) client. Nigel transitioned into the NDIS in 2019.

Nigel has been diagnosed with several mental disorders (namely autism), oppositional defiant disorder, antisocial personality disorder, and intellectual disability.

Nigel was assessed to be substance dependent, to have engaged in a range of violent and other behaviours that placed both himself and others at risk and deemed to require intensive supervision.

His substance use and offending behaviours have seen him spend periods of time in custody. Nigel transitioned to the NDIS in 2018. At the time of his transition he was being held in custody.

Due to the nature of his disability and his presenting behaviours it became impossible for Nigel to remain in the family home. Nigel has been involved with DHHS services in Victoria from a young age including living in out of home care. He has also been transient, homeless and spent periods of time in and out of prison.

Housing has been one of the most significant issues for Nigel and in trying to accommodate his needs there has been a significant strain placed on the service sector. Nigel has a history of unstable housing in several settings, including properties supplied under an 'out of home care' arrangement, properties supplied by community agencies, properties on his own, properties with others and supported disability accommodation. Some of these arrangements have involved the presence of multiple staff, including in a 2:1 24/7 model.

At the time of writing this submission, Nigel is incarcerated as his most recent accommodation option broke down and he subsequently breached his bail conditions. His period of incarceration is currently extended as there is no suitable residential address for Nigel to be released to.

Nigel's NDIS package totals almost $300,000. His family are extremely frustrated that support cannot be provided to Nigel if he has nowhere to go. He is unable to return home and his family are unable to fund private rental for him. In receipt of Centrelink benefits he has limited income, very little prospect of immediate employment so securing appropriate and affordable accommodation is problematic. Whilst he qualifies for an NDIS package of support this is not currently being provided.

It is unclear if Nigel would qualify for SDA.

Case Study
## "Bridget"

Bridget is a young woman with and intellectual disability with traits of autism. She is between 18-23 years of age. She receives support from a Dual Disability Service recognising that she does have a mental health condition. There has been some discussion of her displaying traits of schizophrenia, but no formal diagnosis has been made yet. Previous OT reports describe her as having high anxiety and often talking about self-harm (*"I want to die"* and *"I want to get run over"*).

Bridget presents with significant behaviours of concern, these include violence and physical assaults towards her parent and sibling, whilst living at home, significant property damage / destruction – her parent stated that *"at one point, their home had almost no walls from eye level down"*.

Bridget lived with her parent and sibling in the family home. When she was a young adult, after an escalation in her behaviour, and significant violence she was removed from the family home by the police and was admitted to a local Hospital. From there she was discharged to a respite facility, this placement broke down within days due to self-harm and assaultive behaviour and she was admitted to a major Hospital where she remained for just under a year.

During this time Bridget's challenging behaviours escalated and she would often attack staff posing a risk to the workforce and other patients on the general ward. The only way the hospital was able to manage Bridget's escalated behaviour included calling a "Code Grey" which meant she was physically restrained by hospital staff and then restrained to her bed frequently for the time she remained on the hospital ward. Due to her challenging behaviours Bridget was only allowed outside a few times during her inpatient stay, this was stopped by the hospital when she assaulted a member of the public when she was returning to the ward.

At the time of removal from her family home in her late teens, there was no destination in the community available to Bridget. The hospital accepted her as a social admission as she did not meet the criteria to remain in acute psychiatric care. Bridget remained living in the hospital on the general ward for 10 months. For much of this time she was restrained to her bed. Everyone involved in Bridget's case agreed this situation was unacceptable, however there was no alternative accommodation or service provision available. Again, there was no clear mechanism or process for anyone to intervene in her situation.

During her hospital stay **ermha**365 was approached to develop an NDIS plan and to provide support in the community. Initially **ermha**365 began in reaching into the hospital to provide some respite for hospital staff and to begin to build a relationship with Bridget. **ermha**365 assessed Bridget's needs and developed an NDIS plan.

As the NDIA does not fund housing, and no SDA accommodation option was available DHHS sourced an office of housing property and worked closely with ermha365 to modify the building to meet Bridget's needs.

Significant challenges emerged during discussions with the NDIS with funding shortfalls identified in the areas of Specialist Support Coordination, Specialist Behaviour Intervention Support, Transport and Therapeutic funding. A compromise agreement was reached for 3 months of support given the situation in hospital had become untenable. Again, with no mechanism in place to escalate her case, ermha365 made the decision to self-fund some of her supports to enable a transition into the community.

# 4.Key themes: Complex care needs clients

ermha365 understands that the new NDIS consultation paper "An Ordinary Life at Home" seeks to inform the way NDIS participants are supported to pursue their home and living goals, and to provide NDIS participants with the reasonable and necessary disability supports they require to live their best life and build greater independence.

This submission outlines our position on what we believe the Agency should consider when developing an NDIS Home and Living Policy. As stated in the Executive Summary, there are **five key areas** we believe are particularly important when it comes to providing services for complex care needs clients.

1. **The NDIS Home and Living Policy must consider the needs of the small but significant number of Complex Care needs clients who present with significant behaviours of concern (often an extreme nature) who are unable to live (initially) with others, and where support from untrained staff may not be appropriate.** Fundamentally, an NDIS service design that supports transition from Institutionalised settings as a step down into the community, and ultimately to shared living options, must exist. This is currently individual (stand-alone) SIL, which is considered to be expensive. We believe there are better ways to design this aspect of the service model.

2. **The NDIS Home and Living Policy should consider the unique needs of Complex Care needs clients who do not have strong informal supports and social connections/network, particularly those who are coming through the complex planning pathway.** Such participants have specialist support coordination and a broader care team network that may include state departments (e.g. MACNI, Justice, Disability, Office of the Chief Practitioner and Office of the Chief Psychiatrist, guardians and advocates). This is also important in considering Supporting Decision Making (please also refer to ermha365's separate submission on this matter).

3. **The NDIS Home and Living Policy should consider principles and frameworks that are more fit-for-purpose for Complex Care needs clients who can "fall through the cracks", in particular in circumstances where it is difficult to distinguish between their disability or criminal needs.** This was highlighted in the recent Royal Commission Public Hearing 11, where the Commission explored the NDIS-justice interface. *The Chair suggested it was difficult to distinguish a person's disability and criminal needs, and that this was evidence that the Principles weren't fit for purpose. The panel agreed it was difficult, but said the Principles work well for the majority of participants.*[17]

4. **The NDIS Home and Living Policy should encourage and improve accessibility to a wider variety of housing stock for Complex Care needs clients** so they do not stay incarcerated or remain in hospitals longer than they should. This should include funding incentives to prioritise and give special consideration to people with complex needs, who consistently miss out when compared with other priority clients who are considered more 'desirable' tenants.

[17] https://disability.royalcommission.gov.au/public-hearings/public-hearing-11

For example, incentivising private rental among landlords to rent to the 94% of NDIS participants who will not get access to SDA, and reducing requirements to meet 100-point identification checks where this is difficult for people who do not hold identifications such as passports or drivers' licenses.

5. **The NDIS Home and Living Policy should outline a pathway for an expedited response when support needs change for complex care needs clients.** This will avoid deterioration for the participant, and to allow service providers to claim for otherwise-unfunded supports while we wait for new assessment decisions to be made.

In conclusion, ermha365 strongly supports Policy that INCLUDES the unique long-term support needs for Complex Care needs clients and welcomes the opportunity to be consulted directly on the specifics of this Policy, based on our long experience with this cohort of NDIS participants.

# 5. Recommendations: Complex care needs clients

## Recommendation 1: Individualised Living Options will not appropriate for every Complex Care need client, and a new stepped care approach for Complex Care needs clients' needs to be designed and funded by the agency.

In their current suggested format, as presented in the examples in the discussion paper, Individualised Living Options (ILOs) rely on participants having strong social networks and informal supports to be successfully implemented.

From our extensive experience, people with Complex Care needs do not usually have these networks.

Often, when a client comes to **ermha**365 we are the place of "last resort" for them, and they come from backgrounds of trauma and lengthy institutional care; high contact with multiple service systems (with little success); and a range of complex needs and diagnoses. A stepped model of care must be implemented as a transition from an Institutionalised setting into the community to avoid service and market failures for this particularly vulnerable group of NDIS participants.

For individuals with complex disability and/or mental illness, capacity building and developing independent living skills is vastly unattainable within the maximum 90 days offered by the current transition accommodation options available *(i.e. Medium-Term Accommodation up to 90 days, and Short-Term Accommodation up to 28 days).*

As per best practice, for any capacity building and skill development to be successful, approaches must be adapted and responsive to an individual's unique presentation. Timeframes for these will vary significantly and as such, flexibility in short term and medium-term accommodation duration is required.

Many people with a psychiatric disability are ready or able to live independently, yet some are homeless or living in temporary or inadequate housing with inadequate support. The number of people with a psychiatric disability who can be effectively supported to maintain stability in their housing may well be limited more by the supply of both support and housing, rather than the limitations and challenges presented by their illness and resultant disabilities. With access to adequate support and appropriate housing, ongoing risk management strategies and assistance to deal with a debilitating illness that can jeopardise maintaining housing, these individuals proved they could live independently, which in turn has improved their enjoyment of life.'[18]

**ermha**365 has identified and developed the concept for a new accommodation model aimed at achieving better client outcomes and relieving pressure on the NDIS and public system as an alternative to individual SIL packages: a "Therapeutic Village" that delivers better care and integrated services, specifically catering to the needs of complex Care clients could be introduced into the scheme. *This would be a specialist congregate living model – not a group home.*

[18] O'Brien, A. Inglis, S., Herbert, T., Reynolds, A. - **Linkages between housing and support – what is important from the perspective of people living with a mental illness**, Australian Housing and Urban Research Institute Swinburne/Monash Research Centre, Ecumenical Housing Inc – 2002

This first-of-a-kind village model would enable independent living within a communal setting, that supports the delivery of the full range of services required for each client. It is envisaged that the Therapeutic Village will initially provide a transitional step-down home for particularly vulnerable complex care needs clients. Key benefits include:

- **Improved quality of life** - Clients should be accommodated in a safe and therapeutic environment oriented toward rehabilitation and community reintegration. The ability of clients to live in their own homes, safely and with appropriate support has been demonstrated to improve the quality of life of clients and minimise many of their harmful behaviours.
- **Compliance with human rights laws** - It is highly likely that some of the current situations clients find themselves in result in a breach of their civil and human rights, which inadvertently are a direct result of alternative solutions to housing these clients not being viable or available.
- **Significant cost savings** – bringing together a number of complex care needs clients together in one location will also deliver a significant cost saving when compared to individualised SIL packages of support that the agency is currently funding.

**ermha**365 recommends the Agency funds and pilots a therapeutic village in each state as part of a new model of stepped care, creating a pathway for Complex Care needs clients to be able to move into a range of other accommodation options.

**Further evidence for this model in terms of public investment in housing – particularly for those transitioning from forensic settings – is now available.**

A brand-new study from the University of New South Wales[19] also shows that the evidence strongly supports the need for much greater provision of social housing to people exiting prison, particularly for those with complex support needs. Headline take-outs from this report include that:

- Imprisonment in Australia is growing and ex-prisoner housing need is growing; but at the same time, housing assistance capacity is declining.
- Without real options and resources, prisoner pre-release planning for accommodation is often last-minute. Insecure temporary accommodation is stressful, and diverts ex-prisoners and agencies from addressing other needs, *undermining desistance from offending*.
- *Ex-prisoners with complex support needs who receive public housing have better criminal justice outcomes* than comparable ex-prisoners who receive private rental assistance only.
- Public housing 'flattens the curve' of average predicted police incidents (down 8.9% per year), *time in custody (down 11.2% per year)*, justice system costs per person (down $4,996 initially, then a further $2,040 per year).

[19] Martin, C., Reeve, R., McCausland, R., Baldry, E., Burton, P., White, R. and Thomas, S. (2021) **Exiting prison with complex support needs: the role of housing assistance,** AHURI Final Report No. 361, Australian Housing and Urban Research Institute Limited, Melbourne, https://www.ahuri.edu.au/research/final-reports/361, doi:10.18408/ahuri7124801 - 23 Aug 2021

In dollar terms, *housing an ex-prisoner in a public housing tenancy generates, after five years, a net benefit of between $5,200 and $35,000*, relative to the cost of providing them with assistance in private rental and/or through homelessness services.

## Recommendation 2: The agency establishes eligibility criteria for who can access flexible funding through ILO and who will continue to use the existing SIL structure.

ermha365 strongly recommends that these criteria be developed to ensure those with complex care needs are able to continue to access SIL funding options.

It is essential that this eligibility criteria is clearly communicated - not only to NDIS support providers, support coordinators and SDA providers - but also to non-NDIS agencies that are part of the person's care team such as MACNI, Justice, Disability, Office of the Chief Practitioner and Office of the Chief Psychiatrist, guardians and advocates.

This will enable care teams to work effectively to develop individualised, durable and appropriate models for care for each individual eligible for a SIL package of support.

We are deeply concerned that in the absence of such criteria, and if every NDIS participant currently receiving SIL were to transition to Individualized Living Options (ILOs) at their next plan review, we foresee massive market and service failure for complex participants and an enormous administrative and reputational burden for the NDIA. Furthermore, by the very nature of their complexity and presenting issues, Complex Care needs clients' needs could not be fully met, placing this cohort at extreme risk of harm.

These are just a few examples of such market and service failure that we find deeply concerning:

- Participants receiving ILO would quite likely no longer be eligible for or receive 24/7 professional support (it is assumed this is provided by 'informal networks'), leading to safety risks to the client and community. This means vulnerable NDIS participants and specifically Complex Care needs clients will be at risk of being left on their own overnight without immediate alternative supports, if their 'informal' supports remove themselves from the home that they live in.
- Providers would need to appeal every plan in order to achieve an acceptable level of funding to ensure staff safety, leading to an even smaller pool of providers being willing to undertake unfunded work to support challenging, complex participants. Complex Care needs clients' opportunities to live an 'ordinary life' would quite likely be greatly diminished with people's human rights compromised by spending lengthy periods of detention in institutionalized settings because there is nowhere else for them to go.
- Workcover does not cover risks to people providing informal supports.

## Recommendation 3: Develop policy settings that create additional group models of mixed accommodation that can include SDA and private rental options in congregate settings.

ermha365 recommends the NDIS considers market settings encouraging innovative housing models that include a mix of SDA accommodation and private rental space that opens up housing opportunities for a wider range of NDIS participants and Complex Care Needs clients. This would not only increase opportunities for better housing options for complex care needs clients, improving quality of life for participants, but also have a long-term positive impact on reducing costs and support needs over time.

In addition, ermha365 recommends the NDIS establish policy settings that encourage and incentivise State Government agencies to partner with NDIS providers to develop small non-SDA group congregate living options that can specifically house people with Complex Care needs. This will open up options for participants and reduce pressure on (and demand for) SDA, which cannot be met by the Scheme's constraints.

## Recommendation 4: Incentives could be introduced to enhance Complex Care needs clients' ability to access Social/ Affordable housing and the private rental market.

Although Social and Affordable housing providers have a duty to make reasonable adjustments in providing accessible housing stock to people with disability, there is still a significant shortage. In addition, our clients are often "overlooked" as a suitable tenant because of their background, history of property damage and neighborhood disturbance, risk of eviction, hostile neighbors, and being in an unsafe area (due to affordability). In addition, policies designed to allow access to private rental exclude the additional downstream barriers faced by the people we support, who often do not pass the "review" as a suitable tenant (e.g. cannot demonstrate 100 points of identification, and lack networks and employment to provide references for rental agents).

To deliver on our mission, organisations like ermha365 often have to "step in" and support the tenancy, creating a perceived closed system of supported independent living (SIL) homes (as described in the "An Ordinary Life at Home" paper). What is not acknowledged is that in doing so, ermha365 bears unfunded costs including supporting participants to identify suitable properties; bearing liability risk on damage to properties; and taking on unfunded corporate overheads to manage these properties.

We recommend the NDIS considers how it can change its policy settings to support providers to subsidise rent *specifically* for complex care needs clients as part of a client's funded package of support.

**Recommendation 5: Flexible Home & Living transition funding arrangements (housing and support) that extend for more than 90 days should be made available for complex participants, and be adaptable in acute situations when needs or circumstances change.**

Transitional support is essential for every complex care needs client who is currently incarcerated or in secure hospital settings. From our experience, when a person has not lived in the community for some time, we know it is essential that funding is in place for a comprehensive assessment process that enables a full understanding of the participant and their needs in order to develop an appropriate NDIS plan.

Behaviour Support Plans (BSP) improve an individual's Quality of Life (QoL) and decrease Behaviours of Concern (BOC). For individuals with mental health and/or forensic histories, the evidence-based strategies that BSPs provide are vital to support successful community transition and to address the additional complexities that present.

Having a robust and rigorous BSP in place to ensure successful transition into the community before NDIS supports begin is considered to be essential by the team at ermha365. Funding this phase of support is also considered essential.

The NDIS Home and Living Policy should also outline a pathway for a rapid response when support needs change for complex care needs clients. This will avoid deterioration for the participant, and to allow service providers to claim for otherwise-unfunded supports while we wait for new assessment decisions to be made.

> (ermha is) one of a small number of providers who will not walk away from people, and will not shy away from the very, very real challenges of providing support to the people coming to the complex support pathway. (There is) value in a willingness not to give up on people.
>
> *Senior stakeholder, NDIS*

> (ermha is) one of the few organisations that will actually take our clients….if we took ermha completely out of the equation … There'd be a massive void in the service sector.
>
> *Psychologist working with complex clients*

> I see ermha's willingness to work with complex clients and have been able to observe some of the fantastic outcomes as a result of that intensive work.
>
> *Senior stakeholder, DHHS*

> Thank God for ermha!
> *Senior stakeholder, DHHS*