ermha 365

Mental Health
Disability
Complex Services

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National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024

ermha365 response to the consultation on draft lists of NDIS Supports

Submitted by ermha365

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1. Acknowledgements

ermha365 acknowledges the contribution of staff, consumers and families from the organisation's complex services and community teams, our practice leaders as well as executive management in the preparation of this submission.

ermha365 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.

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3. About ermha365

At **ermha**365 we believe in the potential of everyone. Our purpose is to empower individuals and communities facing life's toughest challenges to overcome adversity and thrive. We support people to live their best lives, find their purpose, a sense of belonging and a safe place in their community.

ermha365 has developed significant practice expertise in providing support to people with exceptionally complex and challenging behaviours for almost 40 years in Victoria and the Northern Territory. Our expertise includes the provision of numerous community and residential based NDIS services including programs where **ermha**365 is often considered the provider of last resort.

4. Our work

Our vision is fuelled by a passion for supporting people where no one is left to face life's challenges alone. We offer purpose, hope, support, and connection to those who need it most, because we believe that everyone deserves the chance to reach their full potential.

We empower the people we support through the provision of compassionate, trauma-informed wraparound services as they work their way through life challenges. These can often include aspects of mental health, psychosocial disability, homelessness, transitioning through the justice

or healthcare systems, alcohol and drugs, trauma, and social isolation. The people we work with trust **ermha**365's highly skilled people to offer high quality support, drawing on their own lived experience.

We partner with others to provide a safe and inclusive community that promotes healing, growth, and resilience. Our passion for positive impact drives us to innovate and break down barriers, creating lasting change towards a more just, equitable, and inclusive country.

5. Our work with High Intensity Supports clients

ermha365 is focusing this submission specifically though the lens of providing high intensity supports for complex care needs participants. From our experience, they are some of the most marginalised people in the NDIS and broader service system today.

ermha365 works with people who receive NDIS supports. The people we support live with complex mental health disorders, co-occurring cognitive disabilities and challenging behaviours and will often have extended histories of self-harm, property damage and violence, placing at risk; staff, family members and the wider community at risk.

These high intensity supports participants 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 and require multi-agency support. Many of our clients will transition from lengthy stays in hospital wards and prison, as well as having ongoing involvement in the criminal justice and mental health services systems into our support in the community.

ermha365 began the provision of NDIS programs at the Barwon Trial site in Victoria in 2013. Today **ermha**365 delivers NDIS programs and services across Victoria and the Northern Territory. **ermha**365's NDIS programs include Specialist Behavioural Support; Specialist Support Co-ordination, Supported Independent Living (SIL) and a range of core supports.

6. Case studies

To illustrate key themes, **ermha**365 highlights challenges 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, ermha**365 **would appreciate the opportunity to be consulted prior to the reproduction or publication of any content arising from such case studies.**

7. Consultation period: Concerns

We are deeply dissatisfied with the consultation period for the National Disability Insurance Scheme (NDIS) Amendment Bill 2024 and the draft lists of NDIS Supports. The consultation period, limited to just two weeks, is insufficient for thorough review and meaningful feedback from stakeholders, participants and carers. This short timeframe undermines the participatory process essential for such significant legislative changes.

Moreover, the consultation has not been widely publicised, limiting awareness and engagement from the broader community. Effective consultation requires ample time and widespread dissemination to ensure all voices, especially those directly impacted, are heard and considered. The lack of adequate notice and promotion of this consultation period raises concerns about the transparency and inclusiveness of the process.

We urge the government to extend the consultation period and enhance its outreach efforts. By doing so, they can ensure that the feedback collected is comprehensive and reflective of the diverse needs and perspectives within the disability community. It is crucial that the voices of NDIS participants, their families, and service providers are genuinely considered in shaping policies that directly affect their lives. Only through a more inclusive and transparent process can we achieve a truly effective and equitable NDIS.

8. Our submission

Please find our response to the three key questions asked as part of this consultation.

9. Supports that are not NDIS supports

Key question requested: Are there goods or services on the exclusion list that you think shouldn't be there?

If yes, please list in order of importance.

1. Supports that are not NDIS supports: Mainstream: Mental Health

Specifically for individuals with dual disabilities due to a co-existing mental health condition, it's crucial to include carve-outs for advocacy and bridging support where none are currently being contemplated.

People with dual disability represent a large proportion of NDIS participants. According to the Australian Institute of Health & Welfare, people with a psychosocial disability formed the fourth largest primary disability group among NDIS participants (62,011 participants or 10%), after Autism (35%) intellectual disability (16%) and developmental delay (11%).

In the year ending 30 June 2023, $4.25 billion of paid supports were provided to NDIS participants with a psychosocial primary disability, with an average payment per participant of $71,600. 1 in 2 NDIS participants with a psychosocial primary disability (50%) had a primary

health diagnosis of schizophrenia (https://www.aihw.gov.au/mental-health/topic-areas/psychosocial-disability-support).

1. **Advocacy workers** can help navigate complex systems, ensuring participant rights and needs are met. Advocacy can also play a critical role in safeguarding against discrimination and ensuring that participants receive fair treatment across all services. For example, a **Dual Disability Advocate** will help individuals with disabilities navigate complex systems including mental health. They ensure participants' rights and needs are met, safeguard against discrimination, and promote fair treatment across all services. For instance, an advocate might assist a participant in accessing appropriate and necessary mental health care in a clinical setting. Without carve outs to allow for this to occur, people with dual disabilities will often fall though the gaps and cracks in service systems without getting access to mainstream mental health supports that they need because of their disability status.

2. **Bridging support**: NDIS-funded inpatient support should cover supports provided in mental health settings that address both the intellectual/developmental disabilities (provided by a support worker) and mental health conditions (supported by the mental health clinical staff team). This should include access to high intensity support staff trained in dual disability care, tailored therapeutic interventions, and continuous support during hospital stays. These supports are not one-off requirements but may be more frequent due to the episodic nature of mental health conditions. An example of how bridging support works in practice can be found in the case study of Sarah (next page).

3. **Assessments:** The lack of comprehensive assessments to distinguish between the influences of disability and mental health often impedes participants' access to necessary mental health services. This issue is exacerbated by the fact that recipients of disability-related supports frequently face barriers to accessing mental health services, which impedes their human rights. Implementing comprehensive assessments for all NDIS participants with mental health diagnosis is vital to accurately determine the interconnection between disability and mental health. These assessments should be readily available and conducted by qualified professionals to ensure that participants receive the appropriate support for both their disability and mental health needs. By doing so, we can:
    - **Ensure Equitable Access:** Guarantee that all participants have equal access to mental health services, regardless of their disability status.
    - **Improve Outcomes:** Provide tailored support that addresses both disability and mental health, leading to better overall outcomes for participants.
    - **Uphold Human Rights:** Protect the human rights of participants by ensuring they receive the comprehensive care they need without discrimination or unnecessary barriers.

Case Study

Sarah*

Background: Sarah, a 28-year-old woman with both an intellectual disability and a diagnosed mental health condition, frequently requires inpatient care due to the episodic nature of her mental health issues.

Support Provided: Through NDIS funding, Sarah receives SIL supports. A dedicated support worker, trained in dual disability supports, assists Sarah with daily activities and ensures her intellectual disability needs are met. There are times when Sarah's mental health and wellbeing decline and a hospital admission to an acute inpatient unit is required.

Challenges with dual disability and access to mainstream mental health supports: Sarah's challenging behaviours have often prevented her from accessing acute mental health supports. These behaviours have included property destruction, and both physical and verbal attacks on clinical staff. In the past this has led to the use of restraint and service refusal.

Example of Support: During a recent hospital stay, Sarah needed access to her high-intensity support staff who were available to provide additional supports for the Mental Health Team as Sarah's behaviours of concern were putting her Mental Health treatment at risk. These staff members coordinated with the mental health team to deliver continuous support, ensuring Sarah's care was holistic and uninterrupted and that Sarah felt safe and supported. The staff were able to help Sarah self-regulate and manage her challenging behaviours so her treatment could continue.

Outcome: The integrated approach allowed Sarah to receive consistent and specialised mental health treatment, significantly improving her overall well-being and reducing the frequency of her hospital admission. This also meant when she returned home, she was much more stable and staffing did not have to be increased due to occupational violence risks.

**Name has been changed.*

Ironically, we can provide supports for Sarah when she is also receiving mental health supports in the community. **Both Sarah's disability** and challenging behaviours when the mental health team visit Sarah in her home to administer her depot, the high-intensity support staff can provide **reasonable and necessary support and further** additional support for the mental health team **to ensure** Sarah's care is holistic, uninterrupted and that Sarah remains calm, feels safe and supported **in her home.**

The high-intensity support staff help Sarah self-regulate and manage her challenging behaviours so her mental health team can safely administer Sarah's injection. By having these supports visit

Sarah in her home, Sarah's mental health and well-being have significantly improved. This type of SIL **with high-intensity** support has been so successful we have reduced our support from 2:1 staff to 1:1 when the mental health team visits.

Including these carve outs for participants with a Dual Disability who require a hospital admission for their mental health is essential. Without these carve-outs, NDIS participants with dual disability will become increasingly unwell and the cost of their NDIS supports will increase, rather than stabilise and decrease, over time.

2. Supports that are not NDIS supports: Mainstream: Justice

For NDIS participants placed on **Supervised Treatment Orders** (STOs) and **Non-Custodial Supervision Order** (NCSOs), it's crucial to **include carve-outs** within the NDIS for comprehensive support where none are currently being contemplated. These should include:

1. **Supervision: Ensuring Safety and Upholding Rights:** Ensuring the safety of NDIS participants under STOs (Supervised Treatment Orders) and NCSOs (Non-Custodial Supervision Orders) involves continuous oversight by skilled and experienced support workers to manage and mitigate risks associated with their conditions. Effective supervision includes managing order conditions (such as line of sight) and tailored interventions to address specific needs.

   For example, several of **ermha**365's high-intensity support participants are currently on an STO or NCSO, and the system relies on our workers to monitor and manage the participant's compliance with their order.

   Without proper supervision, participants can end up in jail for extended periods due to behaviours linked to their disabilities. This not only breaches their human rights but also fails to address the root causes of their actions. Continuous oversight by trained support workers is crucial in preventing such outcomes, ensuring participants receive the care and support they need rather than punitive measures. This approach helps uphold their dignity and rights, providing a more just and effective solution.

2. **Monitoring** ensures compliance with treatment plans and helps in early identification of any issues that may arise, allowing for timely adjustments to care strategies. This comprehensive approach not only supports the individual's well-being but also enhances their safety. This includes time for reporting, attendance at care team meetings, preparation of meetings with tribunals such as VCAT, preparing both VCAT and court reports and supporting NDIS participants to attend these. This can involve days of essential preparatory work.

   For example, specifically for participants who are placed on **a supervised treatment order** the administration work is significant. NDIS providers are required to apply for the VCAT Hearing as directed by the Office of the Senior Practitioner (OSP), list all parties in the submission, and attend the hearings. This can involve days of preparatory work. Additionally, NDIS providers are required to write regular review reports every six months and send them to the OSP for approval. These reports require a lot of incident reporting data collection,

consolidation of weekly reports, and information from Behaviour Support practitioners and allied health professionals for example forensic psychologists, which providers are required to analyse and interpret for VCAT.

This case study illustrates the importance of continuous, intensive support for individuals with complex disabilities, ensuring their safety, well-being, and rights are upheld.

Case Study

Narelle*

Background: Narelle is an autistic woman in her early thirties with an intellectual disability, borderline personality disorder, and complex trauma. She currently lives in public housing while awaiting Specialist Disability Accommodation (SDA). Due to a history of lighting fires, she has spent time in prison and is now on a Non-Custodial Supervision Order (NCSO).

Challenges: Narelle experiences daily suicidal ideation, regularly self-harms, and struggles with personal hygiene. She can be verbally aggressive and damages property when frustrated. Narelle has been exploited and abused by people in her community and sometimes uses non-prescribed substances to manage her distress. Over the past year, more than 300 incidents involving Narelle, including verbal aggression and property damage, have been recorded by the NDIS Quality Safety Commission.

Support Provided: Narelle's support is overseen by her local community mental health team, including a clinical case manager and psychiatrist. She requires intensive daily living support, including prompting for personal care, meal preparation, budgeting, identifying and de-escalating feelings, and decision-making. Highly experienced **ermha**365 staff provide 2:1 support, 24 hours a day, seven days a week.

Impact of Support: This comprehensive support structure allows Narelle to spend more time in her community and less time in hospital, inpatient units, or prison. The Victorian Office of the Chief Psychiatrist and the Victorian Senior Practitioner have reviewed her support needs and confirmed that her behaviours stem from her complex disability.

**Name has been changed.*

Supports required for NDIS participants like Narelle are essential to help her remain in the community. They include but are not limited to:

1. **Reporting:** Support workers regularly document Narelle's progress and incidents, ensuring all relevant information is available for review by the care team and legal authorities.

2. **Attendance at Care Team Meetings:** Support workers and team leaders are often required to attend multidisciplinary care team meetings to discuss Narelle's progress, share insights, and collaborate on adjusting care strategies as needed.

3. **Tribunal Preparation:** Support workers help prepare for tribunal meetings, such as those with VCAT, by gathering necessary documentation, briefing Narelle on what to expect, and providing emotional support during the process.
4. **Court Support:** When Narelle needs to attend court, support workers assist by coordinating transportation, ensuring she understands the proceedings, and providing emotional and practical support throughout the process. This helps Narelle feel more secure and supported, reducing anxiety and improving her ability to engage with the legal system effectively.

Our extensive experience with NDIS participants like Narelle shows that without continuous, intensive support, individuals with complex disabilities are at risk of deteriorating health and increased interactions with the justice system. This not only breaches their human rights but also leads to higher long-term costs for their NDIS supports. Ensuring robust, tailored care is essential for stabilising and improving their well-being, ultimately reducing the need for more intensive and costly NDIS interventions further down the track.

3. Supports that are not NDIS supports: Mainstream: Housing and community infrastructure

Currently the NDIS proposes to carve out rental costs, bond costs, and mortgage repayments from NDIS funding**.**

SIL providers like ermha365 **cannot provide support without a home for an NDIS participant to live in.** There is a critical shortage of public housing, community housing and affordable housing, and the SDA program will service only a tiny fraction of participants with disability.

The State and Commonwealth governments have failed to address this issue and therefore providers have had to step in to provide a stop-gap rental solution, cobbled together from a combination of providers' cash reserves and participants' SIL funds to head lease private properties so that our participants are not homeless.

If this practice is disallowed through Federal legislation, **many thousands of disabled people will become homeless, literally overnight, in every State and Territory** as it will be illegal for providers to find accommodation in which to support them. This will be a humanitarian and public relations disaster for governments.

Until the States and Commonwealth can devise a more sustainable long-term solution NDIS participants with a disability who require SIL support but are not eligible for SDA, they should be prioritised for subsidised housing through the private rental market via rental assistance from the Commonwealth. This should be paid for out of their NDIS plan.

Case Study:

John*

Background: John is a male in his 40s with a physical disability and intellectual disability. John is incontinent and has diabetes. He relies on Supported Independent Living (SIL) services provided by **ermha**365 to manage his daily activities and ensure his safety and wellbeing. John currently lives in a private rental property head-leased by **ermha**365, as there is a critical shortage of public, community, and affordable housing. He is not eligible for Specialist Disability Accommodation (SDA).

Challenges: The NDIS proposes to carve out rental costs, bond costs, and mortgage repayments from its funding. This change would prevent SIL providers like **ermha**365 from using participants' SIL funds to secure private rental properties, leaving John and many others at risk of homelessness.

Impact of support Provided: John does not have enough income to fully pay for his accommodation. To prevent John from becoming homeless, **ermha**365 has been using some of its cash reserves to head lease private properties and help to subsidise John's rent. This stop-gap solution ensures that John has a safe place to live while receiving the necessary support services.

**Name has been changed.*

Our extensive experience with NDIS participants shows that without secure housing, individuals with disabilities will face increased instability and deteriorating health. This will lead to higher long-term costs for their NDIS supports. Ensuring access to stable housing is essential for stabilising and improving their well-being, ultimately reducing the need for more intensive and costly interventions.

4. Supports that are not NDIS supports: Day to day living costs

The consultation paper contains a long list of day 15 categories of day to day living costs, listing goods and services that are proposed as not an 'NDIS support', a description of the category, and any carve outs to the description that are considered an 'NDIS support'.

The proposed exclusion of most of this list of accommodation **and household-related costs** below is wholly unfair and unreasonable for people with disability who cannot work or get access to SDA to cope with the increased cost of living and in particular, access to affordable rental.

We submit that reasonable carve-outs from Accommodation and household related costs should relate to the costs to support SIL participants who do not qualify for SDA including:

- Rent, rental bonds, home deposits, mortgage deposits, strata fees, rental bonds and home deposits
- Water, gas, and electricity bills, council rates

- Water filters, purifiers, or aerators
- Standard household items (dishwasher, fridge, washing machine, non-modified kitchen utensils and crockery, fire alarms, floor rugs, beanbags, lounges, standard mattresses, and bedding), replacement of appliances, including hot water services, solar panels, etc.

We further submit that the proposal to exclude from the NDIS some of what are termed **lifestyle-related costs below** is unfair and unreasonable on social inclusion and hygiene grounds.

- **Sex work:** We believe there are certain circumstances where this could be viewed as an NDIS funded support. This will prevent participants, who may otherwise be unable to have their intimacy needs met, from sexual intimacy fulfilment. This should be supported within specific circumstances to support access to basic human needs and overall well-being. Criteria should be developed to ensure this is appropriate (i.e., pervasive absence of sexual intimate relationship or means of fulfilling intimate sexual needs) as opposed to a blanket refusal of funding. A distinction should be made from sexual gratification and sexual intimacy (i.e., masturbation vs intimacy) as these impact wellbeing differently.
- Regarding the proposed exclusion of **Internet services, land line phone, mobile phones, mobile phone accessories, and mobile phone plans and smart phones**, services providers who work with complex NDIS participants need to maintain contact to provide services. If these items cannot be claimed by the participant under the NDIS, the supports may be jeopardised.
- Regarding the proposed exclusion of **menstrual products**, this is a basic hygiene requirement to enable personal care and hygiene prompting for complex participants. The United Nations notes that period poverty is a global health issue affecting women and girls in both rich and poor countries (Period Poverty – why millions of girls and women cannot afford their periods | UN Women – Headquarters). In the case of NDIS participants, the ability to afford menstrual products (or not) affects not just the participant but the workers who support them. If menstrual products are not able to be claimed by the participant under the NDIS, they may be foregone which is a health and safety risk to our staff – or yet another expense that providers will be forced to step in and subsidise when the scheme fails vulnerable women and girls.

Carve outs that may be considered 'NDIS supports' for certain participants are also highlighted and we provide the following feedback on these.

The following day to day living costs may be funded under the NDIS if they relate to reasonable and necessary supports:

1. Additional costs to upgrade standard household items to household items that include accessibility features to decrease the physical and cognitive requirements of household tasks

- We would expect that this allows for people to purchase a Thermomix or like device to assist participants with cooking nutritious meals.
- We would expect this to include internet capable items (i.e., Google Nest, lights etc) to decrease the physical requirements of household tasks.

- We would expect this to include white good upgrades that also decrease the physical requirements of household tasks (i.e., front loading washing machines, bar low-height fridges).

10. Supports that are NDIS supports

Key question requested: Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included? If not, what changes would you suggest?

1. Supports that are NDIS supports: Disability-Related Health Supports

We acknowledge and appreciate the inclusion of supports for individuals with complex communication needs or challenging behaviours when accessing health services, including hospitals and in-patient facilities. However, **we strongly advocate for an expansion beyond the current list,** which includes continence, dysphagia, respiratory, nutrition, diabetic management, epilepsy, podiatry and foot care, and wound and pressure care supports. It is imperative that all health supports, including mental health supports, are comprehensively included to ensure holistic care for all individuals.

2. Supports that are NDIS supports: Accommodation / tenancy assistance

As noted above currently the NDIS proposes to carve out rental costs, bond costs, and mortgage repayments from NDIS funding. SIL providers like ermha365 **cannot provide support without a home for an NDIS participant to live in. There is a critical shortage of public housing, community housing and affordable housing, and the SDA program will service only a tiny fraction of participants with disability.**

We believe it is essential to INCLUDE rental costs to prevent homelessness for participants needing SIL support who do not qualify for SDA, as the current housing shortage makes it impossible for providers to secure accommodation without this support.

11. Recommendations

We make the following recommendations.

Recommendation 1: Mainstream mental health carve outs. Dual disability

Specifically for **individuals with dual disabilities due to a mental health condition,** it's crucial to include **carve-outs** for both advocacy and bridging support as identified in our submission.

Recommendation 2: Mainstream mental health carve outs. Comprehensive assessments.

Implement and fund **comprehensive assessments** for NDIS participants with a dual disability who require high intensity supports, to accurately determine the interplay between disability and mental health. These assessments should be readily available and conducted by qualified professionals to ensure that participants receive the appropriate support for both their disability and mental health needs.

Recommendation 3: Mainstream Justice carve outs. Compliance with orders.

Include carve-outs to for the **support of participants on STOs and NCSOs**, ensuring continuous supervision and monitoring to uphold their rights, safety, and well-being and to allow NDIS providers who support clients on STOs and NCSOs to deliver on the significant administrative requirements of Justice Schemes.

Recommendation 4: Mainstream housing and community infrastructure carve outs. Rental support for SIL participants.

Ensure NDIS funding **covers rental costs to prevent homelessness for participants needing SIL support who do not qualify for SDA,** as the current housing shortage makes it impossible for providers to secure accommodation without this support.

Recommendation 5: Day to day living costs carve out. Participant communication.

Ensure NDIS funding **covers Internet services, landline phones, mobile phones, accessories, and plans.** Service providers need these to maintain contact and provide essential support to complex NDIS participants. Without this coverage, supports may be jeopardised.

Recommendation 6: Day to day living costs carve outs. Hygiene.

Ensure NDIS funding covers menstrual products. These are essential for personal care and hygiene, and their exclusion risks health and safety for both participants and support staff, exacerbating period poverty.

Recommendation 7: Day to day living costs carve outs. Intimacy support.

Sex Work as NDIS Support: In certain circumstances, sex work should be considered for NDIS funding to meet participants' intimacy needs and enhance their overall well-being. Specific criteria should be established to ensure appropriateness, distinguishing between sexual gratification and sexual intimacy, as these impact well-being differently. This approach will prevent blanket refusal and supports basic human needs.

Recommendation 8: Disability related health supports inclusions. Mental Health.

We recommend **expanding the current supports for individuals with complex communication needs or challenging behaviours** when accessing health services, including hospitals and in-patient facilities. While the existing list includes essential supports such as continence, dysphagia, respiratory, nutrition, diabetic management, epilepsy, podiatry and foot care, and wound and pressure care, it is crucial to broaden this scope. We urge the inclusion of comprehensive mental health supports to ensure holistic and inclusive care for all individuals, including access to mental health professionals, integrated care plans, crisis intervention services, and training for staff to ensure holistic and inclusive care.