

### **Ability to make rules based on arbitrary physical characteristics**

This power as granted by this bill will be the mechanism by which people with high care needs see their funding cut to 1:3, and the mechanism which will be used to remove hundreds of thousands of NDIS participants who have psychosocial disabilities including serious and enduring mental ill health and neurodiverse diagnoses such as autism and ADHD forcing them back into non-existent foundational supports and a state based mental health system that is under funded, under resourced and responsible for causing great harm for many people in this cohort.

### **Early intervention**

While I support front-loading expenditure to invest early in a participant's life, many disabilities are progressive, and participants would benefit more from sustained, flexible support throughout their lives. Continual assessments and a focus on building sufficient capacity for participants to exit the scheme is counterproductive. We must return to the scheme's original focus: ensuring good outcomes through person-centered, rights-based, goal-focused, and trauma-informed planning.

### **Entry assessment**

This bill proposes to reassess every current NDIS and in doing so seek to push around 200 thousand people out of the scheme and back onto non-existent foundational supports. The states have estimated that it will take 8 – 10 years to establish these foundational supports and yet we are already hearing an alarming number of reports of NDIS participants being told by LAC's and NDIA planners that they will soon be pushed out of the scheme and onto foundational supports that do not even exist. Furthermore, this air and attitude of constant reassessment was exactly what the NDIS was meant to prevent and only serves to increase the trauma and marginalisation experienced by NDIS participants.

### **Needs assessment**

As I and others testified last week during the public hearing, the proposed needs assessment fails in many of the same ways that the previous government's proposed "independent assessments" failed to meet the needs of NDIS participants. Specifically, requiring us to have a medical style assessment done in what will inherently be a time limited manner (because there are always KPI's) by a person who does not know us and

whom we do not know, in an environment that may not be safe for many people considering the complex history many disabled people have with trauma, abuse and PTSD. Being forced to undertake such an assessment under such conditions is not even an option for many people in this cohort and just as it did when the NHS attempted a similar proposal, this will result in a significant number of deaths. This is yet another clear example of why co-design directly with disabled people is so crucial and why that co-design needed to occur before this legislation was even drafted. Additionally, as testified by a variety of allied health experts, no tools exist anywhere in the world that are capable of adequately capturing the full impact and needs of an individual across the full range of disabilities, particularly those with multiple impairments. Furthermore, those same experts have testified that an individual clinician's ability and suitability to use a given tool is not simply a matter of their qualifications but also their professional experience and area of specialisation. It is for the above reasons that even if a magical tool were able to be developed, it would not be internationally recognised and there would be essentially no one with both the necessary qualifications and professional experience to use such a tool.

### **Budgets based on qualifying conditions not whole of person impairments**

As addressed further in the sections regarding UN CRPD and the definition of a valid NDIS support, the premise of attempting to limit funding to the needs and functional impacts directly related to accepted qualifying conditions is fundamentally flawed and by its very nature cannot provide a suitable framework for appropriately funding the supports and equipment needed for an NDIS participant to live an ordinary life and fully realise their rights and place in their community. The complex interplay between multiple disabilities and other environmental factors which all contribute to compounding affect on the impact of disability mean that in many cases it would not only be incredibly unfair to attempt to determine which impact of disability or what percentage of that impact was attributable to which condition, in many cases this would simply be impossible to achieve in any even remotely fair, equitable or repeatable fashion. As testified by Rosemary Kayess the Disability Discrimination Commissioner during last week's public hearing, such an approach and the scheme's failure to see the person holistically is also almost certain to fail in upholding the rights and obligations Australia has to all NDIS participants and the wider disabled community under the UN CRPD.

## **God powers**

This bill grants the Minister and the CEO extraordinary powers: \*to remove people from the scheme

\*to compel them to undertake a plethora of assessments / examinations and share the results with the NDIA

\*remove people from the scheme for an array of reasons

These powers are in fact so extraordinary that they exceed powers sought by the previous government which were soundly described as a vast overreach. Not only are these powers truly exceptional in their reach, they fail to be met with appropriate protections for those who find themselves on the receiving end of the impact of these powers. Even if one was to take the stance that this current minister and CEO can be implicitly trusted to always have our needs, rights and best interests at heart, (an assertion that I suspect many would disagree with right now) this legislation expects us to extend that same inherent “Trust me bro” attitude to all future governments, Minister’s and CEO’s of the agency.

Exceptional powers \*MUST\* be met with equally exceptional protections, and those protections must be legislated not left for subordinate regulation.

## **Review rights**

As this bill proposes, if an individual is given a plan with an inadequate budget, they will have to challenge the CEO of the NDIA’s decision to accept the statement of supports. If they win this appeal, this grants them is to have a new needs assessment, however if it is not the needs assessment but rather the design or implementation of the legislative instrument used to convert the needs assessment into a total funding package then it is likely that a new needs assessment will fail to generate a funding package that is more appropriate to the individual needs of the participant. Each individual step and element inherent in the process that leads to a plan, a funding package and a statement of supports must itself be directly open to challenge and review by both internal and external to the agency.

## **Shared supports**

The review takes the stance that people with high support needs should be funded at a 1:3 ratio, stating that this is in line with community norms, that it won’t mean people being forced into shared living arrangements against their will and that it will decrease isolation

and therefore increase safety. The issue with these assertions is the near complete lack of any evidence to support such claims, particularly when the current body of evidence gained from people living in group homes with shared supports demonstrates a clear link between shared supports and increased risk of harm along with increased isolation and decreased meaningful communication engagement and participation. Furthermore, for many people who have high care needs, their basic supports (just the ones that keep them alive, ignoring the supports necessary to work and participate in the community) are already greater than the 8 hours of 1:1 support which is the equivalent of sharing supports between 3 people each funded 24/7 at a 1:3 ratio. For those people, not only would 1:3 funding \*FORCE\* them into a congregate care environment, but it would also remove the supports necessary for them to continue to meaningfully participate in and be full members of their community.

### **Drip feeding of plan funds**

The suggestion to drip feed plan funding by dividing the yearly budget into 12 equal parts and then making each part available at the start of the next plan month is fundamentally flawed. The taskforce and the government would have you believe that this measure is necessary to reduce fraud and control plan spending to assist people not to overspend their allotted plan budget. However the very premise of this measure is flawed by design and fails to recognise the rights and needs of NDIS participants as human beings and full members of the community. Doing a quick review of the data and referencing the 2024 calendar, there are not 2 months in the entire year that share all of the following features:

- \*the same number of days
- \*the same number of Weekdays
- \*the same number of Saturdays
- \*the same number of Sundays
- \*the same number of Public Holidays

In attempting to argue that plan expenditure should be essentially identical each and every month of the year, the government has failed to recognise perhaps that the most fundamental of hurdles that prevents this from occurring. Furthermore, most average member of society do not live their lives according to a rigid and never changing daily schedule and to expect an NDIS participant to do so once again conflicts with the

protected rights upheld by the UN CRPD. Not only is this incompatible with our human rights, such a measure is paternalistic, ableist, and infantilising as it suggests that disabled people are incapable of making decisions for themselves about how best to live their own lives.

### **Restrictions on what is a valid ndis support**

Further to my previous submission and testimony, I would just like to take the opportunity to echo the sentiment of many who testified during the public hearing. A black and white list of approved and banned supports (when compared with the current principles of Reasonable and Necessary supports) is unlikely to represent good value for money in the long term, will absolutely stifle innovative practice and is more than likely to fail in meeting the obligations under the UN CRPD.

### **Co-design**

This process isn't new and is very well understood internationally it's just that Australian governments fail time and time again in implementing the framework regardless of what promises are made.

All effective co-design begins with 3 foundational principles,

1. that everyone has an equal part to play and an equal vote at the table.
2. That every part of the process must be subject to the full co-design framework. Crucially, co-design isn't something that exists to rubber stamp the minister or CEO's plans. The elected lived experience group must be actively involved in all stages of the process from initial brainstorming and identifying issues through to exploration and design of solutions, testing, implementation and every other step in between.
3. Effective co-design depends on properly understanding the full range of the intended audience and so it is necessary to engage a sufficiently large and diverse group to participate in the co-design process such that it is representative of the full range of diversity seen in the wider audience.

Once a suitable group of people to participate in the co-design process have been identified and selected, the following framework is followed, with the discussions typically led by a co-design practitioner. At all stages, the co-design process must be fully open, honest, transparent and subject to an external audit process, the results of which must be openly available to public scrutiny.

1. Understand the risks, audience, and shortfalls of the current thing (scheme / system / product etc)
2. Have a clear vision of what you want the new thing to look like / function etc at a high level and how that meets the needs of your intended audience
3. Identify solutions for each of the issues to get from where we are now to where we want to be with this new thing
4. Extensively test and iterate the solutions / processes / features to ensure they are working as intended across the entire user base so in this context, adults, children, different types of disabilities, different severities, metro / regional / rural / remote / very remote, working / not working, lots of informal supports / little or no informal supports, living independently / living in a group home or other institutional setting, isolated / not isolated and so on and in doing so crucially ensure that unintended consequences are identified and addressed with changes as necessary
5. Come back to the table, talk about what's worked, what hasn't what we learned, what unintended consequences were identified and how they were addressed or mitigated and agree on the path forward
6. Take the necessary steps to move forward with the agreed actions which in this case would then mean drafting legislation
7. Again, check with all stakeholders that the draft legislation achieves the intended outcomes in the agreed manner
8. Now legislate and move forward with the implementation co-design

Co-design is a continuum, one layer of co-design makes way for another layer of co-design so that you are continually following the process

Dream → Identify → Design → Test → Iterate → Implement → Iterate

For a scheme like the NDIS it could take the form of an elected group of around 100 participants nationally across all of the different demographics as I listed above. You'd be on the group for maybe 2 years and then a new bunch would be elected. You'd replace 50% of the group each year so that the ones that had a year of experience could help mentor the new ones. You'd need a trained and qualified facilitator that is entirely outside of the political process and the codesign process, meetings, actions decisions and outcomes must all be transparent and answer to an external audit process to ensure that the process

is working as it should and not being tampered with by people with certain political motivation

### **The need to legislate rules regarding entry, budgets, Co-design, valid supports and rights of review**

The bill's heavy reliance on subordinate regulation via unknown rules is highly problematic. Important aspects like assessments, budgets, and what can and cannot be funded under the scheme should be legislated within the bill itself, not left to subordinate regulations. This approach creates uncertainty and reduces transparency, as the specifics of these critical areas can be changed without parliamentary scrutiny. Subordinate regulations can be amended more easily than primary legislation, which undermines the stability and predictability that participants rely on. This could lead to frequent changes that disrupt participants' lives and erode trust in the scheme. Key elements like assessment processes, budget determination, and funding rules must be clearly defined in the primary legislation to ensure consistency, accountability, and protection of participants' rights. Legislating these aspects within the bill provides a robust framework that participants and their families can understand and rely on. It also ensures that any changes to these critical components undergo proper legislative scrutiny, including debate and consultation, thereby upholding the principles of transparency and democratic accountability.

### **Workforce and Capacity**

Building The ongoing challenges related to workforce and capacity within the NDIS cannot be overstated. The scheme's effectiveness heavily relies on a skilled, adequately trained, and sufficiently large workforce to deliver the necessary supports to participants. Unfortunately, the current shortages and high turnover rates among support workers and allied health professionals are hampering the scheme's potential. It is imperative that the government invests in workforce development strategies, including comprehensive training programs, better pay, and working conditions for NDIS workers. This will not only improve service delivery but also reduce the administrative burden on the NDIA by decreasing the frequency of complaints and disputes related to inadequate or inconsistent support.

Crucially, mandatory registration or training is not the way to address this issue as that will only serve to disproportionately impact self managed participants who run a "service for one" who currently have some of the most innovative and value for money service delivery models while getting on average significantly better outcomes and having staff turnover that is often an order of magnitude less than the industry average.

## **UN CRPD**

The UN CRPD, which Australia is a signatory to, seeks to protect the rights of all people with disabilities. This is particularly relevant to the bill's provisions allowing the Minister and/or CEO to form rules based on particular cohorts of participants and replacing the definition of reasonable and necessary supports with a black and white list of approved supports. In particular, the failure to consider the whole person and allow them to use their funding on supports that best facilitate their needs in living an ordinary life and participating in their community. Some of the rights protected by the UN CRPD that I find particularly relevant, to this situation:

- \* the right to live where and with whom you wish,
- \* the right to have equitable access to community and civic services such as education, health and emergency services
- \*the right to be safe and free from discrimination and persecution
- \*the right to have equitable access to work and the ability to contribute economically to the community
- \*the right to have a family
- \*the right to be treated as an equal member of the community with equitable access to the supports and services necessary to realise that right.
- \*the right to not be subjected to harm from the medical or judicial system primarily based on a disability
- \*the right to realise the same religious and sexual rights and freedoms afforded to the rest of society
- \*the right to have equitable access to sexual and reproductive supports and health services necessary to realise these rights

Forming rules or guidelines based on arbitrary attributes such as disability type, hours, or complexity of support is inherently incompatible with the human rights protected by the UN CRPD and should be seen as direct discrimination against participants. For instance, the recommendation to fund high support needs at a one-to-three ratio, despite promises that this will not force people into group homes, has already led to NDIS participants being told they need to live in shared accommodation. This is unsafe for many and does not meet their basic needs, violating their rights and the original intent of the scheme. Just one



example of such a failure to uphold those rights is the attempt to ban supports of a sexual nature, there are endless other examples where the approach taken by this bill is problematic in upholding these rights.

Removal of the definition of Reasonable and Necessary supports and the guidelines currently used by the National Disability Insurance Agency (NDIA) known as the participant checklist as published in planning booklet 3 entitled “Using your NDIS plan” and replacing the latter with a black and white list of approved and banned supports fundamentally undermines the original intent and purpose of the scheme. In assisting NDIS participants to “live an ordinary life” it is crucial to see the person holistically and understand that their disability is not their diagnosis or even their impairment. Disability is the complex intersection where the functional deficits of an individual (regardless of their cause) meet societies unwillingness or inability to adequately and equitably accommodate those differences in functional capacity and differing needs. As a result, an individuals disability will be entirely unique to them as only they experience their unique disabilities because not only does diagnosis and functional capacity vary greatly between ndis participants but more than that, the individuals unique factors such as where they live, who they live with, their goals, dreams and aspirations, whether they work or study and how they engage with and participate in their community will all weigh heavily in determining a person’s disability and therefore the supports best able or most appropriate in assisting them to minimise the daily impact of disability and maximise their opportunities to live their life their way. For these reasons, a black and white list cannot possibly hope to sufficiently account for the vast array of individual disabilities and not only is such a list almost certain to not offer the flexibility required to ensure innovation, best value for money and good outcomes, it is also very likely to directly or indirectly contravene the protected rights of a person with disability under the UN CRPD as already addressed above.