2024

Submission

Section 10 – draft lists of NDIS Supports

August 2024



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About DANA

DANA is the national representative body for a network of independent disability advocacy organisations throughout Australia.

Our Vision

DANA's vision is of a nation that includes and values people with disabilities and respects human rights for all.

Our Purpose

DANA's purpose is to strengthen, support and provide a collective voice for independent disability advocacy organisations across Australia that advocates for and with people with disability.

We achieve this by:

- promoting the role and value of independent disability advocacy
- providing a collective voice for our members
- providing communication and information sharing between disability advocacy organisations
- providing support and development for members, staff and volunteers of disability advocacy organisations
- building the evidence base to demonstrate the value of disability advocacy
- promoting the human rights, needs, value and diversity of people with disabilities

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List of recommendations

Consultation and involvement of people with disability

Recommendation 1: That Government provide an extension for consultation and delay the implementation of these rules. People with disability and their representative and advocacy organisation need time to meaningfully engage, and to fully examine the extent of likely impacts and risks of the draft lists.

Recommendation 2: That interim rules preserve the definition of supports as currently understood, while work proceeds to build Category A rules, through co-design with people with disability, their representative organisations and advocates.

Recommendation 3: That Government adopt a principles-based approach to replace the lists, to empower people with disability and their families to continue using innovative and cost-effective solutions to live their lives within their communities.

Lists approach is flawed

Recommendation 4: That Government reevaluate their intention to constrict the types of supports the NDIA can fund through these draft lists, in favour of a clearer, principles-focused trust-based approach, accompanied by investments in building capacity and understanding of current definitions of NDIS supports.

Recommendation 5: That Government, if electing to proceed with this course, acknowledge and address the identified problems with the lists approach, and take all action necessary to promote clarity, cost-effectiveness and understanding, and reduce stigma, harm and confusion.

Recommendation 6: That Government allocate increased funding to the provision of independent and rights-focused decision making support to help people with disability understand the NDIS supports definition and make informed decisions about their lives.

Priorities

Foundational Supports not in place

Recommendation 7: That Government commit to the full development of Foundational Supports, including working with states and territories, to ensure people with disability have access to a wide range of supports.

Recommendation 8: That the NDIS supports lists are accompanied by clear accessible resources guiding people with disability to where supports are available.

Recommendation 9: That any definition attached to section 10 should include the ability for people to access disability supports through the NDIS when they are not practically available to them through state or other systems (including where that is due to cost).

Least restrictive approach

Recommendation 10: That Government include a provision in the rules guiding interpretation to presume inclusion when it is unclear which list a support falls under. Supports should be given the green light wherever possible, and circumstances where the prohibition power is used are limited and very specific.

Recommendation 11: That Government remove from the exclusion list all supports that could be in specific circumstances a reasonable and necessary support, and instead detail circumstances in which they can be funded via the approval power.

Recommendation 12: That Government include a provision in the rules that clarifies that supports that are not expressly listed as approved or prohibited supports can still be used.

Recommendation 13: That Government ensures supports currently funded in people's plans that are excluded by section 10 can continue to be used for the remainder of that plan.

Addressing implementation challenges

Recommendation 14: That all staff applying these rules are well trained in applying the nuanced understanding needed for specific contexts.

Recommendation 15: That there be effective oversight of the practical application of these rules by NDIA staff to ensure accuracy and consistency, and guard against the lists being misunderstood or broadly interpreted to exclude supports and narrow access unjustifiably.

Clear and accessible process for challenging decisions

Recommendation 16: That Government must ensure clarity and fairness in the process for reviewing decisions about NDIS supports inclusion or exclusion, including ensuring support is available to assist people with disability to understand their rights and apply for exemptions where appropriate.

Recommendation 17: That people with disability and their representative organisations can codesign a clear and accessible process for challenging the NDIA's interpretation of the NDIS supports definition and exemptions.

Recommendation 18: That Government allocate increased funding to independent disability advocacy organisations to educate and empower people with disability to understand the NDIS supports definition and challenge unfair decisions.

Ongoing review of transitional rules

Recommendation 19: That the transitional rules embed a process for review and evaluation including public consultation and consideration of input from people with disability and advocates. This must take place within three months of implementation and then every six months while interim arrangements are in place.

Executive summary

DANA and our member organisations have very significant concerns about the proposed transitional rules for NDIS Supports under Section 10 of the NDIS Amendment (Getting the NDIS Back on Track No 1) Bill 2023. These transitional rules will both limit how funds can be spent and the application of the reasonable and necessary supports test currently used for plans,¹ as any support must be a 'NDIS Support,' to be eligible for funding from the NDIS should the Bill pass. The timeframe for this process has been deeply inadequate and has allowed for only cursory engagement with the advocacy sector and people with disability.² This has denied many people with disability, families, representatives and supporters the opportunity to understand, consider and provide input on these important definitions for life changing and saving supports they rely on.

These rules will be in place until the Federal and State/Territory Governments agree on a full set of Category A rules, which is likely to be some time. We urge the Federal Government to allow an extension of time to this consultation and delay the implementation of these interim rules. People with disability and their representative and advocacy organisation need time to meaningfully engage, and to fully examine the extent of likely impacts and risks of the draft lists. DANA favours the development of a principles-focused and trust-based approach to guide decisions about the funding of NDIS supports and asks the Federal Government to reconsider the merits and effectiveness of the approach reflected by the draft lists.

Many people with disability have rightly used NDIS funds to adapt mainstream, much cheaper products for their disability related needs. These lists push people with disability towards disability-specific suppliers, which can be more costly. With the existing problems and delays from the NDIA,³ DANA is concerned that decisions will be made that hurt people with disability. The changes to supports that these lists introduce also pose risks to the community through the ability of the Agency to raise debts against people who do not spend their funds in compliance with the definition in section 10. Should the NDIS Bill pass, people will be expected to comply with the rules as early as late October. There has been a lack of communication about what is changing with these lists (and we have deep concerns about those changes). This will be intensely disruptive and distressing for many who have relied on their supports for some time.

Advocates fear much harm, injustice and inefficiency if these lists go ahead. The expertise, knowledge and perspectives of advocates about how the scheme works for people with disability on the ground must be heard by the Federal Government. DANA held a

¹ s34, National Disability Insurance Scheme Act 2013 (Cth)

² A general extension of one week announced late on Thursday 15 August 2024 has been appreciated by many overstretched organisations but has not allowed for meaningful consultation with communities to be planned or undertaken.

³ NDIS akin to a 'Byzantine maze' for frustrated families having to go without funding for months -<u>ABC News</u> -18 April 2024; <u>The NDIS Amendment Bill - questions and answers | Department of Social</u> <u>Services</u>; Justice and Equity Centre (2024) <u>NDIS Insights 2023-24</u>; Justice and Equity Centre and Housing Hub (2023) <u>Housing Delayed and Denied Data Update 2023</u>

consultation session in August 2024 with almost seventy disability advocates to explore the implications of these lists and their concerns - direct quotes are featured throughout this submission.

The first section of this submission considers how the process for co-design and consultation with people with disability about the implications of these consequential lists has been manifestly inadequate in both timeframe and accessibility.

This second section explores the flaws in using a lists approach to define NDIS supports, over an approach informed by trust and based on principles to guide consideration of individual context and need.

The third section outlines priorities we believe should guide any implementation and revisions.

The final section identifies some of the specific areas of concern for advocates where people will experience changes or disruption as a result of the draft lists in their current supports. It seeks to explain the hard limits imposed when attempting to lay out lists in this way. Given the exceptionally short timeline for consultation this does not exhaustively cover or delve into all the areas of the lists.

1. Consultation and involvement of people with disability

In announcing that these rules were out for consultation, the Minister stated that these had been developed with 'disability advocacy groups'. DANA was not one of these groups and we are not aware who they were. A selection of DROs were invited to a short briefing on the rules with the NDIA and Department of Social Services where some details of the planned lists were mentioned. Attendees raised their significant concern and disapproval of the proposed contents and the process, but were not an active part of the development of these rules.

This speaks to a broader issue about the way in which these lists have gone out for consultation. They reflect a top-down approach to building and fleshing out these supports and seem to incorporate many areas where the Government and Agency has been unhappy with judgements made at Federal Court or the AAT. They do not reflect a meaningful, community-led, ground-up approach that would produce a set of criteria that would cover what people need in their lives but encounter difficulty using. As one advocate observed:

...I think that needs to come from the community. People saying 'we don't really know what we can access' or 'we are not really sure how the NDIS can support us', that doesn't mean 'give us a list of the things that we can't have'. I think that means 'hey, how can we think about this, how can we live good lives?' This doesn't read 'how can we ensure that disabled people are happy and thriving and getting the services that they want and need?'. It really reads as 'what's the bare minimum that we can give people?'

This process of developing the draft lists has not included the expertise of people with disability at the forefront and centre of their development and implementation. People with disability must play a leadership role in the design and implementation of instruments enabling or limiting the use of certain supports under the scheme.

Properly testing how these lists delineate between what is and is not able to be funded requires the knowledge and expertise of people with disability, their family members and advocates on how its expected implications will affect them. The short consultation period has not allowed for such interrogation, especially given the level of technicality and detail that requires consideration and evaluation. One advocate commented:

This is the opposite of codesign. This is going to cause people to have severe problems. They will be exited from the scheme, they will have debts incurred that they have no way of challenging, they will be frightened to use their funding, they will have funding cuts.

Recommendation 1: That Government provide an extension for consultation and delay the implementation of these rules. People with disability and their

representative and advocacy organisation need time to meaningfully engage, and to fully examine the extent of likely impacts and risks of the draft lists.

While there is a need for transitional rules to be put in place should the NDIS Bill pass, hasty development of these consequential lists is a step backwards in the project of NDIS reforms. We instead need an approach that preserves the definitions of supports as currently understood, while intergovernmental work is undertaken to establish greater clarity and access to supports through other systems.

Recommendation 2: That interim rules preserve the definition of supports as currently understood, while work proceeds to build Category A rules, through co-design with people with disability, their representative organisations and advocates.

Along with our fellow disability representative organisations⁴, DANA believes these lists in their current form will cause significant harm to people with disability and are completely out of step with the spirit and intent of the NDIS. Rather than detailed lists attempting to address the complexities of disability support needs and the current landscape of non-NDIS supports available to meet these needs, our preferred approach would be more effective and consistent use of principles to guide decisions about what supports can or cannot be funded through the scheme.

The key principles we believe must be included for NDIS supports are:

- Reasonable and necessary
- Related to a person's disability
- Take into account what is provided by other government supports
- Represent value for money

These principles must reflect the precedents established by caselaw from Administrative Appeals Tribunal (AAT) and Federal Court decisions to ensure continuity of supports.

Recommendation 3: That Government adopt a principles-based approach to replace the lists, to empower people with disability and their families to continue using innovative and cost-effective solutions to live their lives within their communities.

The draft lists specifically in their current form, and more broadly using these types of lists would not ease confusion or uncertainty or lead to equity, clarity or efficiency in NDIS supports. The approach taken by these lists, and language surrounding them is problematic, demonstrating a lack of trust and genuine guidance for people with disability.

⁴ <u>Consultation on draft lists of NDIS Supports for NDIS Amendment (Getting the NDIS Back on Track</u> <u>No. 1) Bill 2024</u>

2. Lists approach is flawed

DANA is extremely concerned about the impact of the draft lists on people with disability, and on the already overstretched advocacy and peer support organisations who will be supporting them through NDIS reforms. The draft lists are long, unwieldy, technically oriented and difficult to understand. The two lists are complicated by carve outs and conditions that apply to certain things being in or out of the scheme. We note that the Easy Read and Auslan versions of the draft lists was only published the week the consultation was originally closing, making meaningful consultation with many people with disability impossible.

We have heard from advocates that this purported effort to make things clearer is likely to have the opposite effect. Advocates have questioned whether the challenge of addressing uncertainty can be solved through the introduction of lists that divide categories of support in or out of scheme funding. The level of detail and clarity needed to allow for focused consideration on need in specific contexts of an individual's disability may not be practically workable, even with substantial revisions to the current draft lists.

These lists presuppose that other service systems or arrangements are already in place to provide the needed supports that are not defined as supports under the responsibility of the NDIS – yet the strongest message of the NDIS review was that the scheme has become the 'oasis in the desert', with mainstream supports failing people with disability or inconsistently accessible across jurisdictions, regions or demographics. Furthermore, this approach runs counter to Recommendation 3 from the NDIS Review panel - to provide a fairer and more consistent participant pathway. Action 3.5 of the review recommended that the National Disability Insurance Agency should allow 'greater flexibility in how participants can spend their budget, with minimal exceptions'. As one advocate queried:

I am very concerned how that flexible funding can be achieved when this list means it is going to be far less flexible than the current system.

This reduction of options for NDIS funded supports may actually increase the costs of the NDIS, rather than the Government's stated aim of reducing, through pushing people to rely on more costly supports because the cheaper solutions that would better support them are pushed outside the definition of NDIS supports or into ambiguous territory.

Unclear and confusing

Despite the Discussion Paper professing that the purpose of these draft lists is to provide clarity to participants about what is and is not funded under the NDIS to help them make more informed choices, disability advocates fear increased confusion and misunderstanding. The NDIS Review recommended the provision of better support for people with disability to make decisions and we discuss further below the need for more dedicated resourcing to enable people to understand their options and make choices, informed by an accurate understanding of supports that can and cannot be funded through their NDIS plan.

As one advocate responded to DANA's survey on the NDIS bill in April, the approach reflected in the draft lists appears to worsen rather than reduce uncertainty:

It is concerning that the Rules would be able to 'rule out' providing supports that have previously been found by the AAT or Federal Court to satisfy the threshold of 'reasonable and necessary in some cases. - This is likely to result in more confusion rather than less for participants, particularly those who would no longer be able to access supports which they currently receive as 'reasonable and necessary supports' if Rules are created that explicitly exclude currently funded supports. The overall impact of this change would be promoting more uncertainty rather than less as to how participants will be able to continue accessing the supports which they currently rely on.

Advocates question the theoretical coherence and practical wisdom of creating both a 'green light' list with carve outs of what won't be funded, and a 'red light' list with carve outs that may for 'certain participants' be funded. This opens up a great deal of murky space amongst contradictory indications of where the boundaries and limits lie for funding eligibility and entitlement to NDIS supports. Classifying through broadly expressed categories of costs and support types may capture items that are clearly disability-related support needs when considered in an individual context but are caught in the wording of an exclusion or insufficiently specified in the definition of NDIS supports.

Advocates have significant misgivings about the drafting of these lists:

...these lists ... aren't fit for purpose by end users at all. They are just a maze...and I think they are completely incompatible with ... consistent decision-making and informed decision-making, so on the part of participants to then be able to know what they can use [funding] for or whether they should pursue a review right or not. It just reads like a huge rush job and it just - I .. see.. just a mass of ...more NDIS chaos and confusion ... attaching to this new language.

DANA is concerned that some of the wholesale exclusions have been disproportionately influenced by media and community misunderstanding about the requirement for certain items that can arise from a person's disability. Many people even within the disability community may not have turned their mind to the diverse needs of different disabilities, circumstances and intersectional identities. AAT cases, such as the recent matter of *MKKX and National Disability Insurance Agency*, demonstrates the complexity and nuance well.⁵ The member in that case found that an air conditioner was a reasonable and necessary support for a person who experienced significant temperature dysregulation as the result of Ehlers-Danlos Syndrome. Providing this support, it was found, would allow a significantly greater amount of social and community participation through the management of their symptoms.⁶

⁵ [2024] AATA 805 (19 April 2024).

⁶ MKKX and NDIA, [80].

It's possible that a too broadly construed exclusion to address accommodation and household related 'day to day living costs' in response to these concerns would proscribe what is a highly significant and valuable support. The ongoing, often rapid development of technology is likely to produce innovations in tools, assistive technology and appliances that could have tremendously positive effects on the lives of people with disability and too broadly defining excluded supports may capture those developments.

These problems are analysed in greater detail in Section 4 including how the draft lists collapse and conflate exceptional, disability-related expenses with day-to-day living costs. Taking out categories of items that can and have been funded by the scheme (such as cars, some household items generators/batteries) from the excluded category is crucial.

Negative and harmful

Advocates are very concerned these changes would induce fear and make participants hesitant to use their funding or engage in supports that would improve their wellbeing, inclusion and daily functioning.

These lists are punitive and they will cause harm to participants. The NDIS review said the problem was that people didn't understand what they could use their funding for. There is an easy solution to that, train NDIS staff so they give consistent answers, provide peer support so that people can work together to come up with better innovations and better solutions. This is actually taking us back more than a decade to where you could only use your supports for certain things which made supports unusable for certain people and people are actually going to be afraid to use their supports now.

There are no guardrails for participants that are doing the right thing, including going [through] AAT and now finding themselves with uncertainty while someone from NDIA attempts to interpret what is even more ambiguous than before. Hence without a guarantee for exceptions and/or grandfathering of what is reasonable and necessary as determined to date and have been funded in their plans (so as to safeguard participants) risk [to] life is too high.

Advocates also pointed to the harmful effects of the language of characterising supports as in or out – of associating broad categories of support with binary thinking separating the

- approved, permissible, acceptable, authorised, from the
- unacceptable, forbidden, prohibited, banned.

The structure of these lists groups collapses broad categories of supports with costs that would clearly not meet other elements of the reasonable and necessary test. This association tars people with disability acting in good faith with the same brush as those deliberately engaging in an unambiguous misuse of NDIS funds. For instance, one advocate stated:

...beyond how disappointing and frustrating it is to see these lists in the context of how a lot of these reports have been politicised lately, and how they have been

treated in the media. What's disappointing is even just putting it in the same list or document you've got things like alcohol and gambling, which we know are never going to be disability supports against a lot of supports which we come across frequently. There are very genuine cases that might go to the AAT which are just funded and that's just adding to the stigma by putting it all in the same list.

This associates without distinction broad categories connected with 'rorting', with many types of supports that people with disability need and currently legitimately access through the scheme. Advocates are concerned about the stigmatising effects of some supports being perceived as 'banned' or 'prohibited' or inherently illegitimate with these divisions suggestive of a moral or legal judgement about broadly defined categories of supports.

Though the intended purpose of these lists may be to clearly define what can be funded through the NDIS and in proscribing types of support as not appropriately funded through the scheme, advocates have raised implications for cultural safety,⁷ and the potential for misunderstanding about what is permitted in disability service contexts. For instance, a 'ban' on sexual services being funded through the NDIS may be misconstrued by community members or support workers as denying any access to needed sexual therapy services or purchase of supports enabling healthy expressions of sexuality by a person with disability, even with their own money. One advocate said:

I don't see participants reading this list and thinking, 'oh, I feel so empowered now I know what I can do', but I do see support workers hearing that you can't use your funding for alcohol and saying, 'Sorry mate can't take you to the pub you are not allowed to have alcohol' because that's the kind of knowledge that exists out there in the community about what these rules mean.

On the other side, there may be perceptions that inclusions on the list have a legitimising effect on broad support categories, which may have concerning application on some controversial forms of 'behaviour' support or therapy, despite not exempting such supports from frameworks of evaluating effectiveness, compliance with human rights and obligations to minimise restrictive practices.

Costly and regressive

Many aspects of the lists may result in the increased financial costs of NDIS plans in the medium and long term. These include the removal of mainstream supports that people with disability and families use, which are often much more cost effective than disability specific supports. People with disability have used NDIS funds in a variety of innovative ways to stretch their budgets further. These lists remove and undermine that innovation, and revert to expensive, disability only support types.

⁷ For instance, through the explicit exclusion of healing practices valued by particular ethnic or cultural communities.

As we submitted to the Senate Community Affairs Legislation Committee,⁸ there are particular household items that have qualified as disability supports that can be funded in specific circumstances. For instance, we spoke of the situation of a robot vacuum that might prevent a person who is unable to undertaking cleaning tasks due to their disability. This might be something that is a very efficient use of NDIS funds it saves people having to bring in a cleaner as regularly, but would likely be captured within 'standard household items' or household related maintenance costs.

One advocate explained:

I know there are cases where things like a motor vehicle may be funded in exceptionally rare circumstances and actually in circumstances where if you do the maths and you are familiar with the participants situation the cost saving to the scheme... the funding of a one-off motor vehicle with modifications is an astronomical saving... [The draft lists are] actually not going to assist them in that goal of meeting those cost savings, because if a lot of these supports are taken off the list that need is still there and it just means that need is going to have to be met with a NDIS support which I think in most cases is going to be a support worker that's going to run at a really huge demand into the already very thin markets that are available for the ... the trained and qualified support workers. A lot of people that maybe have training and qualifications may end up taking easier gigs to do the transport costs for someone instead or to assist someone with groceries ... rather than doing the personal care. So I think that if these changes go ahead, there is going to be a limited scope of innovation and that's going to put more demand on that very thin market.

Inhibiting innovation and access to mainstream supports and exacerbating already thin markets and workforce shortages is not only likely to prove costly in terms of the financial sustainability of the NDIS but undermine its core aims to enable more independence, autonomy, inclusion and participation of people with disability in the community. Disability advocates, who support people with disability to realise their rights, are alarmed that such restrictions on the choice of supports may push the lives of people with disability backwards towards outdated models of isolation, exclusion and segregation.

Lack of trust

The NDIS Review panel recommended the Agency 'adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support' (see Action 3.6). The final report noted that compliance 'should be encouraged through guidance and support', with more hands-on intervention used only if there are serious risks or history of issues.⁹ Yet several advocates we engaged with referenced the

⁸ Disability Advocacy Network Australia (2024) National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions], p17-18. See: Key concerns and recommendations on NDIS Bill

⁹ NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme, p89.

lack of trust in participants that the NDIS bill and draft lists reflects on the part of Government. A number of advocates characterised the approach as punitive:

...what these changes say, is that the Government doesn't trust participants...

I think it does speak to a lack of trust of participants... I agree it is punitive. There is already such a need for training of staff working in the system and to add this ... on top rather than going towards maybe a more capacity building approach for people so that they can understand how to support people to have their needs met, I think it is kind of a disappointing approach.

To address the identified need for guidance to support people with disability to understand the available supports, advocates favour investment in capacity building, peer support and supported decision making approaches.

Recommendation 4: That Government reevaluate their intention to constrict the types of supports the NDIA can fund through these draft lists, in favour of a clearer, principles-focused trust-based approach, accompanied by investments in building capacity and understanding of current definitions of NDIS supports.

Recommendation 5: That Government, if electing to proceed with this course, acknowledge and address the identified problems with the lists approach, and take all action necessary to promote clarity, cost-effectiveness and understanding, and reduce stigma, harm and confusion.

The NDIS Review advocated embedding a best practice, rights-based approach to supported decision making. DANA believes significant action is needed operationalise the principles of supported decision making and educate NDIS, non-NDIS and mainstream services. Specialist advocacy organisations have been providing support for decision making for many years and work to uplift the human rights of people with disability. During our NDIS Review Engagement and Solutions Project, we heard about the need for disability advocacy funding for supported decision making for people with disability both in and outside the NDIS, including:

- delivery of supported decision making capacity building for people with disability and their families and supporters;
- resources, training and ongoing capacity to support an expanded role for advocacy organisations in supported decision making; and
- capacity building, resources and training for decision supporters, disability services and providers, NDIA staff and planners and intermediaries.¹⁰

In our pre-Budget submission, DANA recommended that to expand on currently funded project work focused on supported decision making and existing sector expertise, the Federal Government needs to fund supported decision making awareness and outreach

¹⁰ Disability Advocacy Network Australia (2023) NDIS Review Summary Report – Advocates and supported decision making. See <u>Engagement and Solution Project | Disability Advocacy Network</u> <u>Australia (dana.org.au)</u>

work done by people with lived experience of engaging in supported decision making processes.

Recommendation 6: That Government allocate increased funding to the provision of independent and rights-focused decision making support to help people with disability understand the NDIS supports definition and make informed decisions about their lives.

3. Priorities

Whether or not the government listens to the community and re-think their approach regarding these draft lists, several areas need to be at the forefront when refining and implementing section 10.

Foundational supports not yet in existence

When the NDIS Review final report was released, DANA joined with our fellow Disability Representative Organisations to insist that 'continued access to support for people with disability is necessary and non-negotiable. Any changes to how support is provided, either inside or outside the Scheme, must not lead to any gaps in the support we receive.'¹¹ We restated this when the NDIS Bill was first introduced and our organisations have repeatedly made clear that our support for any reforms are contingent on continuity of supports, and no person with disability being left without supports.

People should not be ruled out from accessing supports through the NDIS if state and territory responses are still being implemented, developed, or are not available to them in their local area. The NDIS Review noted the significant development and investment this will require, noting that these changes could be expected to take 5 years,¹² and will be front-of-mind for people in rural and remote areas and those living in areas with very low service provision. This is crucial to ensuring that no one is left behind by these changes.

The NDIS Review, the Disability Royal Commission, the review of Australia's Disability Strategy and the Registration Taskforce have all proposed a wide range of changes to policy and practice for people with disability and their families. Many advocates are concerned these draft lists are contrary to the recommendations of these other reform processes. It is also problematic that the timelines for all these reforms, particularly in relation to developing Foundational Supports, are unclear and plans for consultation have not been communicated transparently to people with disability and their representative organisations.

Recommendation 7: That Government commit to the full development of Foundational Supports, including working with states and territories, to ensure people with disability have access to a wide range of supports.

¹¹ NDIS change must be led by people with disability – Joint media statement | Disability Advocacy Network Australia (dana.org.au)

¹² NDIS Review, <u>'Foundational Supports for all people with disability'</u> 7 December 2023.

As the NDIS Review panel recognised, there should be more support for people with disability to understand how they might use NDIS funding.¹³ As mentioned above, excluding vaguely defined classes of items from NDIS funding carries a large risk of unintended consequences. For instance, limiting supports in this way may also direct people to using more expensive supports, like a support worker instead of a cheaper piece of technology that is a one-off payment. As discussed above, this approach could unintentionally cost the scheme more over the long term.

Rules excluding support types from funding should only be introduced in very limited circumstances and in a highly targeted fashion. There should also be clear indication where exclusions are founded on the availability of supports through other service systems (whether federal or state/territory) so people with disability are aware of where there are where to go to seek this support.

... it sounds promising when you have a list that you can kind of use as a guide, but I have concerns about people not knowing where to go to get the supports. So is there a way that we can have guidance, 'okay, we don't provide it but you go to this place and this place provides'. Then I think it speaks to the impact on advocacy because people know they are going to come to whoever - us, navigators, LACs to help them find those supports that are in any other places – [that] won't be provided by the NDIA anymore...

Recommendation 8: That the NDIS supports lists are accompanied by clear accessible resources guiding people with disability to where supports are available.

The rules also displace the extensive litigation and discussion that has taken place on these at the AAT, introducing new criteria with a level of legislative authority that the Applied Principles did not reach. The decision in *Burchell* stressed that there should be a practical assessment of the circumstances and availability of supports available to the participant.¹⁴ That assessment should consider the circumstances of the person, including their informal support, whether they are located in a rural or remote area, and whether those services are materially and practically available to them. These have been constant battles for users of the scheme and the advocates that support them at the AAT.

There is an opportunity with the powers in section 10 to codify this view and make sure that people are not left without support through this time of reform. It would also encourage planners and the Agency to support people to find practical solutions and avoid people with disability falling between systems or into complex arguments about the different responsibilities of governments within the Federation of Australia.

Clearly stated principles are critically important in interim rules where many new programs will need to be established through the operation of 'Foundational Supports' by the states and territories. Disability Representative Organisations have been clear that nobody must be

¹³ NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme, p89.

¹⁴ Burchell and National Disability Insurance Agency [2019] AATA 1256 (4 June 2019).

left behind by these changes¹⁵ and including people with disability, their representative and advocates is a must.

Anything not fully detailed in these draft lists, which would include the definitions above, will inevitably have to be litigated in the AAT by people with disability. This will include extended and drawn-out fights about funding in a person's plan but could also extend to fights about debts, plan management, and a person's eligibility for the scheme under the new legislation. The current proposal demonstrates the inherent difficulty governments will encounter when attempting to spell out specific supports with the necessary exemptions to account for people's practical support needs.

Recommendation 9: That any definition attached to section 10 should include the ability for people to access disability supports through the NDIS when they are not practically available to them through state or other systems (including where that is due to cost).

Least restrictive approach to defining NDIS supports

The NDIS Supports Discussion Paper asserts that these draft lists would not change the types of supports appropriate to purchase with NDIS funding, with an overarching test to still stand - based on the need being a result of disability and appropriateness of funding through the NDIS. However, the wording of the lists creates potential for very broad interpretations excluding a range of currently funded supports from inclusion going forward. Speaking with advocates, the draft lists are expected to limit access to funding, though there is also acknowledgment that there is much scope for varied interpretations where the language is vague or imprecise:

There is also a bunch of wording in these lists that are pretty vague. Like they'll mention specialist products a bunch of times. What is a specialist product? There will be a mention of for example you can't get specialist support coordination unless there are specific high-level risks? What are those high-level risks? There is a mention of therapeutic supports that will be funded if they improve participation and independence, but what if they are maintenance supports and they are not going to lead to improvement? There is a lot of uncertainty in the language that's going to play out in reviews, I think and it is going to be really hard for all stakeholders to even sort of give helpful advice or feedback or make decisions about whether a decision is correct, or isn't correct. The last comment I will make is just I actually had a bit of a laugh when I was reading the part of the list about what's not an NDIS support and that there is carve outs in those lists. A carve out of a non-NDIS support, isn't that an NDIS support and therefore it should be in the list of NDIS supports that are available? I just think if you are going to go with lists, have it as clear as possible. What's in? What's out? It just seems very obfuscatory.

¹⁵ Joint Media Statement: Co-design and foundations essential to get NDIS right | Disability Advocacy Network Australia (dana.org.au)

It's apparent that this contraction is not solely focused on the prevention of misuse of NDIS funds that the 'crackdown on rorters' rhetoric suggests, but also on the exclusion of types or examples of support that have previously been held as legitimately funded by the existing NDIS Act. One of the inevitable consequences of broad lists like these is that their practical application will not consider the unique circumstances that arise in specific contexts. Supports that are not mentioned or clearly specified in the supports list as 'NDIS supports' or 'not NDIS supports' will be another area of further uncertainty and ambiguity that the current drafts lists would create.

The design of the NDIS has been informed by principles of self-direction, independence and people with disability being the experts in their own lives. Restrictive lists limiting the control, choice and autonomy of people with disability would run counter to the spirit and intent of the National Disability Insurance Scheme. If the intention of Government in establishing these lists is not to overrule current understandings of NDIS supports, this should be explicitly stated in the text of the document and included in the rules.

People with disability and advocates would be somewhat reassured by the rules including a direction to decision makers where ambiguity arises, to take the broadest possible interpretation of inclusions within the NDIS supports definition and the narrowest construction of exclusions.

As is discussed later, these draft lists also include some items that are currently funded in people's existing plans. People with disability would face the sudden situation of having approved funding in their plan for items like generators, additional out of school care supports, or for a vehicle, but would no longer be authorised to spend those funds at the risk of debts being raised or their plan-management being changed. The inclusion of a continuity measure in the rules that allows for the ongoing use of supports already funded in a plan would be essential to minimise disruption.

Recommendation 10: That Government include a provision in the rules guiding interpretation to presume inclusion when it is unclear which list a support falls under. Supports should be given the green light wherever possible, and circumstances where the prohibition power is used are limited and very specific.

Recommendation 11: That Government remove from the exclusion list all supports that could be in specific circumstances a reasonable and necessary support, and instead detail circumstances in which they can be funded via the approval power.

Recommendation 12: That Government include a provision in the rules that clarifies that supports that are not expressly listed as approved or prohibited supports can still be used.

Recommendation 13: That Government ensures supports currently funded in people's plans that are excluded by section 10 can continue to be used for the remainder of that plan.

Addressing implementation challenges

Advocates have expressed apprehension about how these lists would be implemented by the NDIA, which currently is experiencing significant delays across the organisation. Access, plans and reviews are all taking months, which is causing heartache and harm for people with disability and families. Adding such unclear lists will likely contribute to the current crisis in the Agency.

Under the status quo, advocates often encounter frustrating refusals by the Agency to acknowledge or accept that a specific unusual situation may justify a support being funded outside of the support categories the scheme would usually fund, despite strong evidence of meeting the reasonable and necessary criteria.

With the carve outs to these exclusions, the advocacy sector is dubious of the ability or willingness of NDIA decision makers to interpret these lists with nuance and open-minded fairness, to identify when additional contextual information about a person's circumstance and nature of their disability would justify an exception. Advocates noted their inconsistent experiences with the NDIA's processes, guidance and staff:

The people who need to be upskilled are the ones implementing the Scheme, the people at the NDIS and the people using their funding, if they are making mistakes, educate them, support them. I mean giving them a list that's even more confusing than the one we already had isn't educating or supporting anyone.

...educating the actual workers that are looking at what's reasonable and necessary to understand... In the long run this becomes a reasonable and necessary thing.

Advocates noted that without such training, there will be frequent problems with interpretation or misuse of the lists:

if NDIA staff don't have expertise in particular areas, then things that are intended to be 'in scope' are likely to be missed because of the nuance needed and prescriptive nature of the lists. There were significant interface challenges with education and child protection under APTOS but I don't think this goes to the heart of those challenges.

Lists become blunt instruments to include/exclude a support. People are individual and unique and so are their needs. A blunt instrument will be wielded by uninformed planners who will be ignorant to the actual needs of people they are there to serve.

The implementation of the transitional rule would need to be scaffolded by effective oversight and significant training for staff about its application when resourcing is already a major challenge for the Agency.

Recommendation 14: That all staff applying these rules are well trained in applying the nuanced understanding needed for specific contexts.

Recommendation 15: That there be effective oversight of the practical application of these rules by NDIA staff to ensure accuracy and consistency, and guard against the lists being misunderstood or broadly interpreted to exclude supports and narrow access unjustifiably.

Clear accessible process for challenging decisions

Advocates have grave concerns about the lack of detail or clarity about the review process for decisions as to whether a given support falls in or outside the NDIS Supports definition:

Taking the right to appeal from a vulnerable client who is looking for support is appalling. Everyone needs to live their life with dignity

We note that there is currently a Government amendment to the NDIS Amendment (Getting the NDIS Back on Track No 1) Bill 2023in the Senate that would allow people to apply for an exemption to the definition where another support would be cheaper. While ameliorating some of the potential injustice, this is insufficient, and would place the heavy onus to challenge decisions on people with disability in an already complex scheme and will not fix these fundamentally flawed lists. This is discussed further in section 3.

Recommendation 16: That Government must ensure clarity and fairness in the process for reviewing decisions about NDIS supports inclusion or exclusion, including ensuring support is available to assist people with disability to understand their rights and apply for exemptions where appropriate.

Policies pertaining to exceptions and reviewable decisions must both be firstly developed in consultation with people with disability, and secondly made available in accessible formats. While we oppose the lists, ensuring people with disability can contest decisions will be crucial if the lists are implemented.

Recommendation 17: That people with disability and their representative organisations can codesign a clear and accessible process for challenging the NDIA's interpretation of the NDIS supports definition and exemptions.

Some people with disability, their families and supports may have extensive knowledge and energy to pursue challenges, but many do not. Even with accessible well-designed and implemented processes for people with disability to challenge and contest decisions, this often relies on an awareness of rights to internal and external review and an understanding of the system. Secondly, this requires an investment of time and resources and access to independent advocacy or legal support. As one advocate explained:

I don't think that these lists really work. ... even with carve outs and things like that, sure, but at the end of the day for people who aren't well connected who don't know their rights, who don't know what they are able to access, they are just going to go with what they are told. If a person hasn't read all the carve outs then they are not going to know about that.

Currently the advocacy sector is not equipped to meet more than half of the demand for advocacy and this does not include the unmet need among people not aware of, or attempting to access, advocacy.¹⁶ The barriers to accessing legal and advocacy are often intensified by intersectionality, for First Nations people, people from culturally and linguistically divers communities and low socioeconomic backgrounds.¹⁷ The capacity shortfall is expected to worsen as more people seek to understand, navigate and adjust to changes to the NDIS or other disability reforms.¹⁸

Recommendation 18: That Government allocate increased funding to independent disability advocacy organisations to educate and empower people with disability to understand the NDIS supports definition and challenge unfair decisions.

Ongoing review of transitional rules to amend as needed

If these transitional rules are implemented, advocates expect to see many unintended consequences and problems arise. Beyond those described throughout this submission, there are likely to be implications that are unforeseen and difficult to predict prior to implementation. Therefore, there must be a commitment that embeds regular review of their operation with genuine opportunity for input from people with disability, their representative organisations, advocates and other supporters through a much longer, more respectful and accessible process of consultation.

Recommendation 19: That the transitional rules embed a process for review and evaluation including public consultation and consideration of input from people with disability and advocates. This must take place within three months of implementation and then every six months while interim arrangements are in place.

¹⁶ See further: Disability Advocacy Network Australia (2023) <u>Intake Project Summary Report</u>, Commissioned by Department of Social Services. Disability Advocacy Network Australia (2023) <u>A</u> <u>strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector</u>.

¹⁷ See further: Disability Advocacy Network Australia (2022) <u>Independent disability advocacy – DANA</u> submission to the Disability Royal Commission.

¹⁸ Joint Statement: Our disability advocacy organisations are in crisis and need a funding lifeline now | Disability Advocacy Network Australia (dana.org.au)

4. Areas of concern in draft lists

While objecting to the use of lists as described above, we do wish to flag several concerns about parts of the current draft rules. These should be taken to highlight the difficulties experienced when attempting to codify these supports and not an endorsement of the approach should these particular issues be fixed.

Day-to-day living expenses

Our initial submission to the Community Affairs Committee that reviewed the NDIS Bill argued that too broadly limiting how NDIS funds could be spent would impact flexibility, choice and control and ultimately mean more money would be spent on supports than is necessary.¹⁹ The example we provided in our submission was that of household goods, which can address and mitigate disability support needs and reduce the reliance on support workers to do the same tasks. For that reason, it is extremely disappointing to see a broad limitation on several household related items reflected in the list.

These concerns may be addressed in two ways in the draft bill and amended legislation, but we have concerns about both approaches.

The first is a carve out for these supports where they are 'solely and directly as a result of a disability need'. This replicates an exemption in the current *Supports for Participant* rules. This is a very high bar to clear for a typical participant, as particular support needs are often hard to disentangle from those that are typically performed by people but are made more difficult as the result of a disability. An example of the automatic vacuum, as described above, does not solely arise as the result of a disability. There is an ongoing need for all people to maintain a clean home, but a disability can in some instances make that task substantially more difficult or outright impossible.

Many items in this list are not accurately classed as day-to-day living expenses. A recent case at Federal Court, where a person had to move as a result of their disability, did not find that furniture removal and other associated items met the definition of 'day-to-day living expenses' in the first place.²⁰ Instead the case found that these were exceptional, out of the ordinary, and related to their disability support requirements. Subsequently, the inclusion of 'furniture removal' as a prohibited NDIS support is a worrying backwards step.

Other cases before the AAT have considered whether a vehicle may be a NDIS support, and found that a car and the cost to modify it may be a reasonable and necessary support where required as a result of their disability and necessary to fully participate in the community.²¹

¹⁹ Disability Advocacy Network Australia (2024) National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions], pp17-20.

²⁰ Warwick v National Disability Insurance Agency [2024] FCA 616 (12 June 2024).

²¹ Barling and NDIA [2021] AATA (24 November 2021).

Air conditioning and temperature regulation tools have also been found reasonable and necessary,²² but are caught in the crossfire under 'standard household items.'

Indeed, the NDIA's own set of operational guidelines say that generators and batteries are simply a matter for state or territory support rather than a day-to-day cost borne by the NDIS user.²³ However, in these lists, they are included in the day-to-day living expenses category. Several advocates have reported cases that have gone before the AAT featuring these needs that have settled before hearing with the NDIS providing these supports, and they align best with an understanding about funding exceptional costs that inevitably arise for some people with disability that has been developed. These issues are crucial for those who rely on life-preserving devices in the event of a power outage, and is an important part of climate resiliency as the climate changes. As one advocacy organisation relayed:

[Our organisation] assisted a NDIS participant, who due to their disability, was highly reliant on a combination of assistive technology and physical. E.g. reclining chairs, bed, oxygen concentrator and suction machines to prevent chocking due to their disability. The participant lived in an area of NSW prone to unpredictable blackouts. If the participant experienced a blackout, they would be unable to operate their assistive technology and may be stuck (e.g. bedbound, chairbound) without support and at risk of choking. a

[The] matter was appealed to the AAT. The NDIA ultimately settled on the basis the NDIA paid to replace all of his assistive technology with battery powered models, rather than fund the requested electric generator, despite this being a greater cost.

There is also a conflation of menstrual products as a day-to-day living costs. A more accurate definition would include the circumstances in which they are assistive items for personal care and authorise their use there, such as adaptive period underwear or tampon insertion aids. Instead, they are hit with the same broad brush that captures many 'day-to-day items' even where there is a clear need because of disability.

The proposed lists also reverse previous Federal Court and AAT guidance in other areas. The removal of 'Sex Work' services from the scheme directly contradicts the finding in *WRMF and NDIA*,²⁴ which found that such services could be part of a person's NDIS package if they meet the 'reasonable and necessary' test in the circumstances. That test is already quite extensive, requiring that supports be effective, beneficial and value for money. DANA, along with other Disability Representative Organisations, assert that including these services in these lists would 'undermine the fundamental human rights and the choice, control, and access of people with disability to essential supports that enable full participation in all aspects of life, including sexual expression, health, reproduction and relationships'.²⁵

²² MKKX and National Disability Insurance Agency [2024] AATA 805 (19 April 2024).

²³ See further: <u>Would we Fund it: Generators;</u>

²⁴ [2020] FCAFC 79

²⁵ See further: <u>Joint Statement: Ten Organisations Call for People with Disability's Access to NDIS</u> Funded Sexuality Services to be Protected - People with Disability Australia (pwd.org.au)

Even if it is not the Government's intent that these items be excluded and that they be covered by the 'solely and directly' carve out, they have failed to give the clarity that would at least be established by spelling out the concrete examples that have been developed over the last 10 years at Federal Court and AAT. The conflation of 'day-to-day living costs' and 'exceptional costs' in the current lists is deeply unhelpful and problematic.

The second pathway to dodge the incredibly harsh edges of these lists may be amendments proposed by the Government in the Senate. These changes to section 10 would give a framework for people to use supports not listed in the rules where they are both cheaper and would provide the same or a better outcome. This is an improvement and an important pathway to mitigate the worst effects of these rules. However, they add yet another level of administrative complexity to a scheme that is already difficult for many to navigate through and would require additional support for people to navigate and appeal. The power also remains discretionary, relies on the goodwill of the Agency to exercise and limits the ability for people with disability to apply to review the decision, particularly for 'new framework' plans.

Advocates are concerned the broad framing of several other categories may also capture important and necessary supports that may have to interface with the exceptions process, such as:

- Rent Contributions, Bonds etc.
 - We are concerned that the broadness of this definition could capture people's current supports, including for those in some SIL (Supported Independent Living) settings and other accommodation arrangements, such as Independent Living Options.
 - While addressed in other approved parts of the list, there are also other mechanisms where rent is discussed such as medium-term accommodation (in the carve out) as well as in Specialist Disability Accommodation (where a rent contribution comes from the user, but other costs are borne by the scheme).
 - Given the importance of a stable home, any proposed changes to this area should be undertaken with extreme caution.
- Smart watches/smart devices
 - Another example of a personal item which overlap with a non-disability related support need but can be of great assistance for those requiring assistance to manage medication, their schedules, use communication tools, request aid, or to magnify items on a larger screen for those with a vision impairment.
 - Without these devices, people may become more reliant on a support worker or require additional support from the health system, both of which have costs that quickly outstrip the original cost of the device.
 - Advocates have regularly supported people to use these supports to overall reduce the funding they needed. Additionally, their ability to be purchased through Low-Cost Low Risk plan budgets already in many people's plans means that the utility that they provide is not always clearly established with the Agency directly or at the AAT.

As an advocate said in discussing the draft:

The NDIS are saying participants can access a support worker to assist a PWD [person with disability] do all these activities. But they will not pay the costs associated with doing the activities for the worker or the participant. Paying for costs fall to a PWD. With current DSP this is not feasible for many so some providers often include it in their billing ...hence the start of funding issues... and fraud claims...

There are other areas in this part of the list that are confusing when you consider the lists as a whole. 'Takeaway food' is listed as an excluded support, but assistance for meal preparation and delivery is already a common item of support and is recognised as a permitted support under 'household tasks'. However, this is not mentioned as one of the 'carve outs' beneath the day-to-day living costs section, and also fails to consider when such 'takeaway food' might be the only available option if a person's services are disrupted.

Given that these lists would come into effect with the passage of the bill, we are also deeply concerned about how these will be administered by staff on the ground. While the lists profess to streamline and make clear the supports that are in and out there are so many carve outs and contradictions that attempt to cover circumstances (and fail to do so) that makes these lists almost impossible to administer.

These issues make our Recommendation 11 above crucial, as this would require the agency to remove these supports that are not in fact 'day-to-day' costs and instead detail circumstances in which they can be funded via the approval power.

Effective and beneficial

Another area of difficulty is establishing on what basis the decision has been taken to exclude these supports from the scheme. Whereas most legislation and regulations usually include explanatory memorandum, that is not the case here. In the Federal Budget, the Government announced an 'NDIS Evidence Advisory Committee' which would provide advice on these issues but is not yet operational. Such a committee would need to centre the experiences of people with disability, and also need to consider the standards of evidence needed, building out evidence bases and avoid locking in or endorsing certain diagnostic or medical approaches to particular disabilities. We have no evidence of any of these considerations taking place here.

Where Government is seeking to prevent the use of NDIS funding on specific supports, particularly where they are speaking to the effectiveness of methods, they should be detailing where they see the shortfalls of certain therapies. While some prohibitions included in this part of the lists are not likely to be controversial, this would be a key step in making the use of powers under section 10 more procedurally fair. In the meantime, the Government should be reconsidering recommendations in the NDIS review that advocate for a trust-based approach for people to use their supports in a way that will be most effective for them.

Mainstream services interface

One of the main concerns raised by disability groups when the initial legislation was introduced was the use of APTOS as an interim measure to help define 'NDIS Supports' until a more fulsome process with the community and between federal and state and territory governments could take place. These tables, which are upwards of 10 years old, attempt to spell out where state bodies such as local health systems and schools have responsibility to provide disability supports where the NDIS can step in.

These tables did not work in practice, did not account for the unique circumstances of people on the ground, have been widely found to be unclear and ineffective by community groups, and often left people without support while disputes over responsibility between state, territory and federal bodies went unresolved.

For this reason, we were pleased when they were taken out, along with the awkward inclusion of some elements of the CRPD, from the bill. But we are extremely disappointed to see many of the same features replicated in the part of the rules that discusses the interface between state and federal services. In some instances even less support would be offered under the NDIS draft lists. The draft rules are in many ways less detailed than APTOS and have given rise to several areas of concern for Advocates.

An ongoing area of tension is the suggestion that many mental health supports (particularly psychology supports) for people with psychosocial disabilities on the scheme can be funded through Medicare instead of the NDIS. Additionally, many of those services require a gap payment as Medicare does not cover the full cost. The draft rules do not resolve this issue and suggest that clinical ongoing care and those health supports which are time-limited or goal orientated are not the responsibility of the scheme. The rules neglect to give any specific definition of what clinical or ongoing care is, and only speak to a carve out for 'psychosocial recovery supports' generally. They also don't use the language that person will have to know to request support, such as where the agency thinks a mental health care plan might be appropriate for someone as opposed to accessing those services through the NDIS.

Advocates have also raised concerns about the limitation on community transport supports, which is another example where people commonly use transport allowances together to enable efficient ways of getting around and participating in the community. This is another area where this limitation may increase the need for individual transport services that will cost the scheme more.

There is also significant overlap between the approved employment supports in the first half of the list and those prohibited by these rules in the mainstream interface section. The green light section allows NDIS funds to be used on individual employment supports, employment preparation and school leaver supports that will help someone obtain and retain a job. But the red light section covers very similar ground in disallowing the use of 'work-specific support related to recruitment processes, work arrangements or the working environment.' It is possible that some of these supports are envisioned to be funded by Job Access, employers or other services, but is not at all spelled out and again of limited use for a layperson looking at these lists. In relation to justice, advocates have also flagged changes in the mainstream interface section from current arrangements and those included in APTOS. The draft rules appear to envision a smaller role for the NDIS. Where APTOS provided for allied health supports, capacity and skills development where related to a disability, to all be funded by the NDIS, there are no supports that are expressly approved to be undertaken in justice or custodial settings in the draft lists. The section excluding supports relating to mental health facilities and day-to-day support needs of a person in custody has no carve outs to address the above.

Other concerns that should be at the forefront of the Government's thinking should include the impact on parents with disability. The categorisation prohibiting general 'parenting programs [...] including making them accessible' will exclude many parents with disability to be supported. Separately, the prohibition on 'out of school hours care' may capture those who use those services but use extra support from the NDIS to address costs that arise from additional disability-related support needs. Advocates who have fought very hard to help parents with disability access crucial supports through the NDIS,²⁶ are especially dismayed by the potential impact on an already disadvantaged group:

...their kids are being taken off them unfairly by...Child Protection and by the courts because they have had no support. If they'd had support through their NDIS supports, or, in fact, if they had been on the NDIS I think in some cases they are not, then they could have kept their kids.

So where is the CRPD in all of this? ... it is a glaring thing and it has been said many times, but the right to be a parent and the right to have appropriate supports [is very important]. It shouldn't be according to some list when every family situation is so different and every parent is so different.

As is discussed above in relation to our Recommendation 9, the powers offered in section 10 would allow the codification of the principle established in *Burchell* to permit the use of supports that may otherwise be intended to be provided by other systems where they are not practically available to the person. This principle is particularly crucial during the transitional period where foundational supports are getting up and running.

²⁶ DANA submission to the DRC: Advocates Zoom In On... Child Protection Systems – 9 November 2020: <u>Voices of Advocacy | Disability Advocacy Network Australia (dana.org.au)</u>