

Department of Social Services NDIS Consultation Team,

25 August 2024

Dear Team,

Re: Submission on Proposed Changes to NDIS Supports

I am writing to submit my comprehensive feedback on the proposed changes to NDIS supports, as outlined in the recent draft list and discussion paper. As a blind NDIS participant, long-time disability advocate, and former member of the NDIS Independent Advisory Council, I bring a unique and informed perspective to this critical issue.

The attached submission offers an in-depth analysis of the proposed changes and their potential impacts. I urge you to read it in full, as it addresses several crucial points:

- 1. Fundamental Shift in NDIS Principles: The proposed changes represent a significant departure from the NDIS's core principles of choice, control, and person-centred support, potentially undermining the scheme's effectiveness.
- 2. Lack of Genuine Co-Design: The current consultation process falls short of true co-design, risking the implementation of policies that may not reflect the real needs and experiences of NDIS participants.
- 3. Potential Negative Economic Impacts: The proposed changes could lead to increased long-term costs for both the NDIS and broader society, contradicting the goal of improving scheme sustainability.
- 4. Rural and Regional Considerations: As a resident of Far North Queensland, I highlight how the proposed changes fail to adequately address the unique challenges faced by participants in rural and regional areas.
- 5. Overly Prescriptive Approach: The draft list of supports is excessively detailed and rigid, potentially limiting flexibility and innovation in support provision.
- 6. Unintended Consequences: I discuss potential unintended consequences of the proposed changes, including increased reliance on support workers and potential barriers to employment and community participation.

- 7. There are many potential conflicts with my existing three year plan and the supports therein. Exceptions should be made for supports that were obtained after a lengthy and expensive litigation process in the AAT and External Review Process to avoid these costs being incurred all over again.
- 8. Alternatives and Improvements: The submission offers constructive alternatives and suggestions for improvement, including a more flexible, principle-based approach to determining supports.

Key examples of how these changes could impact participants include:

- The exclusion of smart devices like smartwatches, which for many participants are essential assistive technologies rather than mere conveniences.
- Restrictions on employment supports that could hinder participants' ability to access and maintain employment.
- The classification of items like menstrual products as "lifestyle related," ignoring their essential nature for many participants.

My submission isn't just a critique. It offers constructive alternatives and suggestions for improvement. It proposes a path forward that could enhance the NDIS's effectiveness while addressing sustainability concerns, including:

- Implementing a genuine co-design process with the disability community
- Adopting a more flexible, principle-based approach to determining supports
- Improving assessment processes and decision-making transparency
- Investing in innovation and capacity-building supports

The NDIS has been transformative for hundreds of thousands of Australians with disabilities. As we stand at this crossroads, your decisions will shape the future of disability support in Australia. I implore you to consider the full implications of these proposed changes and to work collaboratively with the disability community to develop reforms that enhance, rather than diminish, the NDIS's capacity to support and empower people with disabilities.

Thank you for your time and consideration. I look forward to further discussion on this crucial matter and am available to provide additional insights or clarification as needed.

Yours sincerely,

NDIS Participant and Disability Advocate

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# 1. Executive Summary

As a blind NDIS participant, long-time disability advocate, and former member of the NDIS Independent Advisory Council, I, Dale Reardon, strongly oppose the proposed changes to NDIS supports as outlined in the draft lists and discussion paper provided by the Department of Social Services (DSS). These changes represent a fundamental shift away from the original intent of the NDIS, threatening to undermine the scheme's flexibility, person-centred approach, and capacity to meet the diverse and evolving needs of participants.

The proposed transition to a defined list of supports, implemented through hastily constructed transitional rules, risks creating a rigid, one-size-fits-all system that fails to account for the unique circumstances of individual participants. This approach contradicts the NDIS's foundational principle of choice and control, potentially leaving many participants without access to vital supports that enable their independence and community participation.

Furthermore, the lack of genuine co-design in developing these changes is deeply concerning. The rushed consultation process and the Minister's attempt to implement significant changes through transitional rules bypass the necessary collaboration with the disability community and risk implementing poorly conceived policies that could have far-reaching negative consequences.

This submission will detail the numerous issues with the proposed changes, including their potential impact on participants' daily lives, the economic ramifications, and the conflict with the NDIS's original goals. It will also offer alternatives and suggestions for improvement, emphasizing the need for a more collaborative, flexible, and person-centred approach to NDIS reforms.

There is also a large number of potential conflicts with my existing 3 year plan, which was hard fought in the AAT and the NDIS External Review Process costing myself and the NDIA a lot of time and money. Given there is now a discretion power to allow the use of otherwise excluded supports it would seem sensible and prudent to allow existing plans to continue in their current form rather than causing a lengthy, extensive and expensive re-litigation of many supports. My plan has already been determined to be reasonable and necessary in the nature and extent of supports and that should continue into the future.

# 2. Introduction:

Personal Background:

I am a second blind NDIS participant living in the second second

# 3. Context of the NDIS and Proposed Changes

The National Disability Insurance Scheme (NDIS) was introduced in 2013 as a groundbreaking approach to disability support in Australia. Its core principles of choice, control, and person-centred care represented a paradigm shift in how we as a nation support people with disabilities. The scheme was designed to be flexible, responsive to individual needs, and empowering for participants.

However, the recent proposed changes, as outlined in the Draft List of NDIS Supports and the accompanying discussion paper, threaten to fundamentally alter the nature of the NDIS. These changes, if implemented, would move the scheme away from its original flexible, needs-based model towards a more restrictive, defined-support model. This shift raises serious concerns about the future effectiveness of the NDIS and its ability to meet the diverse and evolving needs of participants.

The Minister for NDIS, Bill Shorten, has stated that the purpose of these changes is to "make it clearer for participants what they can and can't use their NDIS funds to buy" [1]. However, as this submission will argue, the proposed approach may create more problems than it solves.

# 4. Analysis of the Draft List of NDIS Supports:

The draft list of NDIS supports represents a significant departure from the current flexible, individualized approach to determining reasonable and necessary supports. The list includes 36 categories of supports that are considered 'NDIS supports' and 15 categories of goods and services that are not 'NDIS supports' [2].

Key concerns with this approach include:

#### a) Overly Restrictive Definitions:

The proposed list attempts to categorize and define NDIS supports in a way that fails to account for the diverse and often complex needs of participants. By creating rigid categories, the list risks excluding vital supports that don't neatly fit into predefined boxes.

# b) Lack of Flexibility:

The NDIS was designed to be flexible and responsive to individual needs. The proposed list, however, moves away from this principle by attempting to create a one-size-fits-all approach. This lack of flexibility could severely limit participants' ability to tailor their supports to their unique circumstances and goals.

# c) Potential for Increased Inequity:

The proposed changes risk creating a system where only those with the resources and capacity to advocate strongly for themselves will be able to access the full range of supports they need. This could lead to increased inequity within the scheme, particularly disadvantaging those from rural and remote areas, culturally and linguistically diverse backgrounds, or those with complex needs.

# d) Overlooking Individual Circumstances:

Many items on the prohibited list may be essential for some participants due to their specific disabilities. The blanket prohibition of these items fails to consider how they might be necessary and reasonable in certain individual circumstances.

#### e) Bias Towards Traditional Support Worker Model:

The draft list appears to favour traditional support worker services over more innovative, technology-based solutions or community inclusion strategies. This bias could lead to increased costs for the scheme and reduced independence for participants.

# f) Inconsistencies and Contradictions:

There are numerous inconsistencies within the list. For instance, some items are permitted in one category but prohibited in another. This lack of clarity could lead to confusion and disputes over what is and isn't allowed.

# g) Potential for Increased Administrative Burden:

The detailed nature of the list, coupled with the proposed exceptions process, could lead to a significant increase in administrative burden for both the NDIA and

participants. This could result in delays, increased stress for participants, and potential denial of necessary supports.

### h) Failure to Account for Evolving Technology:

The list's approach to technology is particularly concerning. By specifically excluding certain technologies, it fails to account for the rapid pace of technological advancement and how new innovations might benefit participants.

# i) Disregard for Regional and Rural Considerations:

As a resident of Far North Queensland, I'm acutely aware of the challenges faced by participants in regional and rural areas. The proposed list fails to adequately consider these challenges, particularly in terms of access to services and the need for flexibility in how supports are delivered.

# j) Potential Conflict with Other Legislation:

Some of the proposed exclusions, such as those related to employment supports, may conflict with other legislation, including anti-discrimination laws. This could create legal ambiguities and potentially leave participants without necessary supports in critical areas of their lives.

# k) Misclassification of Essential Items:

The classification of certain items as "lifestyle related" fails to recognize their essential nature for people with disabilities. A prime example is the categorization of menstrual products alongside items like vapes and gaming consoles. This classification ignores the fact that for many people with disabilities, these products are crucial for maintaining dignity, hygiene, and participation in daily life. According to research by Share the Dignity, 78% of people with disability who menstruate struggle to afford these products [3]. This misclassification could lead to significant hardship and reduced quality of life for many participants.

# l) Disregard for Necessary Household Maintenance:

The proposed exclusion of pool maintenance, household repairs and maintenance and similar household tasks fails to consider how these can be essential and challenging for participants with certain disabilities. For a blind person like myself, safely maintaining a pool involves unique challenges that may require specialized support. For example getting close to dangerous chemicals such as acid (necessary regularly for pool maintenance) is not safe and I cannot read pool water test strips myself. Perhaps you only mean to exclude materials and not labour but this is not clear and ambiguous.

Household maintenance could even include replacing light globes, maintenance to household fixtures and fittings that might come loose, need replacing or maintaining. All such tasks could be performed by a non disabled person and should be covered for participants.

General home repairs and maintenance exclusion - this is absurd. A non-disabled person can do this for themselves so it is entirely reasonable and necessary for me to need help. There are so many simple things that need doing for repairs and maintenance and the labour costs should be covered. The tasks performed by a handyman could be done by a non-disabled person themselves. I do not have any family myself that can assist either due to location, their own caring responsibilities or for example my father being very elderly and being disabled and on a high level home care package himself. My wife's father is deceased and we do not live near any other family.

I know that even some specialist disability support providers offer these services but I use non registered providers who are more flexible, cheaper and faster and available in my rural and regional location.

# 5. Critique of the Proposed Transitional Rules:

The use of transitional rules to implement these significant changes to the NDIS is deeply problematic for several reasons:

# a) Lack of Parliamentary Scrutiny:

By implementing these changes through transitional rules rather than primary legislation, the government is bypassing proper parliamentary scrutiny. This approach lacks transparency and accountability, particularly for changes of this magnitude.

#### b) Circumventing State and Territory Agreement:

The use of transitional rules allows the Minister to implement changes without the unanimous agreement of state and territory governments, which is required for permanent rules. This undermines the cooperative federalism model on which the NDIS is built.

#### c) Potential for Indefinite Application:

While described as "transitional," there's a risk that these rules could remain in place indefinitely if agreement on permanent rules cannot be reached. This creates uncertainty for participants and could lead to a long-term reduction in supports.

#### d) Rushed Implementation:

The speed at which these changes are being pushed through via transitional rules doesn't allow for proper consideration of their impacts or for genuine co-design with the disability community.

#### e) Lack of Co-Design:

The development of these transitional rules has not involved genuine co-design with people with disabilities, their families, or disability organizations. This contradicts best practice in disability policy development and risks implementing rules that don't reflect the real needs and experiences of participants. Please note that simply allowing for consultation, even with a more reasonable and longer duration, does not amount to co-design. Co-design requires disabled people and their representatives be given a seat at the decision table.

#### f) Potential for Unintended Consequences:

The rushed nature of these changes increases the risk of unintended consequences that could negatively impact participants' lives and the overall effectiveness of the scheme. It is simply impossible for all matters to be thoroughly considered and the views of all PWDs gathered within the very short time period. The time for submissions should be extended by an additional 2-3 months to allow sufficient time for organisations to actually go out into the community and seek the input of participants and their families.

#### g) Inadequate Consideration of Long-term Impacts:

The use of transitional rules risks implementing significant changes without fully considering their long-term impacts. This approach could lead to unintended consequences that are difficult to reverse once embedded in the system.

# 6. Impact on Personal Experiences and Needs:

As a blind NDIS participant, I can attest to the potential negative impacts these proposed changes could have on my daily life and independence. The following examples illustrate how the draft list of supports and proposed changes could affect me and others with similar needs:

#### a) Guide Dog Support:

The narrow definition of assistance animals as those "specially trained by an accredited assistance animal provider" fails to account for the diverse ways in which assistance animals are trained and certified. This could potentially impact my ability to choose the most suitable guide dog training and ongoing support services for my needs. Furthermore, it doesn't consider situations where participants may need to change providers or use independent trainers for ongoing support, as I currently do. Based on international experience it is quite possible that a disabled individual may train their own assistance animal but then have its abilities tested and certified by an appropriate organisation to get legal recognition. Also the organisation that trains the animal may not be the same organisation or person who provides ongoing training and support to the disabled person.

For example with dog guides there is only 1 National organisation being Seeing Eye Dogs Australia and all the other guide dog organisations are separate legal entities and will not automatically take on a dog and handler when that person moves interstate - this has happened to me personally when moving from Tasmania to Western Australia and WA Guide Dogs would not assist me and SEDA stepped in and helped me.

It is even possible that an Australian may have an assistance animal provided by an organisation from another Country. For example in the past I have gotten a guide dog that was supplied by New Zealand Guide Dogs and training and support later provided by both Guide Dogs, SEDA and an independent instructor.

#### b) Smart Devices and Technology:

The exclusion of smart devices, including smartwatches, from NDIS funding is particularly concerning. As a blind person, I rely heavily on my smartphone and smartwatch for navigation, time-telling, and accessing information. These devices are not mere conveniences but essential tools that enable my independence. For instance, my smartwatch's fall detection feature could alert emergency contacts if I have an accident, potentially saving my life or preventing serious injury. (and yes indeed in the past I have been pulled onto the ground and had my guide dog run off after experiencing a dog attack). The proposed exclusion fails to recognize the critical role that mainstream technology can play as assistive devices for people with disabilities. Under these strict criteria I cannot even buy a standard talking watch or a braille watch as all watches are excluded which is very strange - so the NDIS will no longer allow me to have independence through knowing the time!

Smart devices including smart watches and watches generally:

Again this is a blanket prohibition that is not reasonable. For example I am blind and cannot see and use a standard watch. For blind people you can use either a talking

watch or a braille/tactile watch - all these options can be expensive and are disability related.

My Uncle is blind and doesn't use smart devices due to his age and technology reluctance (he was too old for the NDIS rollout) and has gone through multiple talking watches in the last 6 months as they all seem to have poor quality and just don't last very long at all.

By contrast a smart watch may be much more appropriate, have better quality and work in conjunction with a smart phone for other disability tasks as I discuss elsewhere in this submission.

One problem that this criteria and many other criteria miss is that the scheme should be looking at the purpose of the support expenditure and the need it is solving rather than just the name or description or category of the item.

#### c) Employment Supports:

The limitations on work-specific supports are troubling. My experience with the Administrative Appeals Tribunal (AAT) and external review process to secure employment supports demonstrates the importance of these supports for maintaining employment and career development. The proposed restrictions could significantly hinder the ability of participants like myself to access and maintain meaningful employment. For example, the exclusion of "work-specific support related to recruitment processes, work arrangements or the working environment" fails to recognize that these supports are often crucial for people with disabilities to compete on an equal footing in the job market.

I require the assistance of several different types of support persons in order to operate my own business or be employed and all these items were approved as part of my current plan.

# d) Home Modifications and Maintenance:

The exclusion of "standard home security and maintenance costs" and "general home repairs" fails to consider the additional needs of participants with disabilities. As a blind person, I require specific modifications and maintenance services to ensure my home is safe and accessible. For instance, I need highly secure fencing and gates to allow my guide dog to safely exercise in our backyard. This is not a standard cost but is directly related to my disability. In fact, I've experienced the consequences of inadequate fencing when my guide dogs escaped after a passerby opened an unsecured gate, necessitating a major search operation involving police and local media.

General home repairs and maintenance exclusion - this is absurd. A non-disabled person can do this for themselves so it is entirely reasonable and necessary for me to

need help. There are so many simple things that need doing for repairs and maintenance and the labour costs should be covered. I know that even some specialist disability support providers offer these services but I use non registered providers who are more flexible, cheaper and faster and available in my rural and regional location.

### e) Personal Care and Grooming:

The exclusion of services such as nail salons fails to recognize that for many participants, these services are not luxuries but essential for maintaining personal hygiene and dignity. In my case, professional nail care services are a more efficient and cost-effective alternative to podiatry services for maintaining foot health. Similarly, as a blind person, I find it challenging to maintain my beard and benefit from professional barber services. These are not mere conveniences but necessary adaptations to my disability.

# f) Prepared Meals and Food Services:

The blanket exclusion of takeaway and fast food services doesn't account for the necessity of prepared meals for some participants. As someone who has approved prepared meals in my plan, I find the proposed restrictions overly prescriptive and potentially limiting to my independence. The focus should be on whether the food service meets a disability-related need, not on the type of food service.

For example the requirement should simply be that the food items are purchased to be consumed at home or the participants current residence and require only additional delivery, heating, cooling and serving.

For example in **there is a prepared food service that can deliver if you are** sufficiently organised in advance and will be at home but this is not always the case and then they offer pickup from their store of either fresh or frozen meals. Is this take away or just an accessible form of a prepared meal?

Sometimes depending on the hour of the day and how my disability is, it might be necessary to order prepared meals from a limited range of food items and there are services such as Uber, Door Dash, Menu Log etc - varies in regional areas as to which, if any, are available. This is then just the delivery of a prepared meal and should be permitted no matter who the meal comes from.

Even Supermarkets offer excellent prepared meals and it should be possible to use these as part of my prepared meals - it may be possible to get them delivered as part of a grocery order or separately. However the lists seek to exclude groceries so you need to take into account again that not everything from a Supermarket is a grocery item.

Essentially only eating out at a restaurant, cafe etc should be excluded.

### g) Travel and Accommodation:

The exclusion of various travel-related expenses fails to consider the additional support needs of participants when traveling. As a blind person, I often require more extensive support when traveling, especially internationally, where I can't bring my guide dog due to quarantine restrictions. The NDIS should funding necessary disability-related travel expenses to ensure participants can maintain their independence and quality of life while traveling.

Also in a foreign environment (even in Australia domestically) I may have no idea of O&M, not know how to get around even the building/hotel/apartment that I am staying in and need a much wider range of supports and assistance when travelling.

### h) Social and Recreational Activities:

The restrictions on funding for tickets to events and recreational activities don't account for the additional costs often incurred by participants, such as the need to pay for support workers or interpreters to accompany them. This could significantly limit participants' ability to engage in community activities and maintain social connections.

Perhaps you think the Companion Card covers every assistant or carer but that is far from the case in reality. The Companion Cards are a State based scheme with some National recognition - moving interstate and getting a new card is not always automatic). Also not all events, venues or activities support the Companion card and it only allows for 1 additional person at most. Some people may require 2 or more support assistants and may be going places that don't support the Companion Card. On these occasions what you are implying is for social expenses is actually to provide disability assistance.

This is yet another case where the support expense cannot be categorised out of context and without knowing why the item is being purchased.

# i) Household Items and Appliances:

The exclusion of "standard household items" overlooks how these items may need to be specialized or adapted for participants with disabilities. For instance, a "smart" washing machine or dishwasher might be essential for a participant with limited mobility or cognitive impairments. The focus should be on the function and necessity of the item, not its perceived "standard" nature.

# j) Pool Maintenance:

While I understand the desire to exclude capital costs for items like swimming pools, the complete exclusion of pool maintenance support is problematic. As a blind person, I cannot safely conduct water tests or handle pool chemicals. These tasks are not just

difficult but potentially dangerous for me to perform independently. The NDIS should fund the labour costs for such maintenance when it's need is directly related to a participant's disability.

### k) Insurance for Assistive Technology:

The proposed exclusion of insurance costs fails to recognize that participants may incur higher insurance costs due to their disability or assistive technology. As someone who works from home and relies on expensive assistive technology provided by the NDIS and needed due to my disability, it's crucial that I can insure these items. The NDIS should fund the additional cost above standard rates for insurance related to disability supports / AT etc.

# 7. Inconsistencies and Potential Negative Impacts:

The proposed changes contain numerous inconsistencies and potential negative impacts, particularly for participants in rural and regional areas like myself:

### a) Inconsistent Application of Rules:

There are instances where a support is allowed in one category but prohibited in another. For example, some household modifications are permitted while others are excluded, creating confusion about what is truly allowable under the scheme.

# b) Rural and Regional Disadvantage:

As a resident of Far North Queensland, I'm acutely aware of the challenges faced by participants in rural and regional areas. The proposed changes do not adequately account for these challenges, such as:

- Limited availability of specialist services, necessitating more flexible use of available local services.
- Higher costs associated with travel and accessing services.
- The need for more innovative solutions due to lack of traditional support options.

#### c) Over-Reliance on Support Workers:

The proposed changes seem to favour traditional support worker models over more innovative, technology-based solutions. This could lead to increased costs for the scheme and reduced independence for participants, particularly in areas with workforce shortages. It is almost the case that anything done by a disability support worker is permitted.

#### d) Potential for Increased Institutionalization:

By limiting flexible, community-based supports, there's a risk that some participants may be forced into more institutionalized settings, contradicting the NDIS's goal of community inclusion.

#### e) Barrier to Employment:

The restrictions on employment-related supports could create significant barriers to employment for participants, particularly in regional areas where job opportunities may be limited.

#### f) Impact on Participant Choice and Control:

The prescriptive nature of the proposed list significantly reduces participant choice and control, a cornerstone principle of the NDIS.

#### g) Potential for Increased Appeals and Reviews:

The lack of flexibility in the proposed changes could lead to an increase in appeals and reviews, creating additional stress for participants and increasing administrative costs for the scheme.

#### h) Disregard for Evolving Needs:

The rigid categorization of supports fails to account for the evolving needs of participants, particularly those with progressive conditions or changing life circumstances.

#### i) Contradictory Exclusions:

There are instances where the proposed rules contradict themselves. For example, some items are allowed in one category but prohibited in another. There should be an overriding rule that if an item is permitted in one section, a later exclusion or prohibition should be ignored. This would help prevent confusion and ensure participants can access necessary supports.

# 8. Shift from Flexible to Restrictive Support Model:

The proposed changes represent a fundamental shift from the NDIS's original flexible, person-centred approach to a more restrictive, defined-support model. This shift is problematic for several reasons:

#### a) Undermining Person-centred Care:

The NDIS was designed to provide individualized support based on each participant's unique needs and goals. The proposed list of defined supports moves away from this person-centred approach, potentially forcing participants into a standardized model of care that may not meet their specific needs.

### b) Reducing Participant Choice and Control:

A core principle of the NDIS is giving participants choice and control over their supports. The proposed changes significantly limit this choice by prescribing what can and cannot be funded, regardless of individual circumstances.

#### c) Stifling Innovation:

By rigidly defining allowable supports, the proposed changes may discourage innovative solutions and adaptations that could better meet participants' needs and potentially be more cost-effective in the long run.

### d) Ignoring the Diversity of Disability:

The one-size-fits-all approach fails to recognize the vast diversity of disabilities and the unique ways in which individuals experience and manage their conditions. What might be needed by me as a blind person may not be a disability support for another participant. Without considering the purpose you cannot simply exclude certain items as being unreasonable for support.

#### e) Potential for Increased Inequity:

A more restrictive model may advantage participants who are better able to advocate for themselves or navigate complex systems, potentially leading to increased inequity within the scheme.

#### f) Risk of Inadequate Support:

By limiting the range of allowable supports, there's a risk that some participants may not receive adequate support to meet their needs, potentially leading to poorer outcomes and increased reliance on other systems (e.g., healthcare, social services).

#### g) Conflict with Scheme Objectives:

This shift away from flexibility conflicts with the NDIS's objectives of promoting independence, social and economic participation, and choice and control for people with disabilities.

# 9. Co-Design vs. Consultation:

One of the most significant concerns with the proposed changes is the lack of genuine co-design with the disability community. This issue warrants a detailed examination:

### a) Definition of Co-Design:

Co-design is a collaborative process that involves working directly with stakeholders (in this case, people with disabilities, their families, and disability organizations) throughout the entire design process, from problem identification to solution implementation. It's characterized by:

- Equal partnership between designers and users
- Shared decision-making power
- Continuous involvement throughout the process
- Recognition of lived experience as expertise

#### b) Consultation vs. Co-Design:

The current approach taken by the government appears to be more akin to consultation rather than true co-design:

- Consultation typically involves seeking feedback on pre-determined options
- Co-design involves stakeholders in creating the options themselves
- The short timeframe for feedback (initially 14 days, extended to 21 days) is indicative of consultation, not co-design
- True co-design would have involved the disability community from the outset of assessing the problems, determining alternative solutions and developing these changes. The first we, the disability sector, knew of these "in and out" rules was when we were presented with draft rules for 14 days of submissions period that is simply not co-design.

#### c) Importance of Co-Design in Disability Policy:

- Recognizes the principle of "Nothing About Us Without Us"
- Ensures policies are grounded in the lived experiences of people with disabilities
- Leads to more effective, relevant, and accepted policies
- Aligns with Australia's obligations under the UN Convention on the Rights of Persons with Disabilities
- d) Lack of Co-Design in Current Process:
  - The draft list of supports appears to have been developed without significant input from the disability community

- The consultation period is inadequate for meaningful engagement
- There's no clear process for how feedback will be incorporated into the final rules and whether additional advice will be sought and accepted.
- e) Risks of Inadequate Co-Design:
  - Policies may not reflect the real needs and experiences of NDIS participants
  - Could lead to unintended negative consequences
  - May result in reduced trust and buy-in from the disability community
  - Increases the likelihood of the changes being challenged or resisted
- f) Call for Genuine Co-Design:
  - Establish a co-design panel with significant representation from diverse NDIS participants
  - Involve this panel in reviewing and revising the proposed changes from the ground up
  - Allocate adequate time and resources for meaningful participation and iterative development

# 10. Economic Impacts and Unintended Consequences:

The proposed changes, while ostensibly aimed at improving the scheme's sustainability, may have significant negative economic impacts and unintended consequences:

#### a) Increased Reliance on Support Workers:

By limiting funding for assistive technologies and innovative solutions, participants may be forced to rely more heavily on support workers.

This could significantly increase costs for the scheme in the long run.

Example: Funding a smartwatch that allows me to navigate independently is far more cost-effective than paying for a support worker to accompany me. Funding a smart watch and accompanying smart phone is often cheaper, more flexible and more capable than funding a specialist item of disability technology. If you don't fund more mainstream technology then you will have to fund the more expensive and less flexible specialist equipment.

- b) Potential Job Losses:
  - Restrictions on employment supports could lead to job losses among NDIS participants
  - This would not only impact individuals but could increase reliance on other government supports
- c) Impact on Disability Services Sector:
  - Changes could lead to a contraction in the diversity of services available
  - Smaller, specialized providers may struggle, reducing choice for participants

#### d) Increased Administrative Burden:

- The more prescriptive approach could lead to increased appeals and reviews
- This would increase administrative costs for the NDIA and stress for participants

#### e) Potential for Cost-Shifting:

Limiting NDIS supports could lead to increased costs in other areas such as healthcare, mental health services, and social services.

#### f) Impact on Regional Economies:

In rural and regional areas like Cairns, the NDIS has been a significant economic driver. Restricting supports could have broader economic impacts on these communities.

#### g) Increased Healthcare Costs:

- By excluding items like menstrual products or certain personal care services, there's a risk of increased healthcare costs due to potential hygiene issues or health complications
- This could lead to cost-shifting from the NDIS to the healthcare system

#### h) False Economy of Restrictive Lists:

As noted by George Taleporos and Di Winkler in The Conversation,

"banning mainstream items and services may lead to poorer outcomes, not just for the person with disability but for the sustainability of the NDIS".[4]

They provide examples where seemingly everyday items can be more cost-effective and beneficial than traditional disability supports:

- Using a local hairdresser for hair washing could be cheaper and more dignified than employing a support worker
- Subsidizing rent in a home share arrangement can enable a person to remain in their own home and reduce reliance on paid support
- A robotic vacuum or Thermomix can increase independence and safety compared to traditional cleaning or cooking support services

These examples illustrate how a rigid list of supports could inadvertently increase costs and reduce effectiveness, contradicting the goal of improving scheme sustainability.

# 11. Gardening Assistance:

The proposed list of NDIS supports fails to adequately address the importance of gardening assistance for many participants. This oversight could significantly impact the quality of life and independence of many individuals with disabilities.

#### a) Essential Home Maintenance:

For many participants, particularly those with physical disabilities or visual impairments, gardening is an essential aspect of home maintenance.

Neglecting garden maintenance can lead to safety hazards, such as overgrown paths increasing fall risks. For myself in **section** it can lead to snakes and many other dangerous animals and insects. I also need to ensure that certain seeds, seed pods and other branches and fronds from tropical plants are picked up regularly and constantly as they are either dangerous or deadly to my guide dog.

# b) Mental Health and Wellbeing:

Gardening has well-documented mental health benefits, including stress reduction and improved mood.

For participants with mental health conditions, access to a well-maintained garden can be a crucial part of their support plan.

# c) Community Inclusion:

A well-maintained garden helps participants feel part of their community and reduces stigma associated with visible neglect of property.

#### d) Independence and Skill Development:

With appropriate support, gardening can be an opportunity for participants to develop new skills and increase independence.

Adaptive gardening techniques and tools can make this activity accessible to many participants.

#### e) Cost-Effective Support:

Regular garden maintenance can prevent more costly interventions later, such as major clearance operations or repairs to property damaged by overgrown vegetation.

#### f) Inconsistency in Current Proposal:

While the draft list includes "house or yard maintenance" under household tasks, it's unclear whether this extends to regular gardening assistance.

This ambiguity could lead to inconsistent application and denial of necessary supports.

The NDIS should recognize gardening assistance as a valid support for many participants, considering individual circumstances and the multiple benefits it can provide.

# 12. Holidays and Accommodation:

The proposed exclusion of holiday-related expenses from NDIS funding fails to recognize the crucial role that travel and holidays can play in the lives of people with disabilities. This oversight could significantly limit participants' quality of life, community participation, and overall wellbeing.

#### a) Importance of Travel for People with Disabilities:

Travel can be a vital part of personal development, relaxation, and social inclusion for people with disabilities, just as it is for the general population.

For many participants, holidays provide opportunities for new experiences and challenges that contribute to personal growth and independence.

### b) Additional Costs of Accessible Travel:

People with disabilities often face significantly higher costs when traveling due to the need for accessible accommodation, specialized equipment, or additional support staff.

I need to stay places that offer suitable facilities for my guide dog or cater to my blindness. E.g. access to grass for dog toileting and a hotel room with accessible controls and facilities. A newish Novotel in Brisbane has room controls, light switches, aircon controls, curtain and blind controls etc that are all non-talking/non-accessible touch screen controlled.

I may need to hire a larger than otherwise hire vehicle to fit my guide dog. This means sometimes that my accommodation and travel is more expensive due to my disability.

These additional costs can make holidays prohibitively expensive without NDIS support.

### c) Accessible Cruises as an Example:

The article "I'd given up on going abroad. But this accessible cruise changed everything" by Melanie Reid in The Times [1] provides a powerful example of how specialized travel support can be transformative for people with disabilities.

Reid describes how a cruise, with appropriate support and accommodations, allowed her to travel internationally for the first time in a decade.

The article highlights how seemingly simple supports, like assistance with transfers or accessible shore excursions, can make travel possible for people with significant disabilities.

#### d) Benefits of Supported Holidays:

- Supported holidays can provide respite for both participants and their regular carers.
- They offer opportunities for participants to develop new skills, increase confidence, and expand their social networks.
- For some participants, holidays may be the only opportunity to access certain experiences or environments that contribute to their overall wellbeing.

# e) Inconsistency with NDIS Goals:

The exclusion of holiday-related expenses seems inconsistent with the NDIS's goals of promoting independence, community participation, and social inclusion.

It fails to recognize that for many participants, the ability to travel is an essential part of living an ordinary life.

### f) Potential for Cost-Effective Solutions:

With appropriate planning and support, holidays can be a cost-effective way to achieve multiple goals within a participant's plan.

For example, a supported holiday might combine elements of community participation, skill development, and respite care.

### g) Need for Flexible Approach:

Rather than a blanket exclusion, the NDIS should consider holiday-related expenses on a case-by-case basis.

Funding could be considered for additional disability-related costs of travel, rather than covering the entire cost of a holiday.

The NDIS should recognise that for many participants, the ability to travel and take holidays is not a luxury but an essential part of living a full and inclusive life. A more nuanced approach that considers individual circumstances and the potential benefits of travel would be more in line with the scheme's overall goals.

[1] Reid, M. (2024, July 27). I'd given up on going abroad. But this accessible cruise changed everything. The Times. Retrieved from

https://www.thetimes.com/travel/inspiration/cruises/norway-disability-travel-mobilityadvice-

qp8d5hwct?utm\_source=accessinformationnews&utm\_medium=newsletter&utm\_ca mpaign=08052024&utm\_term=editorial

# 13. Wedding, Honeymoon, and Special Events:

The blanket exclusion of supports for weddings, honeymoons, and other special events in the proposed NDIS supports list fails to consider the individual needs of participants and the additional disability-related costs associated with these significant life events. This exclusion could severely limit participants' ability to fully engage in these important social and cultural experiences.

For many participants, attending or hosting such events may require additional supports directly related to their disability. These could include:

- Hiring additional support workers to assist with personal care or communication during the event
- Paying higher rates for support workers during public holidays or nighttime hours when many of these events occur
- Covering additional travel costs for support workers or assistive equipment

• Renting or purchasing specialized equipment to ensure accessibility at venues that may not be fully accessible

Furthermore, some participants may require one-off specialized supports to fully participate in these events. For example, a participant with a mobility impairment might need to hire a portable ramp or lift to access a historic wedding venue that lacks permanent accessibility features.

The blanket ban on these supports fails to recognize the importance of these life events and the right of people with disabilities to participate fully in them. It also disregards the fact that the need for these supports is directly related to the participant's disability and would not be incurred by someone without a disability attending the same event.

A more nuanced, case-by-case approach would be more appropriate, allowing for consideration of individual circumstances and needs. This would align with the NDIS's goal of promoting social inclusion and enabling participants to live an ordinary life.

# 14. Respite:

A general definition of respite is required. I think it would be a good idea to define what respite is and what is not respite.

All of the media hype around expensive holidays has actually related to paying for supports described as respite but seen as a pure holiday. A blanket ban on paying for holidays as currently attempted does not stop the abuse of respite and in fact punishes everyone else for an unwarranted ban on holidays.

# 15. Social Media Production Exclusion:

The proposed blanket exclusion of support for social media production is particularly concerning and fails to recognize the crucial role that social media plays in modern communication, social interaction, and even employment opportunities. This exclusion disproportionately affects participants with certain disabilities who may require specialized assistance to engage effectively with social media platforms.

As a blind person, I can attest to the challenges of using social media without appropriate support. Even with the best available assistive technology (AT), many aspects of social media remain inaccessible. For instance:

- Many social media websites have interfaces that are not fully compatible with screen readers
- Creating and editing visual content such as images and graphics is extremely challenging, if not impossible, without sighted assistance

• Navigating complex platform layouts and interpreting visual feedback (such as reaction emojis or image-based memes) often requires specialized support

In my case, the use of a support assistant for social media tasks has been deemed reasonable and necessary through an external review process. This support enables me to participate fully in online communities, maintain social connections, conduct my self-employment promotional tasks and even pursue professional opportunities that increasingly rely on social media presence. It is essential to me being an employee or running my own business and is a disability support.

The blanket exclusion of social media production support fails to recognize these disability-specific challenges. It could potentially isolate participants from important social and professional networks, hindering their ability to fully participate in modern society.

Moreover, for many participants, especially those with communication-related disabilities, social media can be a crucial tool for self-advocacy and community engagement. Denying support in this area could significantly impact their ability to have their voices heard and to connect with peers and support networks.

Instead of a blanket exclusion, the NDIS should consider social media support on a case-by-case basis, recognizing its importance in today's digital world and the specific challenges it may pose for participants with different disabilities. This approach would be more in line with the NDIS's goals of promoting independence, community participation, and social inclusion in all aspects of modern life.

# 16. Pet Expenses:, Transport etc

In the following section:

Pet Related:

- Animals (other than approved NDIS funded assistance animals),
- pet food for animals other than for approved NDIS assistance animals,
- veterinarian costs, pet boarding, pet grooming, taxidermy, pet cremations/funeral

you have failed to mention an exemption for assistance animals with the final item related to vets, boarding etc but have such an exemption for the previous items. I presume this is an oversight.

Regarding transport costs for pets and companion animals, for clarity this clause should have a note added to say except in relation to assistance animals.

# 17. Employment Supports and the JobAccess Scheme:

The proposed exclusion of "work-specific support related to recruitment processes, work arrangements or the working environment" from NDIS funding is deeply problematic and fails to consider the limitations of existing employment support schemes such as JobAccess.

This exclusion was the subject of my personal Administrative Appeals Tribunal (AAT) and external review process, highlighting its significant impact on participants' ability to access and maintain employment.

The Minister appears to be attempting to shift responsibility for employment supports to other schemes, primarily JobAccess. However, this approach fails to recognize the limitations of these alternative programs:

#### a) Limited Scope

JobAccess, while valuable, has a relatively small budget and primarily focuses on providing assistive technology and limited environmental modifications for disabled employees.

#### b) Support Caps:

JobAccess imposes caps on support for each individual, which may be insufficient for those with more complex needs.

#### c) No Ongoing Support:

Crucially, JobAccess does not fund ongoing costs such as workplace assistants, which are essential for many NDIS participants to maintain employment.

#### d) Theoretical vs. Actual Funding:

The exclusion in the NDIS draft list appears to be based on what JobAccess theoretically covers, rather than what it actually funds in practice.

As part of my AAT case and the External Review I produced evidence from JobAccess that they would not fund the supports I needed for my self-employment on an ongoing basis. They assisted with a range of AT but required that some of the AT be purchased by NDIS and all ongoing supports be covered by my NDIS plan and budget.

#### e) Appeal Process:

Requiring participants to go through appeals with JobAccess before accessing NDIS support creates an additional barrier to employment.

The NDIS exclusion should be narrowly tailored to only cover items that are actually funded by JobAccess, not those that are theoretically covered. Furthermore, participants should not be required to exhaust JobAccess appeals before accessing NDIS support for employment-related needs. All other employment supports should continue to be covered by the NDIS, as is currently the case.

This approach ensures that participants receive comprehensive support to access and maintain employment, aligning with the NDIS's goal of promoting economic participation and independence.

# 18. Specialist vs. Mainstream Equipment:

The draft list's focus on "specialist equipment" or "specialist" supports is misguided and potentially counterproductive. The emphasis should be on the purpose of the item and the need it fulfills, rather than whether it is classified as "specialist" or not.

Specialist disability equipment is often more expensive and may not always incorporate the latest technological advancements compared to mainstream or widely available items. This focus on "specialist" items could lead to increased costs for the NDIS and reduced effectiveness of supports for participants.

For example, as a blind participant, I can use a combination of a smartphone and smartwatch as a personal GPS, note-taker, and for various other tasks that might traditionally be performed by specialist disability equipment. These mainstream devices often provide more functionality, are more portable, and are less expensive than their "specialist" counterparts.

The NDIS should prioritize the functionality and effectiveness of supports, rather than their classification as "specialist" or "mainstream." This approach would:

- Promote cost-effectiveness by allowing the use of cheaper, mainstream alternatives where appropriate.
- Encourage innovation in support provision.
- Provide participants with more flexibility in choosing supports that best meet their needs.
- Reduce stigma by allowing participants to use the same devices and tools as their non-disabled peers where possible.

By focusing on the purpose and effectiveness of supports rather than their classification, the NDIS can better meet participants' needs while potentially reducing costs.

# 19. Transport Within Work Activities:

The proposed exclusion of transport costs within work activities from NDIS funding is overly broad and fails to consider the complex realities of workplace accommodations. While anti-discrimination legislation requires employers to make reasonable adjustments, including potentially covering transport costs, the practical application of these requirements is often more nuanced.

The exclusion should be modified to only exclude transport costs that are actually covered by an employer, rather than those theoretically required. This modification is necessary for several reasons:

#### a) Employer Exemptions:

Even under stringent anti-discrimination legislation, employers may be exempt from providing certain accommodations due to financial hardship. This could leave participants without necessary transport support.

#### b) Varying Interpretations:

What constitutes a "reasonable" adjustment can vary widely and may be subject to negotiation or dispute.

#### c) Self-Employment Considerations:

For self-employed participants or those running small businesses, the distinction between employer and employee is blurred, making this exclusion particularly problematic.

#### d) Changing Work Environments:

Modern work often involves changing locations or remote work, which may not be adequately covered by traditional employer-provided transport accommodations.

A more appropriate approach would be to allow NDIS participants to use their funding for any transport costs related to work activities that are not, in fact, covered by their employer. This ensures that participants are not left without crucial support due to gaps between NDIS funding and employer-provided accommodations.

This nuanced approach would better support participants in accessing and maintaining employment, aligning with the NDIS's goals of promoting economic participation and independence. It would also recognize the diverse and often complex nature of modern

work environments and the varying capacities of employers to provide comprehensive transport support.

# 20. Disability-Related Health Supports:

The proposed changes to the NDIS supports list raise significant concerns regarding disability-related health supports.

While the draft list includes a category for "Disability-Related Health Supports," the definition and scope of these supports require careful examination and expansion.

# a) Importance of Disability-Related Health Supports:

Many NDIS participants have complex health needs that are directly related to their disability.

These needs often fall into a grey area between the healthcare system and disability support, requiring a nuanced approach to ensure comprehensive care.

### b) Current Definition in the Draft List:

The draft list defines disability-related health supports as those "where the supports are a regular part of the participant's daily life, and result from the participant's disability."

It includes examples such as continence, dysphagia, respiratory, nutrition, diabetic management, epilepsy, podiatry and foot care, and wound and pressure care supports.

#### c) Concerns with the Current Approach:

Overly Restrictive Definition:

- The requirement for supports to be a "regular part of the participant's daily life" may exclude crucial but intermittent health needs.
- This could disadvantage participants with episodic conditions or those requiring specialized but infrequent interventions.

Lack of Clarity on Boundaries with Healthcare System:

- The draft list doesn't adequately address the often blurred lines between disability-related health supports and general healthcare.
- This ambiguity could lead to gaps in support or disputes over funding responsibilities.

Potential for Inconsistent Application:

• Without clearer guidelines, there's a risk of inconsistent decision-making about what constitutes a disability-related health support.

Exclusion of Preventative Supports:

• The current definition may not adequately cover preventative health measures that are crucial for many participants with complex health needs.

#### Mental Health Considerations:

- The draft list doesn't explicitly address mental health supports that may be directly related to a participant's disability.
- d) Potential Negative Impacts:
  - Participants may be left without crucial health supports if they fall outside the narrow definition.
  - There's a risk of increased hospitalizations or health complications if appropriate disability-related health supports are not provided.
  - The financial burden on participants could increase if they need to self-fund supports that fall into grey areas.

#### e) Case Study - Personal Experience:

As a blind person, I require regular podiatry services to maintain foot health, as I cannot visually inspect my feet for potential issues.

Under the proposed definition, it's unclear whether these services would be considered a disability-related health support or excluded as a general health service. This ambiguity could lead to the denial of a crucial preventative health measure directly related to my disability.

#### f) Recommendations for Improvement:

- Broaden the Definition: Expand the definition to include supports that may not be daily but are nonetheless crucial for managing disability-related health needs.
- Clarify Boundaries: Provide clearer guidelines on how to determine whether a health support is disability-related or falls under general healthcare.
- Include Preventative Measures: Explicitly include preventative health supports that are directly related to a participant's disability.
- Address Mental Health: Clearly include mental health supports that are related to a participant's disability.

- Flexible Approach: Implement a more flexible, case-by-case approach to determining disability-related health supports, considering the unique needs of each participant.
- Collaboration with Health System: Develop clearer protocols for collaboration between the NDIS and the healthcare system to ensure comprehensive care without gaps or duplication.
- g) Importance of Co-Design:
  - The complexity of disability-related health supports underscores the need for genuine co-design with the disability community in developing these definitions and guidelines.
  - People with lived experience of managing complex health needs alongside their disability are best placed to inform effective policy in this area.

In conclusion, while the inclusion of disability-related health supports in the draft list is positive, the current approach is too narrow and lacks the necessary nuance to meet the diverse and complex health needs of NDIS participants. A more comprehensive, flexible, and clearly defined approach to disability-related health supports is crucial to ensure that participants receive the full range of supports they need to manage their health effectively and maintain their quality of life.

# 21. Alternatives and Suggestions for Improvement:

Instead of the proposed restrictive list approach, we suggest the following alternatives and improvements:

- a) Genuine Co-Design Process:
  - Establish a co-design panel with significant representation from diverse NDIS participants
  - Involve this panel in reviewing and revising the proposed changes from the ground up
  - Allocate adequate time and resources for meaningful participation and iterative development

Disabled people are the experts in their own lives and have far more lived expertise than the DSS and combined with wider disability sector and individual involvement may well lead to ideas that have simply not even been thought of yet.

#### b) Flexible, Principle-Based Approach:

- Instead of a prescriptive list of supports, develop a set of guiding principles for determining reasonable and necessary supports
- These principles should emphasize individual needs, promoting independence, and cost-effectiveness
- Allow for case-by-case assessment based on these principles

This can be considered as akin to the Australian Taxation Office (ATO) with its system of private rulings, public rulings, draft rulings, draft, private and public determinations, test cases, taxpayer advice panels etc.

Essentially the NDIA, DSS and the Minister need to be far more transparent in relation to the decision making process and develop extensive guidance and advice like the ATO rather than hoping to solve everything with some "in and out" lists. Tax law has some absolute prohibitions but many more examples of discretion and sometimes permitted deductions.

A well known example is that self-education expenses and conferences/travel are neither completely permitted or prohibited but rather they are sometimes deductible depending on a very wide range of individual circumstances and there are numerous rulings and determinations that must be considered to decide on the application to an individual taxpayer. The ATO manages to administer a very complex system fairly but allowing individual discretion and regard to individual circumstances and this is what the NDIS should aspire to.

#### c) Improve Assessment Processes:

- Develop more comprehensive, holistic assessment tools that consider the full context of a participant's life and needs
- Ensure assessors have relevant expertise and understanding of different disabilities

#### d) Enhance Decision-Making Transparency:

- Provide clear, accessible explanations for all support decisions
- Establish a readily accessible appeals process for participants who disagree with decisions
- e) Invest in Innovation:
  - Create incentives for the development of cost-effective, innovative supports and technologies

- Establish a process for rapidly assessing and approving new supports as they become available. In doing so do not require every individual to apply and appeal for every new type of support but make public decisions that apply to everyone or a large class of participants.
- f) Strengthen Capacity Building:
  - Increase focus on capacity building supports that enhance participants' independence over time
  - Develop clearer pathways for reducing support needs as capacity increases
- g) Improve Rural and Regional Access:
  - Develop specific strategies to address the unique challenges faced by participants in rural and regional areas
  - This could include more flexible use of local services and innovative delivery models
- h) Reconsider Exclusions:
  - Review the list of excluded items, particularly those classified as "lifestyle related," to ensure essential items are not inadvertently excluded
  - Consider the diverse needs of participants and how seemingly routine items or services may be essential for some individuals with disabilities
- i) Flexible Approach to Therapies:
  - Instead of blanket exclusions on alternative therapies, consider an evidencebased approach that allows for therapies with proven benefits
  - For example, hippotherapy (horse-riding therapy) has shown benefits for some conditions and should not be automatically excluded
- j) Recognize Disability-Specific Counselling Needs:
  - Reconsider the exclusion of marriage and relationship counselling, recognizing that disability-specific counselling may be necessary in some circumstances, such as adjusting to a newly acquired disability. A participant may very well benefit from psychology or counselling to assist them or their spouse or children to adapt, develop strategies etc to cope with their disability. A relationship may be adversely impacted by the onset of disability and the counselling would relate to disability assistance.

- k) Improve Consistency in Rules:
  - Conduct a thorough review of the proposed rules to identify and resolve inconsistencies
  - Implement an overriding principle that if a support is allowed in one section, it should not be prohibited elsewhere in the rules

#### *l)* Adopt a Broad Definition with Limited Exclusions:

As suggested by Taleporos and Winkler,

"A better approach would be to broadly define what may constitute a disability-related support, and then have an 'out' list of supports that are illegal, harmful or not beneficial" [4].

This approach would maintain flexibility while still providing clear boundaries.

m) Regular Review and Update:

- Establish a mechanism for regular review and update of the rules to account for changing needs and technologies
- Ensure ongoing consultation and co-design with the disability community in this process

#### n) Robust Exceptions Process:

- Develop a more comprehensive and accessible exceptions process that allows for consideration of individual circumstances
- Ensure this process is not overly burdensome for participants or the NDIA
- It should not always be necessary to show that a support is cheaper but is just an alternative that achieves the same outcome and is preferred by the participant or available to the participant when the other support is not available.
- o) Clear Guidance on Interpretation:
  - Provide detailed guidance on how to interpret and apply the rules in practice
  - Ensure this guidance is developed in co-design with the disability community and is readily accessible to all stakeholders

# 22. Conclusion:

The proposed changes to the NDIS, as outlined in the draft list of supports and discussion paper, represent a concerning shift away from the scheme's original principles and goals. While the intent to clarify and streamline the NDIS is understandable, the current approach risks undermining the very foundations that have made the NDIS a transformative force in the lives of people with disabilities.

The move towards a more restrictive, defined-support model fails to recognize the diverse and evolving needs of participants. It threatens to replace the scheme's person-centred, flexible approach with a one-size-fits-all system that may leave many participants without the supports they need to live independently and participate fully in society.

As a blind NDIS participant living in regional Australia, I am particularly concerned about how these changes could impact my daily life and independence. The proposed restrictions on supports like smart devices, certain personal care services, and flexible meal options fail to consider how these seemingly ordinary items can be essential assistive tools for people with disabilities.

There is also a large number of potential conflicts with the proposed rules and my existing 3 year plan (and plans of many other participants), which was hard fought in the AAT and the NDIS External Review Process costing myself and the NDIA a lot of time and money - both on lawyers and expert witnesses such as psychologists and Occupational Therapists, blindness experts, O&M experts etc. Given there is now a discretion power to allow the use of otherwise excluded supports it would seem sensible and prudent to allow existing plans and the supports therein to continue in their current form rather than causing a lengthy, extensive and expensive re-litigation of many supports. My plan has already been determined to be reasonable and necessary in the nature and extent of supports and that should continue into the future.

The lack of genuine co-design in developing these changes is deeply troubling. The rushed consultation process and the attempt to implement significant changes through transitional rules bypass the necessary collaboration with the disability community. This approach risks implementing poorly conceived policies that could have far-reaching negative consequences.

Furthermore, the economic impacts of these changes could be significant and counterproductive. By potentially increasing reliance on support workers, limiting employment opportunities, and shifting costs to other systems, these changes may lead to greater long-term costs, both for the NDIS and for society as a whole.

It's crucial to remember that the NDIS was conceived as an investment in people with disabilities, recognizing that providing appropriate supports can lead to increased independence, community participation, and economic contribution. The proposed

changes, with their focus on short-term cost savings, risk undermining this investment approach.

Additionally you are failing to consider that many NDIS supports reduce the costs to other areas of the Government budget.

It's crucial to recognize that what may seem like a convenience to some can be an essential accommodation for others [5]. The NDIS was designed as a flexible, needsbased system, similar to an accidental damage insurance policy that covers a broad range of supports constrained only by the requirement of being reasonable and necessary. The proposed changes risk transforming it into a more restrictive, defined events policy. Such a fundamental shift in the nature of the scheme should not be implemented through transitional rules that may become de facto permanent.

The Labor Party, as the creators of the NDIS, should be wary of changes that alter the scheme's core principles. Everyone knows that accidental damage insurance policies are superior to defined event policies in their ability to meet diverse and often unpredictable needs. Similarly, the NDIS should maintain its flexibility to meet the varied and changing needs of participants.

The NDIS has the potential to continue transforming the lives of people with disabilities, promoting independence, community participation, and economic contribution. However, this potential can only be realized if the scheme remains true to its original principles of choice, control, and person-centred support.

As we navigate the challenges of ensuring the NDIS's long-term sustainability, it's vital that we don't lose sight of the scheme's core purpose. Any changes must be made in genuine partnership with the disability community, guided by the principle of "Nothing About Us Without Us."

In conclusion, I strongly urge the government to reconsider the proposed changes and instead work collaboratively with the disability community to develop reforms that enhance, rather than diminish, the NDIS's capacity to support and empower people with disabilities. The future of the NDIS, and the wellbeing of hundreds of thousands of Australians with disabilities, depends on getting this right.

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# 24. Contact Details