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Consultation on draft lists of NDIS supports

We would like to take the opportunity to provide feedback on the recently released draft list of NDIS supports.

There are several serious concerns that we seek to highlight regarding the consultation, how these items and activities were arrived at, the list itself, the implications of such an approach, as well as interactions with the broader NDIS and other disability reforms. It is our view that this list and approach cannot proceed.

About us

Advocacy for Inclusion (AFI) is an independent organisation delivering reputable national systemic advocacy informed by our experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. AFI speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

AFI operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. AFI is a declared public authority under the Human Rights Act 2004.

Inadequate and inaccessible consultation

Even with a small extension, the consultation period is completely insufficient given the scope of the changes and the number of supports being removed. The lists themselves are dense, unwieldy, complex, and with as many exceptions and 'carve-outs' as there are rules. This specific consultation aims to address the gap created by the removal of the APTOS principles from the draft Bill. However, it is unclear where this list came from, how it was developed, and who, if anyone, from the community was consulted in its development. This list is also devoid of any promises of co-design. Given the lack of clarity surrounding the development and release of this list, it is woefully inadequate to follow its release with a two-week consultation period.

We also draw attention to the late release of the plain English version of the list. This effectively gives people with intellectual disability and others who rely on these versions approximately just over a week to respond to a proposal that calls for a complete re-orientation of disability supports. It is not good enough.

The contents of the plain English version contains discrepancies, biases and misleading information. It oversimplifies the original document and introduces statements about the intention of the rules that are not present in the original document. It also oversimplifies complex support categories without acknowledging limitations or exceptions. It also omits crucial information about eligibility criteria and exceptions.

For example, on page 6, the plain English version states: 'We do not want the new rules to take away disability supports or make people leave the NDIS.' This statement is not present in the original document and introduces a bias by implying that the new rules are designed to protect current supports. This may not be the case. It is critical that such a document includes solid examples and consistent and clear disability-first language

These are arguably the biggest and most impactful changes proposed since the introduction of the scheme and they require appropriate consideration.

Readiness of State and Territory systems

Removing and restricting support types in the way that this list proposes risks pushing people onto State and Territory systems that are not ready or available. This could leave many people falling through the gaps and without the supports that they need in areas such as health, mental health, education, housing, child protection and family support services.

Since the establishment of the NDIS, states and territories have pulled back from providing some services for people with disability. The Final Report of the NDIS Review stresses the unresolved challenges that remain at the interface between the NDIS and the transport, child protection, justice, school education, hospitals, aged care and mental health systems.

The NDIS supports list is particularly damaging in the absence of a working system of foundational supports. People with disability risk being left stranded as different levels of government argue over who is responsible for specific supports.

A parallel system

This list is intended to provide a 'clear direction' and 'greater clarity' of what constitutes NDIS support. This has not been achieved. Instead, the effect of removing 'standard' items and pushing people towards more specialised supports is outdated and arcane. It also risks surrounding people with supports that are unnecessarily complicated, medicalised, stigmatising and institutional in character.

This is fundamentally the wrong approach. The NDIS Review said the government needs to give clarity to participants about how they use their funding. But an extensive list of what can and cannot be funded was not recommended. Rather, the review recommended introducing a support needs assessment for a reasonable and necessary budget that could be spent flexibly, with minimal exceptions.

In addition, the recently released NDIS Provider and Worker Registration Taskforce advice emphasised the importance of NDIS participants having control over their purchases. This is critical to a human rights-based approach and upholds the rights of people with disabilities to autonomy and self-determination set down by the United Nations.

The scheme is meant to level the playing field. It is meant to empower people with disability to live a normal life. The bottom line should always focus on whether supports are reasonable and necessary. This list is likely to become the de facto definition of NDIS support for the foreseeable future. It will change aspects of the APTOS from policy into law and allows the NDIA to say no to supports previously found reasonable and necessary by the Administrative Appeals Tribunal or Federal Court. It is a blunt instrument likely to be applied with force. This is not only reckless but dangerous and contrary to the intent of the NDIS.

This list will be a nightmare to administer and comply with and will raise the likelihood of adverse administrative outcomes – more appeals, holdups in plans and people caught up in debt recovery processes if they use a proscribed support.

Questioning support needs

This list – and especially the banned items – effectively disempowers people with disability as it calls into question their individual support needs. It displays an inherent lack of trust of participants and reflects an outdated model of disability supports. It also adds an extra and unnecessarily complex step where a NDIS participant must demonstrate that their support needs conform to a Procrustean standard, regardless of effectiveness.

Such a list is antithetical to the goal of efficient and effective expenditure. Removing standard items will result in people using specialised items which cost more. There are many examples that have been used to illustrate this point but consider everyday household items such as a robot vacuum. This standard item might grant an individual autonomy and independence by enabling them to undertake cleaning tasks in their own home as needed. Not only is this a more efficient use of NDIS funds, but it saves people from having to rely on a regular and more expensive cleaner who may only be available at set or inconvenient times. The same argument extends to visiting a hairdresser rather than requiring a more expensive and intrusive support worker to wash one's hair.

There are numerous standard items which might not seem like disability supports at first glance but have the potential to fill an individual's support needs at a much lower cost. Such items include shower chairs, voice assisted 'smart home' items such as refrigerators, lighting, temperature controls, security devices, whitegoods, and Thermomixers. These items are often crucial disability supports when used creatively and allow people with disability to live independently in the community.

Funding reasonable and necessary supports

A number of items slated for removal would meet a reasonable and necessary test. For example, the exclusion of electricity generators and batteries is problematic especially in light of changes to the energy supply market currently underway in Australia. Prolonged power outages can be life-threatening to individuals who rely on electricity dependent devices such as CPAP and ventilators and reside at home. For some people with disability, their assistive devices and equipment may be powered by electricity, thus generating greater electricity costs. To make a blanket inflexible decision to exclude such items and costs outside of peoples circumstances risks limiting and restricting people's freedom.

Various excluded items serve genuine therapeutic purposes. For example, there are instances where standard toys including trampolines, games and sports are used for therapy purposes. Gaming therapy has also been found to be an effective support for people with cognitive disability and children with cerebral palsy. Games that utilise motion-sensing technology or virtual reality are especially helpful as part of physical therapy. Certain video games can also enhance cognitive skills, including problem-solving, spatial awareness and strategic thinking.

The exclusion categories also lump together a myriad of controversial and non-controversial supports which risks tarring them with the same brush. For example, in the lifestyle related exclusions, known harmful products such as cigarettes and vapes are grouped in the same category as essential items such as menstrual products and internet services. This ultimately risks stigmatising necessary and essential products.

The exclusion of menstrual products is particularly egregious and a risk to choice, control and personal dignity. These products can also be used to manage continence and there are also many reasons why people with some disabilities might require them in greater quantities than a consumer without disabilities.

Removing batteries, generators, standard household items, recreation items, non-specialised therapy aids, employment supports and services related to sexual expression risks consigning people with disabilities to a barren wasteland of supports that don't reflect contemporary disabled lives or the innovative and adaptive ways disabled people maintain independent living. Specialist supports which themselves are disappearing under pressures stemming from problems with NDIS pricing and other factors so this is also unwise.

There are sweeping and troubling exclusions of health, support and mental health services. These include diagnostic assessments, some therapies, equipment and assistive technology related to clinical care and health related transport. In mental health we are concerned about the blanket exclusion of services delivered through hospitals and health settings or in residential settings where there are clinical staff.

The exclusion of many employment supports and workplace adaptations is also unwise and problematic. It will channel people into the highly dysfunctional disability employment provider system which has never met its targets or achieved its own outcomes set by the Commonwealth for over three decades.

There is also a great deal of confusion and ambiguity inherent in these exclusion categories. For example, there is a fine line between travel-related expenditure and necessary respite. The line between supporting physical well-being and exercise, but excluding membership in recreational clubs, is also bewildering.

The changes appear to be constructing a world where its only a disability support where it is highly bespoke, expensive, unnecessarily complicated and labelled as a specialist item regardless of actual function.

There are so many exclusions it is unclear what will be left for the NDIS to do.

The bottom line

Proposals to remove this wide range of items from being used as NDIS supports reflects an outdated model where disability supports were othering and institutional in form and character, only available from a narrow band of specialist providers and were often unpleasant, painful and unnecessarily complex or costly.

This is not the reform that the NDIS Review recommended nor one that should be prioritised in addressing scheme sustainability.

While the public narrative seeks to direct our attention to the removal of various alternative medicine items this glosses over the attempt to remove a large number of reasonable and necessary items that people need to create good lives.

The way these changes are framed show that the Federal Government and the NDIA seem to be substituting populism for good policy and confusing specialised services and activities with quality, value for money and effectiveness.

It represents a return to an earlier era when medical professionals, occupational therapists and specialists alone decided what was best for us.

Removing these items does not mean that the need for them disappears. The need simply remains unmet. The lack of any plausible path to foundational supports along with a fraying specialist sector struggling with pricing means they may never be met.

We urge you to abandon these flawed simplistic lists and instead work closely with people with disability to develop a more flexible, person-centred approach to defining reasonable and necessary supports, prior to making any further changes to the NDIS.

Any future guidance should empower participants to make choices that work for them, not restrict their options. There is still time to get this right, but it requires slowing down and listening to the disability. Please do not rush through these damaging changes.

This submission is endorsed by Women with Disabilities ACT, ACT Down Syndrome and Intellectual Disability, Imagine More and Rights & Inclusion Australia, ACT Shelter, Sam's Tower Pty Ltd and Focus ACT. Please feel free to contact me to discuss via Craig@advocacyforinclusion.org

Signed



Craig Wallace
A/g Chief Executive Officer
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