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Dear Secretary,

Re: Consultation on draft lists of NDIS supports

Thank you for the opportunity to provide feedback on the draft lists of NDIS supports that could be implemented as transitional rules under Section 10 of the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024. As an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people with disability and their families, JFA Purple Orange has a strong interest in the National Disability Insurance Scheme (NDIS) and ensuring its beneficial impacts for participants are maximised while also strengthening Scheme sustainability. We appreciate the need to improve how the Scheme operates and continue to seek to contribute constructively to the reform process. However, it is critically important that any reforms to the NDIS uphold its original intent and promise.

We strongly believe the Federal Government should rethink its approach to implementing Section 10 of the Bill. Given the legislation was introduced to Parliament without codesign or prior consultation with NDIS participants, the extent to which the Section 10 approach of mandating declared supports and exclusions was assessed against alternatives is unclear. Regardless, we strongly believe there are better approaches to operationalising Section 10 than through lists, yet no alternatives appear to have been considered and are not included in this consultation. We fear this decision has been rushed without a full consideration of the likely implications and inadvertent consequences that will arise. However, there is **still an opportunity to change course**. Section 10 refers to rules – not lists – so it remains possible for the rules to take a form other than lists that ensures necessary funding powers are clear and not subject to legal challenge. Below, we propose a **more effective approach is to apply principles** that are articulated in the rules. But, first, we address the shortcomings of the lists-based approach.

Problems with lists

The implementation of blanket lists of declared supports and exclusions on a Schemewide or class-of-participants-wide basis will prevent a consideration of what supports will

achieve the best and most cost-effective outcomes for each participant based on individual needs and circumstances. Under a lists approach, it is very likely that not only will some participants be prevented from accessing essential supports because they are excluded, but others are likely to receive supports that are on the approved list without an adequate consideration of their needs, especially when NDIA planners are under significant workload pressures. The "substitution rule" Amendment to the Bill is a highly restrictive and burdensome avenue to change a plan decision that has been put forward as a last-minute "add-on" to try to avert concerns with the lists approach. It is an inadequate cumbersome measure and, at best, will mean the lists approach works slightly less bad than it otherwise would.

Regardless, an unintended consequence of the approach is that the approved list of supports is likely to function more like a tick-and-flick checklist for NDIA staff and an order form or shopping list for some participants. Planning will become **list-centred rather than person-centred**. This will adversely impact the quality of planning decisions and, ultimately, further undermine Scheme sustainability. Critically, it will reinforce the Scheme as a transactional one and will further undermine the chances of achieving transformational benefits in participants' lives; something that is also critical for future Scheme sustainability.

Further, lists can never be exhaustive as there are a vast number of possible supports that could be sought. Therefore, there will be a need for repeated planning decisions about which list something falls under, which is likely to continue the problems of inconsistent NDIA decision-making and widespread participant confusion. For example, people with sensory disability often benefit from the use of noise cancelling headphones, but it is unclear and open to staff interpretation which draft list this item would fall under. The Federal Government could amend the list to specify where this item sits but taking that approach to addressing ambiguity will simply result in an endless process of naming more and more supports in the lists.

Additionally, history demonstrates that transitional measures are rarely just temporary; if the lists are implemented now, they will quickly become baked into the Scheme and prevent more effective reforms in the future. While Amendments to the Bill require a "statement of the proposed timeframes" for new rules and for this to be updated when it changes, this is not equivalent to a "sunset clause" that could enforce a deadline on transitional arrangements. There will be changes over time to what is on the lists, but the approach of using lists itself will become very difficult to change the longer it remains in place. Again, this reiterates the importance of giving careful consideration to how the underlying intent of Section 10 is achieved, weighing the merits of a range of options, and not rushing to a decision.

Although the Federal Government may feel cost pressures are forcing it to act with urgency, it is unclear that Section 10 changes will make any significant difference to costs given the dominant role of 'immature' NDIA systems, poor processes, and inadequate oversight of providers, in enabling fraud and wastage in the Scheme. Section 10 reforms will not address any of these problems so investing adequate time and resources in a genuine co-design approach to build an effective model would pay dividends in the long term.

Adopt a principles-based approach

We strongly argue a more effective approach to Section 10 would be to scrap the lists approach and start again with a genuine co-design process to establish a clear set of principles to direct NDIA decision making about whether a support can be a funded NDIS support or not for each individual participant. This approach would be better able to account for individual needs and circumstances, as well as questions arising from the substantial 'grey area' between the types of supports that are clearly included or excluded. These principles would be applied in the context of Section 33 of the Bill whereby a reasonable and necessary budget is set at a whole-of-Plan level. Hence, the principles would determine what choices a participant can make within the parameters of an overall budget and not in a process whereby each support approved adds to the total cost of the Plan.

It has been suggested the lists approach will provide certainty, but we believe the focus should be on **overall budget certainty** that is fair and consistent, coupled with **maximum flexibility in choices about what supports will achieve the greatest impact** in a person's life within the parameter of their overall budget and guided by principles that inform NDIA decisions about supports. We recognise that adjusting to this approach will likely result in some angst in the disability community given the expectations of funding top-ups that have been created since the establishment of the NDIS, however we believe over the long-term greater budget certainty and more support flexibility will best serve NDIS participants and their families and allies.

This will also address Scheme inflation and sustainability concerns. It will require clear safeguarding rules to protect participants and severe consequences for providers that exhaust a participant's funds unreasonably. Likewise, there needs to be provisions for changing participant circumstances. The implications of this for the NDIA in navigating reduced provider availability due to stronger accountability and consequences (such as, a sanctioned provider threatening to leave a participant at a hospital emergency department) can be mitigated through the NDIA and/or government establishing an accord or similar with the whole provider sector that sets clear standards and expectations and invests in the human resources pipeline to ensure a high-quality, well-trained workforce is created.

We have previously written about the importance of implementing a <u>simple participant</u> <u>pathway</u> with a <u>straightforward assessment process</u> that produces an indicative draft budget for a participant's overall Plan. The participant is then empowered to make choices about what supports will be most impactful for them within an overall budget guided by these clear principles of what can constitute a funded support. Effectively, participants would compare and prioritise the supports they choose for their Plan. Then, they would meet with a NDIA planner who would check these choices against the same clear principles and finalise the Plan. An evaluation at the end of a Plan would also provide a solid basis for accountability to follow the agreed Plan because it would feed into the parameters and decisions for the next Plan.

We propose each funded NDIS support adheres to one or more of the following draft principles based on fundamental Scheme values (and does not unduly negatively impact any other principle/s):

- 1. A NDIS support enhances the participant's independence and individual choice and control.
- 2. A NDIS support advances the participant into meaningful roles in mainstream community life, including increased social, economic, community, civic, and/or cultural participation, excluding introducing a participant into any new segregated or exploitative settings.
- 3. A NDIS support represents value for money in the context of the participant's Plan and is not manifestly unreasonable in the context of Scheme costs and sustainability, including endorsing a NDIS support that demonstrably offsets the need for other more expensive supports to be included in a Plan.
- 4. A NDIS support is not unlawful in Australia or in the state or territory where it will be provided; and is not demonstrably harmful to the participant or other/s to an extent greater than providing for a reasonable dignity of risk, thereby excluding, for example, alcohol, gambling, tobacco, vapes, and other recreational drugs as a NDIS support.

Given the number of participants in the Scheme, NDIA planners would quickly develop a clear set of precedents and boundaries for how to reasonably apply these principles in specific decisions based on individual needs and circumstances. These could be compiled into an accessible set of guidelines that also enhance consistency and ensure transparency in decision making. Because these principles are applied in the context of a reasonable and necessary overall budget, there is scope for planners to err on the side of participant choice and control whenever a desired support falls into a 'grey area' under the principles without this increasing the cost of the Plan or generating flow on effects for Scheme sustainability.

Below, we elaborate further on each proposed principle.

Principle 1:

A NDIS support enhances the participant's independence and individual choice and control.

Advancing individual choice and control is a foundational Scheme value and a core function of the NDIA. NDIS supports should move a person forward in their life, not backwards or maintain an unsatisfactory status quo. For example, genuine mainstream employment moves a person forward while a day program maintains an unsatisfactory status quo (and the longer a person spends in a day program the more it sets a person back from taking up valued roles in community life). Achieving independence and choice and control is very contextual and subject to the varied circumstances of each participant's life. A one-size-fits-all approach of lists will never deliver the individualised and nuanced approaches required of a social insurance mechanism such as the NDIS. This principle highlights a number of issues and clear contrasts with the proposed lists, and we address these below.

The proposed lists exclude smart watches and phones as NDIS supports despite their role in enabling independence for some participants through assistive technologies including for smart home features. For some participants, there are clear disability specific reasons to require smart devices that they, like many other Australians, would not otherwise need or have. Indeed, there are many implicit class-based and other

subjective judgements in the proposed lists of what items constitute "day-to-day living costs". We are aware that a lack of access to enabling devices is a significant barrier to providing participants with bespoke assistive technologies that increase independence through environmental control. Most smart home products rely on a smart device for set up and control of their features, such as opening and closing blinds, controlling heaters and air conditioners, and operating appliances. Without this independence, participants require more formal support worker hours to undertake these tasks.

Smart watches also make available health and safety features that are beneficial for participant safeguarding including falls alerts, emergency phone calls, medication reminders in a form suitable to the participant such as haptic or audio, health monitoring and feedback, navigation tools, accessible payment methods allowing a person to independently control their finances, fitness goal setting, and alternative methods of operating a device including through voice or gesture. The benefits of existing and emerging assistive technologies cannot be overstated. We strongly believe that smart devices should be funded in the NDIS when they enable participant independence, safety, and the operation of other assistive technologies. Often, they produce significant cost savings in reducing a participant's reliance on formal in-person supports, which is discussed further below.

Similarly, the cost of some whitegoods, such as a clothes dryer that enables a participant to dry clothes, towels, linen, and other items independently, is a far better and more costeffective investment than ongoing funding for formal support worker hours to assist with washing. This is even more so when a person has higher laundry needs because of their disability. The same applies to a dishwasher and other similar items. Again, the suggestion that items such as these are "day-to-day living costs" does not reflect the reality of appliances typically owned by Australian households, particularly those living on lower incomes or income support payments.

These examples demonstrate how a more nuanced principles-based approach to Section 10 will be more effective than blanket lists. Excluding smart devices, whitegoods, and other household items regardless of individual needs and circumstances undermines fundamental Scheme values and will generate perverse cost outcomes with more expensive options like ongoing formal support worker hours funded instead. This demonstrates the folly of attempting to cut costs through implementing one-size-fits-all lists for all NDIA decision making about approved supports.

Principle 2:

A NDIS support advances the participant into meaningful roles in mainstream community life, including increased social, economic, community, civic, and/or cultural participation, excluding introducing a participant into any new segregated or exploitative settings.

Advancing participants into meaningful valued roles in mainstream community life is another fundamental Scheme value and core function of the NDIA. Indeed, the landmark *Shut Out* report that contributed to the momentum for the creation of the NDIS reflects the deeply entrenched problem of Australians with disability being shut out of our communities and excluded from ordinary life opportunities like employment. This principle would direct NDIA decision making to addressing this for each and every participant and could ensure goals such as employment or education are in the Plans of all working age participants not already accessing these opportunities.

In contrast, the lists approach is likely to exacerbate the perennial problem of the NDIA making decisions to fund supports that do not achieve authentic participation in social and economic community life. For example, the NDIA is known to steer participants into one-to-one art therapy with a professional worker rather than into much cheaper mainstream community art classes that increase social participation because therapy is said to be a disability-related cost while community activities are regarded as everyday expenses. This occurs even where a participant requests support for in-community activities in order to develop their social connections. NDIS reforms need to address this problem to not only deliver improved outcomes for participants but to ensure decisions reflect value for money (the next principle).

When participants establish community connections and personal relationships, their wellbeing improves, informal safeguards become present in their lives, and their need for funded formal supports often reduces at least somewhat. The principles-based approach will facilitate individual case-by-case decision making that is more likely to achieve individual social and economic participation outcomes and be cheaper for the Scheme in the long term than a reliance on blanket lists. Indeed, the lists approach is likely to promote short-termism in decision making rather than long-term return-on-investment strategies.

Principle 3:

A NDIS support represents value for money in the context of the participant's Plan and is not manifestly unreasonable in the context of Scheme costs and sustainability, including endorsing a NDIS support that demonstrably offsets the need for other more expensive supports to be included in a Plan.

As noted throughout this submission, the NDIA is known to make a myriad of decisions to prevent participants accessing a range of supports that are cheaper and more effective while, instead, preferring to approve budgets for more expensive formal supports, including extra support worker hours or therapy, due to overly rigid rules. A principlesbased approach will enable the flexibility for planners to take a more adaptive and forward-thinking lens to decision-making reflecting each participant's individual needs and circumstances. On the other hand, the list approach is highly restrictive and prevents bespoke supports that are fit-for-purpose for a person. In this way, we believe arguments about consistency should focus on consistency in decision making, not consistency in supports in Plans, because each participant is unique. Indeed, the Federal Government should consider investing in an educational campaign to inform participants and the broader community that no two participants are the same and, therefore, no two Plans will ever be identical.

A further example of the lists approach failing to adhere to the principle of delivering value for money supports relates to the paying of rent, which is excluded in the proposed model. Yet, shared and hosted accommodation are a well-established approach (albeit underused within the NDIS due to apparent Scheme constraints) that may enable a reduction in funded formal support hours if a participant is allowed to pay rent contributions in exchange for semi-formal supports provided by co-residents. Such

arrangements will also enable participants to live in the community rather than in segregated or congregated settings and to establish typical neighbourhood connections. The list approach would likely continue the default NDIA position of directing participants into group homes with quasi-block-funded Supported Independent Living (SIL) supports despite the fact this does not uphold Scheme values and undermines sustainability because SIL plans cost more and often produce greater intra-plan and inter-plan inflation.

We recognise and endorse the intention in the lists to ensure NDIS supports are reliably beneficial to participants based on evidence. However, this intent can be achieved just as well or better through a principles-based approach. Likewise, we concur that supports should deliver benefits commensurate to their costs, but, again, the nuanced decision making facilitated through a principles-based approach is more likely to achieve this than blanket one-size-fits-all lists. Similarly, this proposed principle would ensure a support is provided at a reasonable cost relative to its benefits. We are not suggesting that top-of-the-range products or higher cost brands be approved over effective, reasonable, and cheaper alternatives.

Principle 4:

A NDIS support is not unlawful in Australia or in the state or territory where it will be provided; and is not demonstrably harmful to the participant or other/s to an extent greater than providing for a reasonable dignity of risk, thereby excluding, for example, alcohol, gambling, tobacco, vapes, and other recreational drugs as a NDIS support.

We also appreciate concerns that have been raised in recent debates about NDIS reforms regarding the misuse and abuse of funding on unapproved supports including illegal items. This principle would prevent that. This is also the reason we argued earlier in this submission that supports not only be required to fulfil at least one of the four principles, but also to not unduly undermine others. We support this safeguard and assert it can be achieved very effectively within a principles-based approach.

Recommendation 1: The Federal Government should not proceed with enshrining lists of declared NDIS supports and exclusions in transitional NDIS rules and, instead, adopt a clear set of principles that can be applied to decisions about valid funded supports based on individual needs and circumstances.

Other matters of concern

In addition to our core feedback on the proposed lists of declared supports and exclusions set out above, it would be remiss of us not to express our deep concern with the manner in which the Federal Government has conducted this consultation and, indeed, the broader process of legislating amendments to the NDIS Act. A two-week consultation period (extended very late to three weeks with additional elements to consider) on such an impactful element of the proposed reforms is not accessible to many people with disability – the very people who will experience the greatest impact as a result of these reforms – and does not facilitate thoughtful consideration of the proposal, or feedback that could significantly improve the effectiveness of the reforms. As it stands, we believe there is a significant risk that poorly designed reforms will

proceed and not produce their intended results, or, worse still, harm participants. Either outcome will further erode community support for the NDIS.

Many people in the disability community now express distaste at the term "co-design" because of the repeated misuse and abuse of the term to mean anything but <u>genuine</u> <u>co-design</u>. As an organisation committed to co-designing with people with disability and to promoting best practice approaches because we have firsthand experience of the immense benefits gained, we are troubled by the likely implications of the erosion of goodwill toward participating in reform processes in the disability community. Many people are exhausted from their repeated efforts to contribute yet feel unheard. These negative experiences are leading to a growing distrust of governments' intentions. We strongly urge the Federal Government to change its current approach to engaging with the disability community or risk serious flow-on consequences for the community's acceptance of reforms.

Recommendation 2: The Federal Government should urgently rethink the manner in which it is engaging with people with disability in relation to NDIS reforms (among other matters) and take immediate steps to establish genuine co-design approaches for all reforms to ensure changes to the Scheme can benefit from broad input and innovative ideas.

Thank you again for the opportunity to provide feedback to this important consultation. We are available to discuss the ideas presented in this submission further. To arrange this, please contact Mr Robbi Williams, CEO of JFA Purple Orange, on (08) 8373 8333 or <u>robbiw@purpleorange.org.au</u>.

Yours sincerely

Robbi Williams CEO JFA Purple Orange