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**Review of proposed changes to the National Disability Insurance Scheme Act 2013**

 **(NDIS Act)**

Joint submission

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**ACKNOWLEDGEMENTS**

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**EXECUTIVE SUMMARY**

People with deafblindness remain some of the most marginalised in Australia, with their complex needs frequently being poorly understood and inadequately addressed. While it is envisaged that the National Disability Insurance Scheme will to some extent address current issues experienced by people with deafblindness, unless systemic changes are made to approaches to service delivery to this group, their needs will not only not be fully addressed, but in some instances current services may diminish.

It is recognised that the proposed changes to the NDIA Act will improve the NDIS for all participants including those with deafblindness. However, providing sufficient time for people with disabilities to respond to proposed changes and accessible information about all aspects of the NDIA remain poorly addressed.

This submission makes nine recommendations with relation to the proposed legislative changes, to improve the NDIA for NDIS participants, in particular those with deafblindness.

**SUMMARY OF RECOMMENDATIONS**

**Recommendation 1.** To extend the time frame to allow for full consultation with the national deafblind community

**Recommendation 2:** To facilitate full access to information regarding these legislative changes and their implementation. Deafblind participants require face to face forums in conjunction with organisations who provide services to participants with deafblindness, to ensure each individual’s communication needs are met e.g.: tactile interpreters, visual frame interpreters, close range interpreters, captions / note takers, audio loop or chuchotage.

**Recommendation 3.** Include in the legislation that all decisions made by plan reviewers which reject proposed supports, be accompanied by a letter stating the reason for the rejection (in preferred formats). Every decision made by an NDIA reviewer must be accompanied by a statement of reasons.

**Recommendation 4**: That the NDIA cannot vary plans without consultation with or consent of the participant or their guardian, except in rare cases of urgency where the participant cannot be consulted within a reasonable time frame.

**Recommendation 5**: Any complex new changes to legislation need to be considered, integrated and delivered (in preferred formats) ongoing in consultation with participants who are deafblind and inclusive of their unique communication, access and support needs.

**Recommendation 6**: Choice and control regarding service provision/providers should remain with the participant

**Recommendation 7:** People with sensory and other disabilities must be given the same considerations as those with psychosocial disabilities. The NDIA must regard “the overall effect of the impairment or impairments over a period of time that is reasonable, considering the nature of the impairment or impairments (and in particular considering whether an impairment is episodic or fluctuates).

**Recommendation 8**: Proposed changes to the payment systems must be accessible to all participants

**Recommendation 9.** Clear articulation of how codesign processes will be implemented, particularly with NDIS participants with deafblindness.

**Introduction**

This is a joint submission from Able Australia, SensesWA and Deafblind Australia regarding the legislative reforms proposed by the NDIA. Able Australia and SensesWA are the two lead agencies providing services to Australians with deafblindness, Able Australia in Victoria, and SensesWA in Western Australia. Deafblind Australia is the peak body for people with deafblindness and those that support them in Australia.

Unfortunately, the review time frame has not allowed full consultation with the national deafblind community. This short time frame is a violation of Article 29 of the CRPD and insufficient for people with disabilities to provide feedback given the communication and accessibility issues faced daily, particularly by people with deafblindness. This short window for public feedback contradicts the government’s commitment to co-design, especially given a good proportion of the country is currently in lock down due to COVID outbreaks. There has been great frustration expressed across the disability sector with the lack of accessibility to lodge a submission, lack of clarity of the processes, rules and amendments, and lack of resources and time to review the proposed changes comprehensively. Many of the issues with this Act stem from a common source, **a lack of clear interpretation**. Without an understanding of how these changes will be **interpreted** in practice, we cannot accurately assess their impact. We feel that without full consultation this submission is not comprehensive nor inclusive of the opinions and requirements of the community we work with. The recommendations in this submission are also without the benefit of legal consultation to support understanding the implications and intricacies of all the proposed changes.

**Recommendation 1.** To extended the time frame for full consultation with the national deafblind community

**Introduction to deafblindness**

Throughout this submission, the terms deafblind, combined vision and hearing impairment and dual sensory impairment will be used interchangeably as all three are used to describe people with deafblindness. Deafblindness is described by Deafblind Australia as:

“a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation mobility and daily living.

People with deafblindness form a very diverse group due to the varying degrees of their vision and hearing impairments plus possible additional disabilities. This leads to a wide range of communication methods including speech, oral/aural communication, various forms of sign language including tactile, Deafblind fingerspelling, alternative and augmentative communication and print / braille”

“Representing between 0.2% to 2% of the population, persons with deafblindness are a very diverse yet hidden group and are, overall, more likely to be poor and unemployed, and with lower educational outcomes. Because deafblindness is less well-known and often misunderstood, people struggle to obtain the right support, and are often excluded from both development and disability programmes.”

World Federation of the Deafblind (2018)

People with deafblindness will ALL require the provision of hearing services at some stage in their lives, though services for those with the single sensory impairment often do not fully address the needs of, or remain inaccessible to people with deafblindness.

**Causes of deafblindness and prevalence**

The below background information is given regarding prevalence and causes of deafblindness to support recommendations made throughout this submission. While exact prevalence of deafblindness is not known, it was estimated that in 2013, there were 13,700 Australian’s with deafblindness under 60 years old (Dyke, 2013).

There are a number of syndromes and other causes which result in hearing impairment combined with vision impairment (deafblindness). Usher syndrome results in the combination of a hearing impairment and retinitis pigmentosa (a vision condition causing tunnel vision and night blindness). There are multiple types of Usher syndrome and those born with Usher syndrome type 1 have associated balance problems. Kimberling et al (2010) found 11% of all children diagnosed with a hearing impairment carried a gene for Usher syndrome and estimate the prevalence may be as high as one in 6,000. All individuals with Usher syndrome will fulfil the criteria for acceptance into the National Disability Insurance Scheme given they are born with a hearing impairment and have a progressive vision condition which will significantly impact on their functioning well before the age of 65 years.

CHARGE Association also results in combined vision and hearing impairment. The true incidence of CHARGE syndrome is not known, with estimates ranging from 0.1 to 1.2 in 10,000. The highest incidence of CHARGE syndrome in Canada was estimated at 1 in 8,500 in provinces with a research interest in CHARGE syndrome, so the true incidence of CHARGE syndrome reported internationally may therefore be underestimated. (Blake and Prasad, 2006)

Research has shown that prevalence of deafblindness in adults with an intellectual disability is 5% which is considerably higher than the rest of the population (MeuweseJongejeugd et al., 2008). It is important to note this figure does not include children so the number will be higher across the whole population of individuals with a developmental or intellectual disability who are eligible to participate in the National Disability Insurance Scheme. The prevalence of hearing impairment is at least 40 times higher in people with intellectual disability compared with the general population (Carvill, 2001). However, vision and hearing impairments are frequently inadequately diagnosed and poorly addressed in people with intellectual disabilities (Kiani and Miller, 2010).

The prevalence of deaf-blindness is about 1 in 10000 school-age children in the UK (Kiana and Miller, 2010).

Norrie disease is an inherited eye disorder resulting in blindness in male infants at birth or soon after birth. Additional symptoms occur in some cases, however this varies from case to case. Most individuals with Norrie disease develop sensorineural hearing loss and many exhibit cognitive abnormalities such as developmental delay, and behavioral issues including psychotic-like behaviours. Treatment focuses on the specific symptoms present in each individual. The coordinated efforts of a team of specialists, including pediatricians, ophthalmologists, and audiologists are typically needed. Early intervention and special education services are important to ensure that children with Norrie disease reach their full potential. (National Centre for Advancing Translational Sciences, 2016)

**Feedback on review of proposed changes to the National Disability Insurance Scheme Act 2013 (NDIS Act)**

**Schedule 1 – Participant Service Guarantee**

The NDIA will have more flexibility to make quick changes to plans, through a plan variation, without needing to go through a full plan review. This will make it easier and faster for participants to get their NDIS supports. It will be particularly helpful when a quote for assistive technology is received, and will mean the quote will not result in a full plan review.

It also sets out that the new Participant Service Guarantee Rule can include timeframes for processes in relation to the development of plans, and timeframes for processes in relation to plans.

It enables a person affected by a reviewable decision to request the CEO or their delegate to give the person reasons for the decision and the ability for participants to ask to see their **draft plan** before it is approved.

Together these amendments if appropriately implemented will substantially improve the experience of current and prospective participants.

**Recommendation 2:** To facilitate full access to information regarding these legislative changes and their implementation. Deafblind participants require face to face forums in conjunction with organisations who provide services to participants with deafblindness, to ensure each individual’s communication needs are met e.g.: tactile interpreters, visual frame interpreters, close range interpreters, captions / note takers, audio loop or chuchotage.

**Recommendation 3.**  Include in the legislation that all decisions made by plan reviewers which reject proposed supports, be accompanied by a letter stating the reason for the rejection (in preferred formats). Every decision made by an NDIA reviewer must be accompanied by a statement of reasons.

 It is very positive to see timeframes for making decisions being given legislative backing . The Guarantee also includes subjective standards for the NDIA’s interactions with participants, including increased transparency, responsiveness, respect, empowerment of participants and connectedness. While these reforms are welcome, it is unclear how the Agency going to be held accountable to these principles.

Streamlining processes with provision of draft plans, which we have been requesting for many years, fast tracking the review process and assistive tech applications not automatically triggering reviews, again are very positive outcomes. The unique support needs of the deafblind community are frequently misunderstood and not appropriately accommodated in planning meetings requiring frequent requests to review despite significant supporting evidence. Deafblind participants often fall through the cracks. Issue is often related to the knowledge base of LACs and planners and decisions being made on the support needs of people who are deafblind without full understanding or acknowledgement of this unique cohort. This links firmly back to the NDIA’s interactions with participants being: transparent, responsive, respectful, empowering and connecting participants

Finally, proposed s 100(1B) and (1C) of the Act allows participants to request reasons for decisions made by the NDIA, prior to any internal review application. This is a welcome change, as it can empower individuals to understand decisions made about them at the initial stage – for example, initial decisions about access or participant plans.

However, we suggest this could be improved in two ways. First, the provision of reasons should not be on request by the participant. It should be given automatically, as a matter of course, for all participants when a decision is made about them. This is consistent with the Tune Review, which said (at [3.59]):

‘Providing people with disability with an explanation of a decision should be a routine operational process for the NDIA when making access, planning and plan review decisions. However, in the event this does not occur, the Participant Service Guarantee should empower the person with disability to require the NDIA provide this information in a manner that is accessible to them”.

This is important as it will enable all participants to receive reasons for decisions made about them, not just those who are willing or able to go through the further process of making a request.

Second, there is no corresponding requirement for reasons to be provided once a review of the reviewable decision has been made under s 100(6). In practice, we understand that reasons are often – but not always provided in relation to internal reviews.

We consider that a provision should be inserted to make this a legislated requirement. That is, every decision made by an NDIA reviewer must be accompanied by a statement of reasons. Again, this is consistent with the intentions of the Tune recommendation, and with good administrative decision-making principles. [Public Interest Advocacy Centre (piac.asn.au)](https://piac.asn.au/)

Schedule 1 gives effect to key findings of the Tune Review in Chapter 8 to improve plan reviews and enable plans to be amended without requiring a full plan review in circumstances where it is clear that the support or change to be made is reasonable and necessary. Plan reviews will be renamed as reassessments of a participant’s plan to prevent confusion with decision reviews where a participant seeks a review of a planning decision under section 99 of the Act. Further, Schedule 1 introduces the new ability to vary existing plans without reassessing and replacing the plan. Under the proposed legislation, there would be 3 concepts: *plan variation*, *plan reassessment*and *plan review*. A plan variation edits an existing plan without creating a new one. A plan reassessment is an end of plan review. A review is a review of a decision in dispute. These changes are in response to the Tune Review recommendation that acknowledged that people can’t make small changes to their plans without triggering a whole review.

There is no clear criteria for deciding when a plan will be varied, reassessed, reviewed or have no action taken. In the Plan Administration Rules, the following are set as things to be considered when deciding whether to vary a plan:

* *whether the variation is minor or technical;*
* *if the variation is to add a particular support to the statement of participant supports included in the participant’s plan—both of the following:*
	+ *how that support is to be delivered to the participant;*
	+ *the cost of that support;*
* *whether the variation is of the reassessment date of the participant’s plan;*
* *whether the variation is to how a particular support covered by the statement of participant supports included in the participant’s plan is to be delivered to the participant;*
* *whether the variation relates to the cost of a particular support covered by the statement of participant supports included in the participant’s plan;*
* *whether the variation relates to compensation received, or to be received, by the participant;*
* *whether the variation relates to the management of any aspect of the participant’s plan, including the funding for supports under the plan;*
* *whether the variation increases the total funding for supports under the participant’s plan;*
* *whether the variation mitigates an immediate risk of harm to the participant or another person.*

While some of these answers lead to obvious outcomes, for others it is not clear what response would warrant a review as opposed to a variation. In summary: it is not clear how this change will be implemented nor how this will be communicated to participants. This issue has caused extreme distress for so many participants and the changes will go a long way to address these issues but there needs to be further transparency surrounding the communication as to how these processes will be implemented.

Plans can be varied or reviewed at the initiative of the NDIA or the participant. This has been a source of concern for many people who do not feel comfortable with the Agency just deciding to vary their plan or particularly those who do not have full access to information regarding these processes. There remains a risk that these changes will be made without their knowledge. Under the current Act, the NDIA does have the power to review a plan on their own initiative. People who are deafblind often do not have appropriate supports to ensure full access and understanding of how the processes will work, what their rights are and how decisions and changes will impact them. To address these concerns, we need more detail on what the process of variation will look like and what checks are in place to ensure a person centred approach and full access to information is achieved. The decision to vary a plan will be reviewable, meaning there is some inbuilt accountability. However, without clear criteria for the circumstances that warrant a plan variation, participants risk being left out of the process and we can expect an influx of frustrating, unnecessary delays and complex AAT cases. If not addressed some of these key changes could lead to misinterpretation or unintended consequences. There is no reason why the NDIA should be able to vary plans without consultation or consent by the participant, except in rare cases of urgency where the participant cannot be consulted within a reasonable time frame**.**

**Recommendation 4**: That the NDIA cannot vary plans without consultation with or consent of the participant or their guardian, except in rare cases of urgency where the participant cannot be consulted within a reasonable time frame.

**Recommendation 5**: Any complex new changes to legislation need to be considered, integrated and delivered (in preferred formats ) ongoing in consultation with participants who are deafblind and inclusive of their unique communication, access and support needs.

**Recommendation 6**: Choice and control regarding service provision/providers should remain with the participant

**Schedule 2 – Flexibility Measures**

**Implications for deafblind**

Changes to the ‘Becoming a Participant Rules’ include new requirements for determining whether a person has a ‘permanent’ impairment or ‘substantially reduced functional capacity’ for the purposes of accessing the NDIS. The clarification of what these phrases mean is welcome. A longstanding issue has been fitting people with psychosocial disabilities into the language of ‘permanence’, especially when it comes to episodic or fluctuating impairments. While the language of ‘permanence’ remains, the clarification around what this means for psychosocial disabilities is helpful. However, people with disability and advocates should consider the new requirements carefully.

Rule 8 of the ‘Becoming a Participant Rules’ requires that, ‘to access the NDIS, a person must be undergoing or have undergone ‘appropriate treatment’ for the purposes of ‘managing’ their condition, and that the treatment has not led to a ‘substantial improvement’ in their functional capacity after a reasonable period of time. Alternatively, there must be no ‘appropriate treatment’ ‘reasonably available’ to the person.’ These terms in inverted commas are not defined.

In practice, it will be the CEO and delegate considering in each instance what ‘appropriate treatment’, ‘managing’ a condition, ‘substantial improvement’ and ‘reasonably available’ means. There is a risk that the capacity of delegates to make accurate and appropriate decisions will be inadequate when working with complex populations such as those with deafblindness.

It would assist if the Rules provided guidance on these terms, especially given the highly personal decisions involved in medical treatment, and the subjective nature of these thresholds. ‘Appropriate treatment’ for instance, should take into account matters like a participant’s risk appetite for treatments and personal choices over medical procedures. Cultural influences also need to be considered particularly within the deafblind community, given many belong to the Deaf community. ‘Substantial improvement’ should include objective assessments of a person’s functional capacity. The absence of these considerations would reduce a person’s choice and control over their own health.

Similar considerations apply in rule 9(2) (b) of the Rules, which relates to non-psychosocial disabilities. This rule requires that there are no ‘known, available and appropriate evidence-based clinical, medical or other treatments’ that would be likely to lead to a person’s impairment no longer resulting in substantially reduced functional capacity. Again, the term ‘appropriate’ is vague and should include respect for bodily autonomy and cultural influences. ‘Other treatment’ is also vague. What non-clinical, non-medical treatment should a participant be required to undergo? Should those treatments in any case be funded under the NDIS, for example, capacity building supports? [Public Interest Advocacy Centre (piac.asn.au)](https://piac.asn.au/)

The ability of participants to access their funded supports will be improved, as Schedule 2 will enable the NDIA CEO to provide funding outside of a plan for the purpose of enabling a participant to access the supports in their plan (*recommendation 17*), and to provide funding to service providers for children under the age of seven in order to meet their disability needs before the plan is approved (*recommendation 13*), furthering the NDIS principle of effective early intervention. It is unclear how this will be implemented.

The proposed amended Plan Management Rules would stipulate that the NDIA has the power to prevent a particular provider delivering a support to a participant. Currently, the Agency can direct a support to be delivered “by a particular person or through a particular delivery mode.” However, this new power would go beyond deciding who *will* provide a support to specifying particular providers who *cannot.*There is a long list of things the NDIA must consider before prohibiting a provider in a plan, the essence of it being that they can use this power if there is a risk to the wellbeing of the participant, particularly if using a provider might limit the person’s choice and control with other supports or community inclusion. Concerns have been flagged when participants only have a limited number of providers they can access who can support specialised needs, generic providers are not appropriate in these instances. People with deafblindness require services and supports from those with whom they can communicate, which is often limited particularly for those who are Auslan users.

In the new proposed ‘Becoming a Participant Rule’, the legislative definitions of permanency and significantly reduced functional capacity are separated for people with or without psychosocial disability. If a person has a psychosocial disability, it may be considered permanent if they have

• undergone appropriate treatment that has not led to substantial improvement over a reasonable period of time; or

• there is no appropriate treatment.

When considering reduction in functional capacity, the NDIA will regard “the overall effect of the impairment or impairments over a period of time that is reasonable, considering the nature of the impairment or impairments (and in particular considering whether an impairment is episodic or fluctuates).” In the past, it has been debated whether the NDIA should be judging a person’s function on a “good day,” “bad day” or “average day.” Under this proposal, it appears they would look at the cumulative impact over months or years. Questions need to be asked if this ruling should be extended to people with other disabilities e.g. deafblind. It is not clear why they have been limited to psychosocial disability and not made available to all cohorts who experience fluctuating disabilities and disabilities with complex treatment pathways (e.g. participants who are deafblind).

**Recommendation 7:** People with sensory and other disabilities must be given the same considerations as those with psychosocial disabilities. The NDIA must regard “the overall effect of the impairment or impairments over a period of time that is reasonable, considering the nature of the impairment or impairments (and in particular considering whether an impairment is episodic or fluctuates).

In addition to plan management, there are also proposed changes to the way in which supports are paid by the NDIA. These changes are set out in the proposed amendments to section 45 of the Act. The Government has indicated that these changes are intended to make it easier for self-managing participants to make claims, by using a ‘tap and go’ system on a smartphone app with their service provider, rather than paying out of pocket first and seeking a reimbursement. These changes appear to be positive however, we are concerned for populations who would be unable to access the technology required Also some participants may be concerned by the inability for self-managed participants to opt out of this system and pay for their own supports first, or to mix-and-match their preferred payment method.

**Recommendation 8**: Proposed changes to the payment systems must be accessible to all participants

Finally the principles of the Act have been updated to say that people with disability should be considered in a co-design capacity. However, co-design has not been defined, so we still have no idea what this might look like, again we need transparency and fluid, accessible communication regarding how this will be implemented.

**Recommendation 9.** Clear articulation of how codesign processes will be implemented, particularly with NDIS participants with deafblindness.

**REFERENCES**

Able Australia, Deafblind Australia, Senses Australia (2019) Submission to parliamentary inquiry into NDIS planning.

Blake, K. D. and Prasad, C (2006) CHARGE Syndrome, Orphanet J Rare Dis. 1: 34. Accessed 25 Nov ember, 2016 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1586184/

Carvill S (2001) Sensory impairment, intellectual disability and psychiatry. Journal of Intellectual Disability Research 45: 467–83.

Deafblind Australia (n.d) What is deafblindness? Retrieved from <https://www.deafblind.org.au/deafblind-information/what-is-deafblindness/> 2nd September, 2019

Dyke, P. (2013) A clear view: Identifying Australians who live with deafblindness and dual sensory loss, Senses Australia

Kiani, R. and Miller, H. (2010) Sensory impairment and intellectual disability. Advances in psychiatric treatment 16, 228–235

Kimberling W. J., Hildebrand M. S., Shearer A. E., Jensen M. L., Halder J. A., Trzupek K., Cohn E. S., Weleber R. G., Stone E. M,. Smith R. J. (2010) Frequency of Usher syndrome in two pediatric populations: Implications for genetic screening of deaf and hard of hearing children. Genetics in Medicine 12, 512–516.

National Centre for Advancing Translational Sciences (2016), Norrie disease, retrieved from <https://rarediseases.info.nih.gov/diseases/7224/norrie-disease>

World Federation of the deafblind (2018) At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness- Initial global report on the situation and rights of persons with deafblindness