

Deaf Victoria submission to the National Disability Insurance Scheme in response to the "Access and eligibility policy for independent assessments" consultation papers.

February 23, 2021

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## **Background**

Deaf Victoria, established in 1982, has conducted a number of systemic advocacy campaigns and provided individual advocacy services to Deaf consumers for whom Auslan (Australian Sign Language) is a first language for almost 40 years. In recent times, our reach has also included those who identify as hard of hearing. Deaf Victoria is the only remaining active and funded state-based advocacy organisation for deaf and hard of hearing people in Australia. Our board is majority deaf/hard of hearing led and all but one of our paid staff members have a lived experience of deafness.

#### Our vision is:

Deaf and hard of hearing people experience equality, opportunity and connection, and are valued for their unique contributions towards a diverse society.

Deaf Victoria is funded by the Victorian Department of Families, Fairness and Housing (previously DHHS) to provide individual advocacy support for deaf and hard of hearing Victorians. Our core business is to ensure access and inclusion in mainstream services across Victoria for deaf and hard of hearing people. In addition to individual capacity building and advocacy, the organisation works with government and private providers to increase access to services and to educate the wider community on how to interact with and serve Deaf and hard of hearing people community members.

Current projects underway span areas such as: The Disability Royal Commission, Access to Interpreters in Hospitals and training programs to build individual capacity in relation to advocacy. Funding for these projects comes from a number of state and federal agencies. We also successfully completed a project funded by the NDIA ILC Program in 2020 which focused on improving self-advocacy skills and resources for the Deaf Community. This model is soon to be replicated in other states.

At an advisory level, Deaf Victoria also represents deaf and hard of hearing interests in various state government settings and works with other disability groups and our peak organisation, Deaf Australia to ensure those we represent are able to participate on equal footing in society and fully activate their citizenship with pride. In addition, we have a sitting member of the NDIS Independent Advisory Council IAS reference group for children, young people and families.



### **Deaf and hard of hearing Community**

According to the *Listen Hear* report, one in six Australians has some degree of hearing loss and this is expected to increase to one in four by 2050 (Listen Hear: the economic impact and cost of hearing loss, Access Economics, 2006). Many deaf and hard of hearing people use Auslan as their first and primary language for everyday communication. Auslan is the language of Australia's Deaf community and first officially recognised as a legitimate language by the Australian Government in 1987 in a white paper on the languages of Australia (Lo Bianco, J, 1987). Later, in 1991, Auslan was recognised as an Australian Community Language (Dawkins, Australia's Language: The Australian Language and Literacy Policy). The 2016 census recorded that there are 3,130 Auslan users who live in Victoria (Australian Bureau of Statistics, 2017).

Even though Auslan is acknowledged as a legitimate Australian Community Language, access to information, education, services and everyday communications in Auslan is sparce. In fact, approximately 95 percent of children with hearing loss are born to parents with normal hearing (Listen Hear: the economic impact and cost of hearing loss, Access Economics, 2006). This means that many deaf and hard of hearing children grow up in households without a native language user of what is or will become, their primary language. Thus, many deaf and hard of hearing people experience through their home lives, schooling, medical care, employment and social interactions a lack of access and disconnectedness their whole lives. In addition, the barriers placed upon them by societal attitudes or lack of access (rare access to news in Auslan; lack of or poor captioning on television, social media and other platforms; medical, educational or other professionals dismissing their access requests) compound this. These deficits endure throughout childhood, into adulthood and can result in poor education, employment, healthcare and/or financial outcomes or literacy as well as reduced capacity to fully activate one's citizenship.

Often deaf and hard of hearing people are forced to employ other communication techniques due to the lack of Auslan access in mainstream society. Many do this with aplomb, although it should always be remembered, that these strategies do not offer full access to communication and they are not in line with the communication method best suited to the deaf or hard of hearing individual.

More often than not, deafness itself is not disabling but rather societal attitudes or inherent barriers to access and inclusion in the broader community that render deaf and hard of hearing people as such. In fact, rather than identifying as "disabled", many deaf and hard of hearing people view themselves as part of a cultural and linguistic minority group who use Auslan. This is at odds with how deaf and hard of hearing people are required to interact with the NDIA and problematic for a number of reasons. The responses contained in this submission are the amalgamation of consultations and interviews with Deaf and hard of hearing NDIS participants, parents, health professionals who are culturally competent in the Deaf sector, Auslan/English Interpreters. Much of the information contained herein is directly from participants who have sought advocacy support from Deaf Victoria for either themselves, their family members, or clients.



### **Response to NDIS Reforms**

The responses contained in this submission are the amalgamation of consultations and interviews with deaf and hard of hearing community members- many of whom are NDIA participants as well as, parents, Auslan/English Interpreters and the Deaf Victoria Board. Much of the information contained herein is directly from individuals who have sought advocacy support from Deaf Victoria for either themselves or their children on matters related to the NDIA. Deaf Victoria staff also attended a consultation session on "Access and eligibility policy for independent assessments" and "Planning policy for personalised budgets and plan flexibility" facilitated in Auslan by NDIA Senior Community Engagement Officer, Meg Aumann on February 9.

### - The 'independence' of independent assessors:

Independent Assessors like any employees employed by the NDIA cannot be independent by virtue of who is paying their wage. The NDIA acknowledges the need for independent final rulings with the option for decision reviews to be undertaken by the Administrative Appeals Tribunal but the introduction of the Independent Assessments defeat this purpose and disempowers participants.

## - Quality of a disability-neutral approach to independent assessments:

How will 'disability-neutral' assessors understand the complexities of specific disabilities and cohorts? What training will health professionals who conduct the assessments have- especially around regarding cultural competency for the Deaf Community and Auslan. At present, *many* Deaf people report that they need to educate NDIA (or NDIA registered organisation) staff themselves about their disability as their knowledge is very limited. This causes much undue stress and fatigue which negatively affects their NDIS outcomes and plan which the introduction of independent assessments will further compound this. In addition, given that for deaf Auslan users, these assessments will be mediated through Auslan Interpreters, there is a need for training to be provided for Independent Assessors to work with Auslan Interpreters during these assessments and for Auslan Interpreters themselves. It is not possible to conduct these assessments in a culturally and linguistically safe and competent manner if a 'disability-neutral' approach is adopted. Instead, we would argue that specialist Independent Assessors for disability cohorts (such as Auslan users) would be preferable.

#### - Medical model of disability bias of independent assessments:

With medical professionals conducting these assessments, how can the Deaf Community feel confident that the assessment will not follow the medical rather than social model of disability? The medical model of disability for the Deaf Community can lead to significant disadvantage as cultural elements (i.e. Auslan, Deaf Community, culture and connectedness, need for Deaf role models, need for family members to learn Auslan to prevent isolation) are minimised in favour of medical and low cost interventions such as hearing devices.

The Independent Assessments Framework is clearly underpinned by the medical model of disability which puts many participants at disadvantage. The Disability Royal Commission's Interim Report (p. 431, 2020) highlighted the bias throughout assessments undertaken by medical professionals which



neglects the holistic understanding of individual needs. These findings depict the medical bias of the NDIA's Independent Assessments through the allocation of health professionals as the assessors which put participants at disadvantage in being assessed on their capacity rather than their disability. For deaf and hard of hearing participants, the main barrier they face is communication which renders the Independent Assessments counterintuitive with single assessments that provide no opportunity for communication clarification or cultural safety. For the Independent Assessments to truly effective there needs to be opportunities for Independent Assessment reviews to ensure communication and cultural competency as well as training for Auslan.

### - The cost of Independent Assessments for participants:

Whilst we understand the introduction of independent assessments is underpinned by a desire reduce the cost constraints for participants, it neglects the out-of-pocket costs participants pay for the specialised knowledge and skills required to apply for the NDIS initially nor the expertise required to understand for many and varied disabilities and the intersectionality of these. A better solution to this would be to allow these types of appointments to be bulk billed if they are for the purposes of demonstrating eligibility and need for the NDIS.

### - The 'functional capacity' model of assessment:

For the Deaf Community, someone's "functional capacity" for example their ability to lipread and speak in some situations- for example in a one-on-one independent assessment- may be interpreted to mean that they do not require Auslan Interpreters at an adequate funding level to meet their needs. Moreover, Deaf people who use Auslan as their method of communication should have the right to self-disclose in what settings and with whom they choose to use Interpreters. Not all one-on-one appointments place the same demands on communication and how a Deaf Auslan user might perform when understanding questions related to themselves and talking about their needs could and most likely would be severely at odds with how they would perform in a specialist medical, legal or financial appointment for example.

Given that the type of training these independent assessors will have is unclear, there is a major concern that without cultural competency skills related to the Deaf Community and Auslan, the Deaf Community could be significantly disadvantaged by this. This disadvantage faced by participants is compounded for those who are cultural and linguistically diverse (CALD) as the Independent Assessment Framework lacks any consideration for how CALD participants are given equitable opportunity to explain their needs to the Independent Assessor which provides a substantial influence on their plan outcomes.

#### Recommendations

## - Independence of Assessors

Assessors cannot be truly independent if they are employed with or contracted by the NDIA. Therefore, we would recommend that assessments pertaining to eligibility, capacity and need





remain the jurisdiction of professionals with specialist expertise in this area who are not affiliated with the NDIA.

# - Recruiting diverse independent assessors:

Independent Assessors need to be recruited and allocated to participants based upon relevant knowledge and expertise such as social workers not just health professionals e.g social workers who are deaf or hard of hearing and/or fluent in Auslan. Empowering participants with the choice to choose Independent Assessors in regard to their skill set in correlation to their disability reduces the workload for participants in needing to self-advocate which puts them at a disadvantage. This approach acknowledges the industry gap in the demand for specialists by providing a sustainable approach which reduces the medical bias and provides accommodations for participants with intersectional experiences.

## - Medicare rebate to cover out of pocket costs for participants:

A Medicare rebate would enable all participants to seek appropriate specialists required to apply for the NDIS and rectify the financial inequity amongst NDIS applicants. The Medicare rebate would enable all participants a fair chance in the NDIS as well as recognising the mental and emotional costs such as undue trauma, stress and self-advocacy fatigue in explaining their story time and time again to various specialists and various appointments.

In closing, it would be Deaf Victoria's position that in order for the NDIS to provide an equitable pathway for deaf and hard of hearing participants into the scheme, our recommendations need to be undertaken and further investment into the expertise and experience of intersectional disabilities.

Further information on this submission can be obtained by contacting Maxine Buxton, General Manager- Deaf Victoria. manager@deafvictoria.org.au 0419 586 979.