



# Submission to the parliamentary inquiry into Independent Assessments

Joint Standing Committee on the National Disability  
Insurance Scheme

March 2021

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## **SUMMARY OF RECOMMENDATIONS**

### **Recommendation 1.**

That further consultation is undertaken specifically with the Australian deafblind community so the NDIA has a better understanding of key issues, and put measures in place to ensure people with deafblindness are not disadvantaged by independent assessments, and that these assessments are accessible, inclusive of and meaningful to people with deafblindness.

Note: this is consistent with recommendation 4 from Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021).

### **Recommendation 2**

That if a person is identified as having combined vision and hearing disabilities, they do NOT have to identify a primary disability as blindness or deafness, but can identify their primary disability as being deafblindness for the purpose of independent assessments.

Note: this recommendation is consistent with recommendation 1 of Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

### **Recommendation 3**

That if a person is identified as having combined vision and hearing disabilities, that an Independent Assessor must have a minimum of 3 years' experience in the disability sector and undertake mandatory deafblind awareness training developed specifically for independent assessors.

Note: this recommendation is consistent with recommendation 2 of Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

### **Recommendation 4.**

To ensure children with complex, deteriorating conditions including those causing deafblindness, are adequately supported through independent assessments, and that future functional capacity is taken into consideration to optimise children's capacity to cope with and manage their changing abilities.

**Recommendation 5.**

That if an Auslan interpreter is required for the independent assessment that ideally an interpreter familiar with the person with deafblindness is booked, and as a minimum that an Auslan interpreter with experience working with people with deafblindness is booked.

Note: this recommendation is consistent with recommendation 3 of Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

**Recommendation 6.**

That people with deafblindness are supported to bring a familiar person with them to their independent assessment to provide additional required communications support to minimise communication breakdown.

**Recommendation 7.**

If a person is identified as having combined vision and hearing disability (deafblindness) independent assessments MUST occur face to face, and additional time MUST be allocated.

## **EXECUTIVE SUMMARY**

People with deafblindness remain some of the most marginalised in Australia, with their complex needs being poorly understood and inadequately addressed. While it is understood that the National Disability Insurance Agency's introduction of independent assessments is to increase equity of provision of services and supports to Australians with disability, unless systemic changes are made to delivery of the independent assessments, it is likely the needs of people with deafblindness will not only not be fully addressed, but in some instances current services may diminish.

People with deafblindness require some specific supports to meet even basic daily needs which differ considerably from other disability groups. These supports include use of Auslan interpreters with an understanding of the communication needs of people with deafblindness, including tactile sign language, and the use of communication guides trained specifically to work with people with deafblindness. Without these supports people with deafblindness often cannot access medical and therapy services and education and employment settings as well as community services and facilities, and these same barriers will be faced when trying to access independent assessments.

The current disability workforce is poorly equipped to meet the needs of people with deafblindness. Even if funding is available, there are inadequate numbers of qualified experienced and trained staff to meet the demands. Workforce development needs to be addressed by the National Disability Insurance Agency if the needs of people with deafblindness are to be addressed effectively.

Access to information and services remains problematic for people with deafblindness due to issues accessing standard print and audiovisual media. These barriers to accessing information go both ways, as it is currently extremely difficult for people with deafblindness to have their needs and perspectives understood by service providers and government agencies due to the complexity of communication needs.

All of these issues directly impact on the NDIA's independent assessment processes. Issues are experienced by Australians with deafblindness in accessing information

about independent assessments, having NDIS staff and other independent staff understand their needs, and participating fully in all NDIS processes.

## **ACKNOWLEDGEMENTS**

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## **BACKGROUND**

### **Introduction**

This is a joint submission to the parliamentary inquiry into independent assessments from the below group of National peak bodies, disabled peoples and families organisations, and service providers.

Able Australia

Australian Sign Language Interpreters Association

CHARGE Syndrome Australasia

Children's Tumor Foundation

Deafblind Association, NSW

Deafblind Australia

Deafblind Victoria

Deafblind West Australians

NextSense

Parents of Deaf Children

Senses Australia

South Pacific Educators in Vision Impaired

Usher Kids Australia

### **Introduction to deafblindness**

Throughout this submission, the terms deafblind, combined vision and hearing disability 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)

### **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). All individuals with deafblindness will fulfil the criteria for acceptance into the National Disability Insurance Scheme given their sensory impairments will significantly impact on their functioning well before the age of 65 years.

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.

CHARGE syndrome, a genetic disorder with multiple congenital anomalies, results in combined vision and hearing impairment and other sensory impairments, all of which require long term health care and intervention. Patients with CHARGE syndrome experience a wide spectrum of medical, physical, and psychological issues. Thus, a multi-disciplinary team is usually involved in their care, often beginning at birth. 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). Anecdotally, CHARGE Syndrome Australasia Ltd is aware of approximately 100 children and adults in Australia with CHARGE syndrome.

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 (Kiani 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).

## **RESPONSE TO TERMS OF REFERENCE**

- a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;

The rationale underpinning the introduction of Independent Assessments, to address the current inconsistencies, and improve equity of the NDIS is sound. However, the modelling and development are lacking.

Able Australia, Deafblind Australia and Senses Australia are only aware of a small number (less than 5) Australians with deafblindness who have taken part in the Independent Assessment trials. While calls for volunteers were made, the lack of uptake of people with deafblindness and their support networks highlights one of the key issues for this group. Due to the inherent complexities of communication support needs, their engagement is challenging for those without significant skills and experience with this population.

Generic disability service provision, including assessment, and even single sensory specific service provision has repeatedly failed the needs of people with deafblindness, and no measures have been put in place to address the need for understanding the complexities of working with people with deafblindness for independent assessors. Of those people with deafblindness who took part in the Independent Assessments, reports have been that:

- The language used by the assessor, and in the assessments was too abstract and complex
- The assessors requested that the person with deafblindness complete two separate assessments, one for hearing and one for vision, completely overlooking and not understanding that it is the interaction of the two disabilities which creates the one complex disability of deafblindness and that it is misleading and does not adequately address the complexity of the disability if the two sensory disabilities are viewed as separate and discrete.

### **Recommendation 1.**

That further consultation is undertaken specifically with the Australian deafblind community so the NDIA has a better understanding of key issues and put measures in place to ensure people with deafblindness are not disadvantaged by independent assessments, and that these assessments are accessible, inclusive of and meaningful to people with deafblindness.

Note: this is consistent with recommendation 4 from Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

### **Recommendation 2**

That if a person is identified as having combined vision and hearing disabilities, they do NOT have to identify a primary disability as blindness or deafness, but can identify their primary disability as being deafblindness for the purpose of independent assessments.

Note: this recommendation is consistent with recommendation 1 of Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

- b. the impact of similar policies in other jurisdictions and in the provision of other government services;

As mentioned above, generic disability services are inadequately equipped to address the inherently complex needs of Australians with deafblindness. This is true also for the provision of healthcare and education.

The submission made to the review of Disability Standards for Education 2005 (Deafblind Australia, 2020) highlights the ways in which Australian education systems are inadequately meeting the needs of students with deafblindness.

There is also an increasing body of evidence that mainstream health services do not adequately meet the needs of people with deafblindness (see Alexander & Alper 2014; Ellis, Keenan & Hodges 2015; Fernández-Valderas, Macías-Seda & Gil-García 2017; Sense UK 2016; Stoffel 2012; Takahashi 2019).

This recognition that people with deafblindness require specialist supports and approaches to ensure they can access and be included in all aspects of civic life is equally true for the process of independent assessments.

- c. the human and financial resources needed to effectively implement independent assessments;

Throughout Australia there are insufficient skilled, trained and experienced service providers to meet the needs of Australians with deafblindness.

No work has been undertaken by the NDIA to address the need for workforce development to upskill staff to ensure the level of quality of services required to meet the needs of people with complex disabilities such as those with deafblindness.

While it is recognised initial financial investment is required to increase workforce capacity and skill, this will ultimately lead to improved sustainable outcomes for people with deafblindness, increased independence and greater achievement of the NDIA's objectives.

- d. the independence, qualifications, training, expertise and quality assurance of assessors;

It is concerning to see advertisements for Independent Assessors stipulating only one years' experience required. Plena healthcare posted an advertisement on Seek on the 2<sup>nd</sup> March, 2021 advertising roles for Independent Assessors stating:

'To best support our clients, you will need:

A bachelor's degree

Current AHPRA registration or limited registration & Australian working rights

12 months work experience post your general registration

Working With Children Check / Working With Vulnerable People Check

A genuine focus on client centered care and assessment / paediatric care and assessment'

Without specific training an independent assessor is unlikely, with the standard assessment tools, to adequately recognise and address the complexities, including the broader social and service environment faced by children with complex deteriorating conditions and the needs of their families. Research shows that the mental health and well-being of parents caring for a child with a disability are well below that of parents of children without disability (Davis et al., 2019) reducing their capacity to provide the additional high-level care required, risking poorer outcomes for the child. In addition, if the condition is rare, such as the case with Usher syndrome, parents can carry a significant additional burden of care due to the limited and insufficient knowledge among health care professionals and service providers about the particular condition and relevant clinical protocols (Currie & Szabo, 2018), and are often left feeling isolated and unsupported (Zurynski, Frith, Leonard & Elliott, 2008).

One of the biggest frustrations for parents is the variation of symptoms and progression trajectories for those living with Usher syndrome, making it difficult for health care professionals to accurately predict the timeline for the deteriorating loss of vision associated with Usher syndrome in children. Living with the stress of this uncertainty can be at times insurmountable for parents, impacting their capacity to care, support and advocate for their children. A primary caregiver who is capable of, and has access to a multitude of resources is better equipped to be able to support the health and development of their child living with rare disease (Bourke-Taylor, Howie, Law, & Pallant, 2011).

In the case of CHARGE syndrome, the developmental challenges are amongst the most significant of any congenital condition. Individuals with CHARGE syndrome have impaired hearing, vision, smell, taste, touch, proprioception, balance and mobility, in addition to heart defects and gastro-intestinal anomalies. Young children will typically spend many months in hospital, have numerous surgeries and will need support from a wide range of medical specialists. Multiple disciplines are involved long term in the lives of these individuals, including medical, communication, sensory integration, behaviour management and education support.

### **Recommendation 3**

That if a person is identified as having combined vision and hearing disabilities, that an Independent Assessor must have a minimum of 3 years' experience in the disability sector and undertake mandatory deafblind awareness training developed specifically for independent assessors.

Note: this recommendation is consistent with recommendation 2 of Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

- e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;

There are several rating instruments available to assess cognitive abilities in children, some examples include: (a) the ability to carry out tasks of daily living/adaptive behavior [i.e., Vineland Adaptive Behavior Scales (Vineland-3); Sparrow et al., 2016 and Adaptive Behavior Evaluation Scale (ABES-3); Harrison and Oakland, 2015] and (b) the ability to manage oneself in flexible ways/executive functions [i.e., Behavior Rating Inventory of Executive Function (BRIEF); Gioia et al., 2000]. The Vineland, ABES, and BRIEF have been used to assess cognitive abilities in children with CHARGE syndrome (Salem-Hartshorne and Jacob, 2005; Hartshorne et al., 2007; Abadie et al., 2020).

It is reasonable to say that there are almost no standardized rating instruments that include specific norms for comparisons with children who are deafblind. Consequently, adaptive behavior scales “are not especially sensitive to the development and learning modalities of children who are deafblind” (Chen et al., 2009, p. 326). Thus, the evaluator must be aware that some items or domains in traditional rating measures are probably inappropriate and could be easily misinterpreted (Salem-Hartshorne and Jacob, 2005). Accordingly, the overall scale profile would appear atypical and might not cover the scope of the functional skills that a child who is deafblind has achieved. Hence, when an adaptive behavior scale is applied, it is important that information about the child’s functional ability is gathered from multiple sources and then integrated with the results from the behavior scale to make important decisions about the overall cognitive functioning of a child who is deafblind.

However, there are a few rating measures designed specifically for children with deafblindness, for example, the Callier-Azusa Scale (Stillman, 1974) and the Child-Guided Strategies (Nelson et al., 2002). A case study has shown that when using the Child-Guided Strategies as an assessment measure, it was possible to reveal fundamental problem solving and memory skills that provided information for further support for a child with deafblindness (Damen, 2020).

In essence, the use of standardized normative measures alone is insufficient to yield accurate predictions of cognitive abilities in children with deafblindness (Nicholas, 2020). It is, therefore, essential that a child who is deafblind be afforded multiple assessment pathways for cognitive assessments.

As a standardized assessment tool, the WHODAS 2.0 has many limitations in use with people with deafblindness. The questions are abstract and subjective. Most questions use flashcards to remind the respondent of key information. The text (point to flashcard #) appears at each point where a flashcard is to be shown. This is inappropriate for people who are blind and deafblind.

The WHODAS 2.0 covers mainly the activities and participation domains of the ICF, so bodily impairments and environmental factors are not included (Kulnik & Nikolettou,



2013). The WHODAS 2.0 implicitly favors a medical interpretation of disability rather than viewing disability through a functional and more progressive social lens, as it does not consider environmental factors or their impact on the six functioning domains which it assesses (Ustun et al., 2010). As such, the WHODAS 2.0 may not be appropriate in contexts where social perspectives on disability are considered important (Kulnik & Nikoletou, 2013).

The WHODAS 2.0 does not capture the extra time that activities often take for a person with disability in general and deafblindness in particular (e.g. I can do the vacuuming, but it takes me hours because in order to find the dust I have to go over every inch of the house, whereas a sighted person can see where the dust is and get the job done in minutes) and, they provide no way of measuring the impact when activities are not undertaken because of uncertainties about whether you'll receive support as a person with a disability. For example a person with deafblindness stated "I've lost count of the number of times I haven't gone to events because I have no confidence that hearing loops work in practice". Also, the tools don't take into account the varying situations in which activities are undertaken e.g "do you have trouble eating" – "well it depends on where I am and what I'm eating - which isn't one of the options in the tool".

With the increased availability and accessibility of genetic testing, many syndromes contributing to deafblindness are now diagnosed in the first years of a child's life. In the case of CHARGE Syndrome, neonates are usually diagnosed shortly after birth. Usher syndrome is now diagnosed in children in their first years of life, often before the onset of retinitis pigmentosa, the eye condition causing deteriorating vision loss in children with Usher syndrome. An independent assessment may show good functional vision for the child, but does not address the functional capacity required for the child to ensure they have the skills to cope with deteriorating vision loss.

Due to progressive vision loss, adults with Usher syndrome become more dependent on others for daily tasks, have higher rates of unemployment, and are more likely to use health services compared to those without the condition (Garip & Kamal, 2019). Also, those living with Usher syndrome are more likely to experience higher levels of distress

and depression and report lower levels of quality of life compared to adults living without the condition. Supporting young people with Usher syndrome and their families to develop approaches to cope, manage, and adapt to living with Usher syndrome before the functional impact of vision loss is significant, will improve the quality of life, as well as ameliorate the costs to society. Similarly, families of children with CHARGE syndrome and Norrie disease require considerable support to manage the multiple challenges associated with having a child with multiple and complex disabilities. Information provided by a family of a 34 year old woman with CHARGE syndrome who took part in the independent assessment trials is below and highlights the inadequacy of the assessment tools for someone with CHARGE syndrome.

*“The interview was conducted over about 3 hours with a psychologist from NDIS doing the interview. Due to the person's inability to hear and answer questions the interview was conducted mostly by her parents and carer. The interview was mainly a question and answer interview. As the person does not have any significant physical disabilities many of the physical questions were not applicable. Many of the answers were either “never” or “not usually”. During the interview, the person demonstrated some typical CHARGE behaviours and we were aware this was being assessed by the psychologist. At the end of the interview, we expressed concern that this assessment would be read by a third party who would not understand the person's many behavioural patterns and abilities and that the report would be assessed purely from a financial point of view. The assessor gave us reason to believe we are not alone with this concern. We feel that 'adequate assessments of NDIS users can only be carried out at the coalface by persons who have had experience in the disability field and that "assessments done at a distance and conforming to the structured model they are adopting, would not succeed with people with CHARGE syndrome.”*

#### **Recommendation 4.**

To ensure children with complex, deteriorating conditions including those causing deafblindness, are adequately supported through independent assessments, and that

future functional capacity is taken into consideration to optimise children's capacity to cope with and manage their changing abilities.

- f. the implications of independent assessments for access to and eligibility for the NDIS;

Possibly the most concerning implication of the introduction of Independent Assessments is the likelihood of already marginalised individuals who are eligible for the NDIS falling through the cracks and being underserved or worse, receiving no service.

The level of communication breakdown experienced by people with deafblindness even with skilled, familiar communication partners will be significantly multiplied with unfamiliar and unskilled (in deafblindness) Independent Assessors.

The combination of the need for Auslan interpreters, complex and abstract language of assessment tools, and individuals with deafblindness wanting to present as competent and independent (as we all do) will most likely lead to the complexities and daily challenges with ALL tasks being over simplified and overlooked.

People with deafblindness who are Auslan users require Auslan interpreters who are experienced in working with people with deafblindness to optimise efficacy of interpretation.

People with deafblindness should also be supported to bring a familiar person to the independent assessment to assist in bridging the access and inclusion gap which interacting with an unfamiliar person will precipitate. Some individuals with deafblindness, due to limited educational opportunities and limited access to high quality communication support over many years, have developed idiosyncratic ways of communicating which an Auslan interpreter even skilled in deafblindness may experience difficulty interpreting. In these instances it is imperative that a

communication partner who knows the person well, is present at an independent assessment to ensure access.

It has been reported that there is an increasing number of NDIA services being provided via phone or online. For people with deafblindness, including those who are Auslan users and require an interpreter, it is imperative that meetings are held face to face in order to allow for optimal communication access and reduce communication breakdown.

#### **Recommendation 5.**

That if an Auslan interpreter is required for the independent assessment that ideally an interpreter familiar with the person with deafblindness is booked, and as a minimum that an Auslan interpreter with experience working with people with deafblindness is booked.

Note: this recommendation is consistent with recommendation 3 of Consultation – Deafblind Community WA NDIA Easy English (Deafblind West Australians, 2021)

#### **Recommendation 6.**

That people with deafblindness are supported to bring a familiar person with them to their independent assessment to provide additional required communications support to minimise communication breakdown.

#### **Recommendation 7.**

If a person is identified as having combined vision and hearing disability (deafblindness) independent assessments MUST occur face to face, and additional time MUST be allocated.

- g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports;

There remains a lack of clarity about how Independent Assessments interact with an individual's goals to ensure adequate supports are in place to achieve the stated goals. Functional assessment alone should not dictate the level of supports required, as two people with the same functional ability may have significantly different goals and aspirations requiring a high frequency and duration of support.

- h. the circumstances in which a person may not be required to complete an independent assessment;

The report from the Tune Review discussed the opportunity for independent functional capacity assessments to be used “for every person with disability who would like to test their access for the NDIS or who require further evidence to support decision-making about the supports in their plan.” However, the report specifically highlights:

- The need for consultation with people with disability in implementing this approach
- The risk of disengagement by people with disability if there are concerns around the independence of assessors and their appointment by the NDIA, and if assessments are perceived to be “a tool designed to cut supports from participants.

For these reasons, the report recommends the NDIA be given discretionary powers to require participants undergo assessments. There is no mention of mandatory IA in the report. Further, the report largely focused on IA as a tool to support more equitable entry as many potential participants cannot access or afford the required appointments and assessments needed to enter the scheme.

Further work and consultation is required to determine when and how it is appropriate to conduct an independent assessment.

- i. opportunities to review or challenge the outcomes of independent assessments;

It is imperative that there are clear and transparent processes for individuals who have received an Independent Assessment to request a review or challenge decisions made by the independent assessors.

- j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds;

People with deafblindness who are Auslan users fall in the category of Culturally and Linguistically Diverse, yet have the compounding complexity of their language other than English (Auslan) being accessed through either vision which is impaired, or touch which cannot simultaneously relay the same level of information as can be relayed visually. As previously stated, this contributes to complex communication support needs and again lends weight to the need for recommendations 5, 6 and 7 to be adopted.

- k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability;

This submission focuses on how poorly equipped Independent Assessors are and the NDIA in general is, to adequately meeting the complex needs of individuals with deafblindness. The recommendations made in this submission are aimed at ensuring the independent assessment process can be optimised to ensure people with deafblindness have equal access and do not fall through the cracks of this new system.

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