Disparity between the Australian National Disability Insurance Scheme Access Requirements and the Needs of People with Vision Impairment

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ABSTRACT

When a person of any age has vision impairment the impact of this on their everyday life may be lessened with appropriate support. To ensure this support meets the person's needs it is essential that the criteria used to assess the person's vision impairment are valid and align with the nature of the support being offered. Australia's new National Disability Insurance Scheme (NDIS) relies on eligibility criteria known as access requirements that include two clinical vision measurements - visual acuity and visual fields. However, to align with the stated NDIS goals,

INTRODUCTION

ustralia's new National Disability Insurance Scheme (NDIS) is a scheme that takes a lifetime approach, investing in people with disability early to improve their life outcomes.¹ The intent is to provide support funding for people with disability from birth to 65 years of age, including those people with vision impairment. The NDIS supports needs in accordance with realistic life goals, where this support is reasonable and necessary. This paper will explore the NDIS eligibility criteria (also known as access requirements), currently being applied when people with vision impairment wish to enter the scheme, and questions whether these requirements align with people's needs, particularly in the case of children. Other global approaches to vision impairment, such as those adopted by the World Health Organization (WHO) and by the United Kingdom (UK) and the United States of America (USA), will be compared to the approach taken by Australia. The need for further development of the NDIS access requirements to ensure better alignment with the stated NDIS goals, and to specifically meet the needs of children with vision impairment will be highlighted.

Corresponding author: **Susan Silveira, Research Fellow** Renwick Centre, Royal Institute for Deaf and Blind Children 361-365 North Rocks Road, North Rocks 2151 NSW Email: sue.silveira@ridbc.org.au these access requirements should also reveal the functional impact of the person's vision impairment. The disparity between the current access requirements for vision impairment and the intended NDIS goals, particularly those for children with vision impairment will be explored in this paper, including a comparison to existing global approaches and suggestions for future development.

Keywords: vision impairment, National Disability Insurance Scheme, eligibility criteria, functional vision

National Disability Insurance Scheme

In response to longstanding scrutiny and criticism of existing disability support schemes, the NDIS became a reality for Australians with disability in 2012. The NDIS was described as a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers.² Through the NDIS, support for Australians with disability will be offered according to the impact of their impairment on their functional capacity.³ This applies specifically when the impairment substantially reduces functional capacity and/or psychosocial functioning in communication, social interaction, learning, mobility, self-care and/or self-management.⁴ The person's eligibility for entrance into the scheme will depend on meeting certain prescribed NDIS access requirements.¹

NDIS access requirements for people with vision impairment

When applying for NDIS funding, people with vision impairment are required to provide information on their diagnosis, and evidence of the impact of their visual condition.¹ The National Disability Insurance Agency (NDIA), the new organisation responsible for implementing the NDIS, has stated that automatic entrance into the scheme is granted when the person has been assessed and diagnosed by an ophthalmologist as having permanent blindness¹ in both eyes, and when the following clinical standards are met: 1. Corrected visual acuity on the Snellen Scale that must be less than or equal to 6/60 in both eyes; or

2. Constriction to within 10 degrees or less of arc of central fixation in the better eye, irrespective of corrected visual acuity, ie visual fields reduced to a measured arc of 10 degrees or less; or

3. A combination of visual defects resulting in the same degree of visual impairment as that occurring in the above points.¹ It should be noted that the National Disability Insurance Agency (NDIA) has not provided further qualification regarding this combination.

Entry without further assessment is also granted by the NDIA when a person has dual sensory impairment or deafblindness that has been assessed as resulting in permanent and severe to total impairment of visual function and hearing, as determined by an ophthalmologist and an audiologist.¹ Again the NDIA has not provided specific clinical standards for vision or hearing in the case of dual sensory impairment. Certain people with vision impairment may not meet the NDIS access requirements outlined in points 1 to 3. For example, when a person has vision impairment within the range of 6/18 to better than 6/60, or when it is not possible to gain a definitive measure of visual acuity and visual fields because the person is limited in their capacity to participate in assessment; for example, when the person is a young child and/or has additional disabilities. When this occurs the NDIA states that the person's eligibility will be assessed using specialist evidence that details the impact of the condition on the person's life, including any impact on mobility, communication, social interaction, learning, self-care and self-management.1 However, no further information on the requirements of this specialist evidence is currently available.

Concerns with the NDIS access requirements for vision impairment

The NDIS goal of aligning disability support funding with the impact of disability on the person's life¹ should be commended. However, it is reasonable to question whether this has been achieved in the current NDIS implementation. Several key concerns related to the access requirements have come to light, including whether these requirements actually reflect functional impact; whether these requirements can be successfully implemented across all age groups, especially in the case of children; and whether these requirements are judged acceptable by the people they are designed to support.

When the NDIS access requirements are explored, it is evident that there has been reliance on clinical measurements rather than measures of the functional impact of vision impairment. Communications with the NDIA revealed that the NDIS access requirements for vision impairment had originated from those used by the Department of Social Services (DSS), described in the Social Security Act 1991,⁵ for the purposes of the Disability Support Pension (NDIA, personal communication, February 2017). These DSS criteria were limited to clinical measurements of vision.⁵ No further information was forthcoming when Australian Government documents such as the NDIS Bill³ and NDIS Act⁴ were reviewed for information on the development and evaluation of the NDIS access requirements.

The current NDIS access requirements for vision impairment rely on visual acuity and visual fields. These clinical measurements are accepted as integral components of the ophthalmic examination^{6,7} and are readily available for reporting purposes. However, Colenbrander⁸ described the aim of such clinical measurements as elucidating the cause rather than predicating the impact of vision impairment. As such, the temptation to default to clinical measurements as evidence of the functional impact of vision impairment must be avoided. The application of clinical measurements has been criticised in the literature for failing to determine the functional impact of visual disability.^{7,9,10} It is known that visual acuity and visual fields do not quantify functional vision,⁷ nor do they adequately explain variations in everyday performance of people with vision impairment.⁷

There is no doubt regarding the relative ease that exists in applying the outcome of an adult eye examination to the current NDIS access requirements. However, in the case of children, it is perhaps erroneous to assume that clinical measurements will be readily available for NDIS application. Determining a child's clinical measurements may prove challenging, due to limitations imposed by the child's age, capacity to participate, and often the presence of accompanying disabilities.^{11,12} Despite the best efforts of the clinician – usually an orthoptist – it may not be possible to reliably measure the child's visual acuity and visual fields. No advice is offered by the NDIA in this scenario, other than the application of 'specialist evidence', and as such, should be clarified.

It is also erroneous to assume that the current NDIS access requirements will align disability support funding with specific needs experienced by children when their vision impairment is congenital and/or early-onset in nature. Such needs are met by habilitation or the development of compensatory and visual efficiency skills that are unlikely to develop without support.⁹ Some children may also need rehabilitation or the maintenance or relearning of skills already acquired prior to the onset of vision impairment.9 The primary need for habilitation means the strategy for supporting children should not default to an adult-centric rehabilitation model, one that assumes a life of quality visual experiences prior to the onset of vision impairment. To be relevant, assessment must aim to capture the nature and impact of vision impairment on the developing child. A 'one size fits all' NDIS model for vision impairment is problematic for children.

It is vital that the NDIS access requirements are acceptable

to the people they are designed to support. The current NDIS access requirements describe a state of permanent blindness for a person with visual acuity of \leq 6/60. However, this terminology and visual standard do not align with the descriptor or vision standard applied by the World Health Organization International Statistical Classification of Diseases and Related Health Problems version 10 (WHO ICD-10).¹³ This NDIS standard assumes a state of sight or no sight, whereas people at this level of visual acuity are classified by the WHO ICD-10 as vision-impaired not blind. Further, it is generally accepted that a person with visual acuity of 6/60 is able to demonstrate a high level of functional visual capacity.⁹ Hence, a cautious approach needs to be applied when using strong labelling such as permanently blind; such labelling can impact on the person's sense of self, and have societal and legal implications. Colenbrander⁸ commented that a black and white dichotomy does not exist between those people with sight and those who are blind, so describing $\leq 6/60$ as permanently blind is inappropriate, particularly by a disability support scheme.

Examining global approaches

To explore solutions to the concerns identified in relation to the NDIS access requirements, approaches adopted by other countries are worthy of review. Several countries have implemented systems that rely on eligibility criteria for disability support including the UK's Department of Health Certification of Vision Impairment (CVI)¹⁴ and the Functional Vision Score (FVS)⁶ prepared by the International Society for Low Vision Research and Rehabilitation¹⁵ and implemented by the American Medical Association (AMA).

Both the CVI and FVS were examined for alignment with the NDIS goal of support for the functional impact of disability and approaches to eligibility criteria. Brief reference to nonclinical considerations appear in the CVI. Clinicians are advised when certifying a person with vision impairment that consideration should be given to how recently the person's vision had failed and how old the person was when this had happened, to include consideration of the potential difficulty of adaptation to recent visual loss and the general impact of advancing years.¹⁴ However, no further instruction was provided on how this information should be applied to the certification process.

The FVS was described as a theoretical construct in which visual acuity and visual field measurements were translated to a single linear score.¹⁶ This score was slightly modified when the person had other significant vision problems that were not reflected in their visual acuity and visual field measurements, such as glare.¹⁵ The FVS was defined as a global ability estimate for the person, however the authors commented that a true assessment of a person's functional vision could only be determined by observing how the person performed in certain vision related activities.¹⁵ Interestingly, the limited evaluative research available reporting on the application of the FVS showed strong alignment between

self-reported, vision-targeted quality of life measures and the FVS, This was in contrast to the sole application of visual acuity and/or visual field measurements.¹⁷ Despite this, Colenbrander¹⁶ discouraged using a formula such as the FVS as a sole determinant for eligibility.

A comparison was made across the clinical standards used to define vision impairment by WHO ICD-10, NDIS and CVI. The FVS was not included in this comparison given that it produced an actual score without revealing comparable visual acuity and visual field standards. In defining vision impairment, the WHO ICD-10, NDIS and CVI all rely on visual acuity and visual fields as measures of impairment. However, alignment did not exist regarding the visual acuity standard nor the degree of visual field loss that qualified a certain level of vision impairment. For example, the CVI recognised a person as vision impaired with a combination of visual acuity of \geq 6/18 with a gross visual field defect such as hemianopia, $^{\underline{14}}$ whereas the WHO ICD-10 did not factor in visual field loss until a person had significantly reduced visual acuity of < 3/60 to $\geq 1/60$, and visual field no greater than 10° in radius around central fixation.¹³ The NDIS used a similar visual field standard but did not apply a visual acuity standard when the visual field was reduced to 10 degrees or less.¹

A further disparity became apparent in the differing nomenclature used by the WHO ICD-10, NDIS, CVI and FVS when describing the degree of vision impairment. For example, the NDIS access requirements referred only to permanent blindness,¹ whereas the WHO ICD-10 referred to a range from mild vision impairment to blindness,¹³ and the CVI described a person as either sight impaired or severely sight impaired.¹⁴ Interestingly, the CVI also made reference to the impact of media opacities and aphakia, while the others did not. The CVI was also unique in that people with longstanding visual field loss were not included, presumably because such people were thought to have adapted to, and thus have compensated for, their visual field loss.¹⁴ The FVS recommended ranges of deficit from mild to total deficit that could be applied to visual acuity and/or visual fields.¹⁶

All approaches were examined for alignment with the specific needs of children. Reference to children was made within the CVI, with the advice that children with congenital abnormalities causing vision defects should be certified as sight-impaired unless they were obviously severely sight-impaired.¹⁴ However, no recommendation was made regarding visual acuity or visual field standards. The authors of the FVS clearly stated that the FVS was directed at adults with acquired vision loss, rather than children, and noted that any system that relied heavily on visual acuity and visual fields would be difficult to apply to children, unless the child had been able to fully participate in vision assessment.¹⁶

DISCUSSION

It is reasonable for people with vision impairment to assume that the criteria used to judge their eligibility for NDIS disability support are valid. To be valid, these criteria must be tailored to measure what they are intended to measure, that is, the impact of vision impairment on each individual's functional capacity.¹ Without an assurance that this impact is being measured, how can people with vision impairment be confident that NDIS support will align with their specific goals and needs? Further, the areas of uncertainty pertaining to the NDIS access requirements identified in this paper need to be clarified for the sake of all persons with vision impairment, and particularly for children and those professionals supporting them.

It is tempting to be critical of the NDIS access requirements for vision impairment. However, examination of approaches from WHO, the UK and the USA has shown that defining suitable eligibility criteria is not an easy task, and hence a reason why globally-ratified criteria are not currently available. This comparison has identified that a current global variation exists, that these approaches are not revealing the true functional impact of vision impairment on the person, nor can they be suitably applied to childhood vision impairment. Clearly, for Australia this is problematic given the aim of the NDIS is to support all people up to the age of 65 years to meet their life goals despite the impact of their vision impairment.³

In the event that it is possible to re-evaluate the NDIS access requirements for vision impairment, two recommendations are offered: that additional measures of visual function are included, and that the specific needs of children are considered.

To capture the true nature of a person's vision, assessment of their visual function should be broad. The NDIS access requirements, the WHO ICD-10 and the CVI include two visual measures, visual acuity and visual fields, but exclude additional measures that contribute to the broad understanding of the person's vision. One such measure that warrants inclusion is near vision. Without knowledge of a person's near vision, information is lacking regarding their potential for reading and near tasks, and the functional impact of vision impairment on these activities.^{6,16,18} Other measures that should be considered include contrast sensitivity^{18,19,20} colour vision testing and assessment for eye movement disorders.^{6,18}

The International Council of Ophthalmology (ICO) has recently made recommendations for the revision of the WHO ICD-10. Within the new WHO ICD-11¹⁶ due to be released in 2018, the ICO has included sub-categories for visual disability that include near vision; specific visual dysfunctions such as spatial neglect and agnosias; complex vision-related dysfunctions such as reading and orientation and mobility difficulties; the effects of non-visual disabilities such as dual sensory impairment; and the visual interactions from cerebral vision impairment, acquired brain injury and stroke.¹⁶ These new ICD-11 subcategories are significant additions. These may be readily applied to childhood vision impairment and contribute to professionals achieving the broad but personalised assessment of visual function that is needed in the case of the NDIS.

Another measure that could support a comprehensive understanding of the functional impact of vision impairment is the Functional Vision Questionnaire for Children and Young people with Visual Impairment.²¹ Although the development of this questionnaire is still in preliminary stages, the authors report that as a tool, it will allow a broader understanding of the impact of living with childhood vision impairment. Perhaps such a questionnaire should be included in the NDIS access requirements for childhood vision impairment.

In reconceptualising NDIS access requirements for vision impairment, the disability paradigm defined within the WHO International Classification of Function (ICF) could be considered. The ICF employs a biopsychosocial model of disability to represent disability as an outcome of interaction between health conditions and contextual factors, including environmental and personal factors.²² The ICF is an approach that highlights the functional impact of disability,²² and can be applied to children, adolescents and adults.

Regardless of the approach taken, re-evaluation of the NDIS access requirements for vision impairment should be considered. The next step should ensure that consultation represents all age groups affected by vision impairment, their families and those professionals who support them.

CONCLUSION

The Australian Government has shown commitment to disability support and willingness to engage with the disability sector through the recent implementation of the NDIS. However, disparity exists between the current NDIS access requirements and the functional abilities and needs of Australians with vision impairment. The NDIS access requirements must be revisited and clarified. Further, there is an urgent need to redefine the NDIS access requirements for childhood vision impairment. The issues raised, and the recommendations made in this paper, may provide a catalyst for discussions that begin to address these concerns.

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