Reporting for the National Disability Insurance Scheme: Incorporating the Functional Impact of Vision Impairment

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ABSTRACT

The Commonwealth of Australia has recently adopted a new innovative system of supporting people with disability; the National Disability Insurance Scheme (NDIS). Its objectives are grounded in a disability rights framework that endeavours to support people with permanent and significant disability in improved independence, community involvement, education, employment, health and well-being. To align with NDIS objectives, a major shift in perspective has occurred that moves disability service provision from a traditional funding scheme based entirely on the presence of a health condition, to one focussed on the functional impact of the person's health condition. However, despite this new approach, the capacity of a person with vision impairment to meet NDIS eligibility criteria for funding will not be judged by measures that indicate the functional impact of their vision impairment. Rather, the person's clinical measurements such as visual acuity and visual fields will be applied to predetermined criteria that have been deemed as suitable indicators of vision impairment.

This paper examined the existing professional literature that questions the application of clinical measurements to determine the functional impact of a person's vision impairment. Several models that recognise vision as a more complex entity were discussed. It is suggested that a broader approach to the assessment of a person's vision inclusive of both the clinical and functional domains, will assist ophthalmic reporting to more closely align with NDIS objectives, to enhance the support of Australians with vision impairment.

Keywords: vision impairment, disability, visual function, functional vision

INTRODUCTION

It is commonplace for clinicians to assess and then report on the health status of people in order to determine their eligibility for disability-related support funding. The implementation of the National Disability Insurance Scheme (NDIS) by the Commonwealth Government in 2012 has heralded a significant shift away from funding to support a person with disability based on the presence of a health condition, to funding based on the functional impact of their health condition. A need all across Australia now exists for assessment and reporting protocols to align with this shift. Orthoptists have always played an integral role in determining the clinical measurements of people with ophthalmic disease and vision impairment. To now ensure that this reporting remains relevant for those people with vision impairment seeking NDIS funding, consideration needs to be given to a methodology that captures the impact of vision impairment on the person's day-to-day functional capacity. This paper discussed the challenges faced in developing and implementing a new reporting methodology that assesses the person in both the functional and clinical domains. Current work in this area that might guide the development of such a methodology was also examined.

A new model of disability support funding for Australia

The Commonwealth of Australia has chosen to adopt a new approach to supporting people with disability following the detailed public enquiry in 2011 by the Australian Government Productivity Commission (APC), into long-term disability care and support.[1] The APC report stated that people with disabilities are among the most disadvantaged in Australia due to the many social and financial challenges they and their families face,[1] and concluded that 'while Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.'[1] The report findings resolved that the need existed for a new government funded national insurance scheme for Australians with disability modelled upon Medicare, and in 2012 the NDIS became a reality.

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The NDIS objectives are described in the NDIS Act 2013[2] and these include (a) supporting the independence and social and economic participation of people with disability; (b) providing reasonable and necessary supports including early intervention; (c) enabling people with disability to exercise choice and control in pursuit of their goals and the planning and delivery of their supports; (d) providing high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in mainstream community; (e) raising awareness of issues that affect the social and economic participation of people with disability; (f) facilitating greater community inclusion of people with disability; and, (g) giving effect to certain obligations that Australia has as a party to such as the Convention on the Rights of the Child (1989).[2]

The NDIS will financially support people with disability, with assessment for this funding generally based on the person's functional capacity. This notion draws from the World Health Organization (WHO) framework termed the International Classification of Functions, Disability and Health (ICF). The ICF is a member of the WHO family of international classifications that complement the International Classification of Disease and Related Health Problems (ICD).[3] The ICD classifies such health conditions as disease, disorders and injury, whereas the ICF classifies the functioning and disability associated with health conditions.[3]

The ICF conceptualises disability in terms of function by de-emphasising the medical diagnosis and reframing the focus to functional outcomes.[4] Within the ICF, a person's function is conceived as a dynamic interaction between their health condition, environmental factors and personal factors,[3] and the Commonwealth Government and the states and territories have embraced this notion in developing the NDIS. As such, the recent NDIS legislation states that people with disability are considered eligible for NDIS funded support when their disability results in 'substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of communication, social interaction, learning, mobility, self-care, self-management'.[5] The planning for support funding occurs as a partnership between the person and the National Disability Insurance Agency (NDIA), with emphasis on individuality and direction by the person; in consideration and respect of the role of carers, family, community and other significant people; underpinned by the right of the person to exercise control over his or her own life; to advance the inclusion and participation in their own community; and with the goal of maximising the choice and independence of the person.[6]

To determine eligibility for disability funding, the NDIS draws on methodology that assesses the person across ten core areas of functional capacity, related to areas of activity, social and economic participation as identified in the ICF.[6] In the case of vision impairment, ophthalmic expertise is sought when it is deemed that further vision-related assessment is necessary.[6] Blais (2011) in the AMA Guide to Evaluation of Ophthalmic Impairment and Disability, comments that disability 'stems from an individual's inability to perform a task successfully because of an insufficiency in one or more areas of functional capacity'[7] and recommends that the measurement of disability impact should encompass the domains of physical, psychological, psychosocial, behavioural and contextual issues.[7] Given this recommendation, and the emphasis the NDIS places on the person's functional capacity, it is interesting to note that the current NDIS requirements for vision impairment involve reporting clinical measurements such as visual acuity and visual fields, and do not include measures grounded in functional domains.[8] These clinical measurements are applied to the NDIS criteria to determine eligibility, and the person will be funded if they have 'permanent blindness in both eyes, diagnosed and assessed by an ophthalmologist with corrected visual acuity on the Snellen Scale less than or equal to 6/60 in both eyes; or constriction to within 10 degrees or less of arc of central fixation in the better eye, irrespective of corrected visual acuity (ie visual fields are reduced to a measured arc of 10 degrees or less); or a combination of visual defects resulting in the same degree of visual impairment as that occurring in the above points'.[9] However, such reliance on clinical measurements does not occur consistently across all NDIS eligibility criteria. For example the NDIS Access Disability Requirements[9] list criteria from the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) to be applied for autism. A significant component of the DSM-V assesses the functional consequences of autism,[10] and when the person with autism demonstrates a severity level of 2 (requiring substantial support), or level 3 (requiring very substantial support) on the DSM-V, they are deemed eligible for NDIS funding.[9] A similar situation exists when a person has cerebral palsy. The Gross Motor Function Classification System (GMFS)[11] is used to assess a person's ability in sitting and walking, and they are deemed eligible for NDIS funded support when they are assessed as severely affected, at level 3, 4 or 5.[9]

Translating clinical measurements to reflect a person's visual functional capacity

Clinical measurements have long been accepted as integral components of vision assessments,[12] and are commonly available for reporting purposes once a person has undergone ophthalmic investigation. However it is open to question whether or not clinical measurements are true indicators of the possible functional consequences for the person when the visual system is affected by ophthalmic disease.[7] Commonly, people with vision impairment experience fluctuations in the quality of their vision caused by variations in the levels of light and glare in their immediate environment.[13] Quality of vision can also be influenced by the level of stress and fatigue the person is experiencing,[13] resulting in reduced clarity and contrast sensitivity[14] and influencing the ability to sustain reading even when low

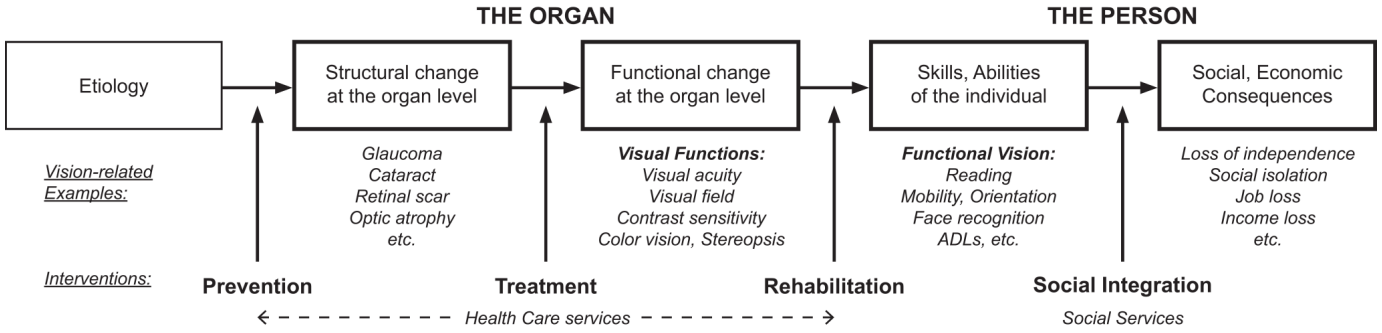

Figure 1. The four aspects of health and deficits.
('The four aspects of health and deficits' from A Colenbrander 2003.[17] Permission to reproduce given by Taylor and Francis www.tandfonline.com)

vision devices and assistive technology are used. It is widely acknowledged that clinical measurements alone do not quantify functional vision,[15] nor do they adequately explain variations in everyday performance of people with vision impairment.[16] This brings into question the suitability of the current reliance on clinical measurements alone in determining a person's eligibility for NDIS funding.

In addressing such a dilemma, Colenbrander has led in the exploration of vision from a functional perspective. Colenbrander[17] draws a clear distinction between clinical measurements and functional vision in a model that defines the four aspects of health and health deficits (Figure 1).

The model incorporates both visual function and functional vision. Colenbrander defines the former as how the eyes and the visual system function,[17] evidenced by the aggregate of precise psychophysical clinical measurements of the person's performance in such clinical tests as visual acuity, visual fields, contrast sensitivity, colour vision and stereopsis.[7] Through each test the clinician strives to determine the person's visual threshold capacity. For example when assessing visual acuity, the person is encouraged to indicate the smallest letter they can see on a vision chart, rather than just confirming that they can see a subthreshold letter size, one that is larger than the smallest letter they can see. These clinical measurements may indicate change at what Colenbrander terms the organ level (Figure 1), or the eye. These measurements are considered critical for attaining the person's diagnosis, and in grading the severity of ophthalmic disease.[7] They are also used over time to plot improvement or decline in vision and are thus indicative of the success of ophthalmic management.

Colenbrander describes functional vision as the way the person functions in vision-related activities,[17] for example facial recognition, orientation and mobility, reading and writing. In people with vision impairment, functional vision refers to their capacity to engage in vision-related activities while relying on a sustainable suprathreshold visual level that includes a comfortable performance reserve.[7] The measurement of functional vision is generally conducted in uncontrolled environments that are influenced by a variety of factors, for example light and glare, whereas visual function is measured in static, controlled environments.[18]

Colenbrander's model acknowledges the point at which the interpretation of a person's visual status shifts from reliance on clinical measurements to reliance on functional vision information, that is, when rehabilitation becomes relevant for the person. Although clinical measurements are commonly used to determine eligibility for rehabilitation, they are not considered a true indicator of the person's skills and abilities, or the social and economic consequences when measurements are suboptimal, as for example, when vision impairment exists.[19] As Colenbrander stresses 'knowing how the eye functions does not tell us how the person functions'.[20] The conclusion might therefore be drawn that clinical measurements alone do not translate to a complete understanding of a person's functional vision capacity.

The Functional Vision Score

In exploring the potential role that clinical measurements (visual function) have in estimating the person's ability to participate in generic activities of daily living (functional vision), Colenbrander[17] has proposed the calculation of a Functional Vision Score (FVS). Blais describes the FVS as a theoretical construct '… that provides a composite of the visual acuity and visual field scores for those situations in which it is helpful to distil the multifaceted reality of vision into a single number'.[7] The FVS has been incorporated into the methodology used by the American Medical Association Guides (2011) for evaluation of ophthalmic impairment and disability.[7]

To arrive at a FVS individual visual acuities and visual field outcomes are allocated an arbitrary score that follows the rule as the impairment increases, the score reduces. The uniocular score (worth 20% per eye) and binocular score (worth 60%) for both visual acuity and visual field (when available) are summed to calculate the Functional Vision Score.[17] The FVS is then subtracted from 100 to achieve the Visual Impairment Rating.[17] Colenbrander also adjusts for significant factors that affect the person's functional vision, for example reduced contrast sensitivity, glare, colour vision defects and reduced or absent binocularity, and suggests that this adjustment should be limited to

an increase in the impairment rating of the visual system (or a reduction of the FVS) by no more than 15 points.[21] This adjustment value has been selected as it potentially represents a clinically significant change, for example the equivalent of three lines on the ETDRS acuity chart. An adjustment of greater than 15 points might override the most important determinants of visual ability, visual acuity and visual fields (A. Colenbrander personal communication September, 2015).

A similar method of adjusting for the impact of significant factors has been reported in a study that attempted to develop guidelines for the evaluation of vision impairment in Korean adults.[22] The authors described adjusting by up to 15% for diplopia, accommodation error, eyelid disorders, epiphora, media opacities, cosmetic problems due to corneal opacity, aphakia and glare sensitivity. However, adjustment was not recommended for contrast sensitivity due to the unavailability of contrast sensitivity tests across locations; colour vision defects due to the rare nature of these defects and the fact that the impact on the person's generic activities of daily living (ADL) remains undetermined; and such binocularity defects as suppression and lack of stereopsis, again both of which vary in their effect on the person's ADL.[22]

Evaluating the Functional Vision Score

Several researchers have attempted to empirically evaluate the FVS, by comparing it to vision-specific measures or estimates of performance as in Quality of Life (QOL) measures.[23] QOL is known to be an important construct when determining the impact of such diseases as those that cause vision impairment. This impact can be measured by the degree to which vision-related activities of daily living are altered, ie impaired daily function becomes a proxy for visual function.[23] In evaluating the FVS developed by Colenbrander, researchers compared the FVS of 200 adults with ophthalmic disease (38% had macular disease, 18% glaucoma, 10% cataracts, 7% diabetic retinopathy, and the remaining 27% had various aetiologies) causing visual acuity of 6/18 or less and/or loss of visual field to their QOL determined using the National Eye Institute Visual Function Questionnaire 25 items (NEI VFQ 25).[23] The authors concluded that the FVS was the best predictor of QOL from the NEI VFQ scores, which '… lends evidence towards its validity as a measure of vision disability'.[23] Another study that compared the NEI VFQ 25 to FVS in 108 people with retinitis pigmentosa also concluded that vision-specific quality of life determined from the NEI VFQ 25 correlated well with the FVS.[24]

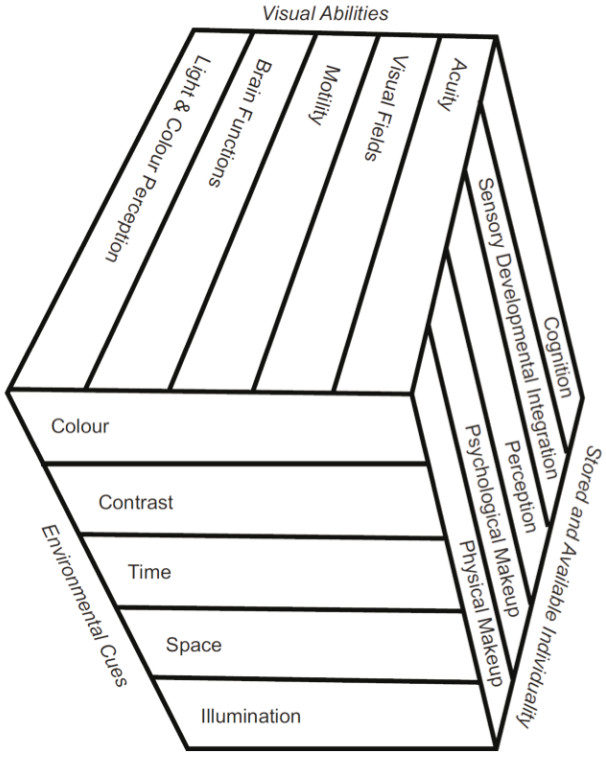

Figure 2. Model of Visual Functioning.

('Model of Visual Functioning' from AL Corn 1983.[27] Copyright 1983 by American Foundation for the Blind. All rights reserved.)

Limitations of the Functional Vision Score

Undoubtedly when compared to the clinical measurements for both the right and left eye the FVS better represents the reality of a person's visual function by considering their binocular status. However, the FVS remains constrained somewhat since it represents the person's vision within a clinical environment, rather than the person's habitual environment. Such habitual environments are visually dynamic, complex and demanding due to fluctuations in lighting, colour and contrast,[19] and present additional challenges to people with vision impairment not posed in static clinical environments. Also, the FVS does not account for the person as an individual and the ways they choose to use their vision, and cannot be applied to people who are unable to undergo standard vision assessment.

Reshaping concepts and assessments of vision

To ensure that reporting aligns with the paradigm shift that our states and territories have assented to through adoption of the NDIS, it is perhaps timely to reshape commonly held notions of vision, to formulate a broader definition that captures the complexity and individuality of the way a person sees. Several authors have attempted to deconstruct the known visual process into areas that can be potentially assessed and scored. One such author is Flom who comments that an 'individual's ability to see and function visually is determined largely by the relative contributions of a number of underlying components of vision'.[25] Further, understanding which of these components is affected by the person's vision impairment can provide insight into the way the person actually sees.[25] Jackson describes these components as resolution of high contrast detail, discrimination of low contrast features, colour differences, brightness, depth and utilisation of information from the full visual field.[26]

To broaden the concept of how a person sees, Geruschat and

Smith suggest an innovative extension of the traditional clinical measurements to include determination of the person's functional visual acuity and functional visual fields. Functional visual acuity consists of awareness acuity or the farthest possible distance that a person can detect rather than identify form; identification acuity or the farthest possible distance at which form is first correctly identified; and the person's preferred viewing distance or the most comfortable distance for a detected form.[19] Where possible, determination of the functional visual field is also recommended which includes two components, the static visual field and the preferred visual field. The static visual field is a measure of the outermost boundaries of the visual field performed in a non-clinical environment. The person is asked to describe the full extent of what they can see out to the boundaries of their visual field, whilst their eyes and head are still. The preferred visual field represents a dynamic measure of the person's regular pattern of viewing in everyday environments, determining the full extent of the person's visual awareness as they move their eyes and head. Although the functional visual acuity and functional visual field do not result in a numerical value as do the traditional clinical measurements of visual acuity and visual fields, they may provide an opportunity to better understand the person's functional use of vision and insights into the impact of their vision impairment.[19]

Corn perhaps takes a broader view by describing the three essential components of vision in her Model of Visual Functioning[27] (Figure 2). The model is composed of (a) the person's visual abilities including visual acuity, visual fields, ocular motility, brain functions, light and colour perception; (b) environmental clues including colour, contrast, time, space and illumination and (c) the person's stored and available individuality such as cognition, sensory developmental integration, perception, psychological and physical makeup. Corn discusses the need for each component to be present to the degree that will provide the person with the capacity to meet the demands of a visual task.[27] Perhaps this model begins to better represent a person's visual reality and as such can guide discussion regarding identification of the key components of visual function.

A further need exists to reshape assessment tools that address the complex nature of vision. For example, application of clinical measurements to the Corn model will only inform on one component of the person's visual function. These tools must somehow lead to establishing an understanding of the person's functional visual capacity to be meaningful for NDIS funding purposes. Recommendations by Blais begin to establish the key areas to be assessed which include the structural change at the organ level; functional change that includes visual acuity, visual fields and contrast sensitivity; the person's ability to perform such tasks as reading, mobility and face recognition; and the impact on the person's participation in society, the effect on employment and the potential for reduced quality of life.[7] Similarly Watson and Echt suggest that such a tool should assess the person's ability to discriminate detail, location and colour of objects in the environment at different distances and lighting levels, centrally and peripherally; and their ability to maintain fixation, and then to move the eyes, head and body to localise and track objects with ease and speed.[28]

Hyvärinen,[29] who has contributed extensively to paediatric ophthalmology, advocates for the assessment of four key areas when determining a child's functional visual capacity. These areas include vision for communication, vision for orientation and mobility, vision for activities of daily life, and vision for sustained near vision tasks. Hyvärinen further suggests that when a child has severe vision impairment, consideration should be given to the impact of the lack of visual information that may lead to decreased or absent initiation of communication and action.[29]

There is also merit in considering the potential that QOL assessments might play in determining a person's functional capacity, by such surveys as the NEI VFQ 25. Other measures might also warrant exploring, for example the Real Life Vision Test (RLVT) which is a vision-specific performance-based measure. The RLVT presents a person with commonly encountered tasks of daily living and grades their visual ability to complete these tasks.[12] Another form of QOL assessment that could also be contemplated is the Assessment of Function Related to Vision (AFREV)[30] which is administered by an observer and tests a spectrum of vision-related activities. The AFREV has been reported to correlate well with standard measures of visual function and certain aspects of self-reported assessments.[30] A further validated tool worthy of consideration is the Massof Activity Inventory (AI). AI is described as an adaptive visual function questionnaire that is based on a hierarchical theoretical framework.[31] The framework evaluates the person's ability to perform a task and the goals the task serves, the type of function required to achieve the goal; and the objective served by the goal. Massof comments that the AI 'can be used to take a structured and detailed functional history tailored to individual patients in a way that their responses still can be used effectively to estimate a quantitative measure of functional ability'.[31]

In summary, a review of the contemporary literature reveals the strength in a positive trend towards a broader approach to conceptualising vision and vision assessment. It reveals a foundation that could inspire a person-focused, theory-driven approach[32] to the development of a new methodology; one grounded both in the clinical and functional domains of vision.

DISCUSSION

The NDIS has been developed in the context of a person-centered, disability-focused framework to provide a strong policy base for empowerment and participation by Australians with disability.[32] The aim of this paper has been to raise an awareness of the need to develop a methodology that aligns with the main NDIS assessment objective, ie to identify core areas of functional capacity that are significantly and permanently impaired across a range of life functions, that present specific challenges for the person.[33] There is no doubt that it is convenient for clinicians to report on clinical measurements such as visual acuity and visual fields, as they are reproducible and easily measured,[7] and this remains the current NDIS expectation of reporting related to a person's vision.[9] However, the discussions in this paper have shown that clinical measurements cannot be easily translated to an understanding of a person's functional vision capacity.

To ensure that reporting aligns with NDIS objectives, it seems likely that a broader approach to vision and its assessment must be adopted. Work by Corn[27] provides thoughtful insights into the foundational components of vision that warrant consideration. A review of the literature reveals much consensus on the need to consider the person's functional vision to better understand the impact of vision impairment. Perhaps a marrying of the FVS and vision-specific performance measures should be considered as part of a solution? Additionally, the methodology that is developed will need to be suitable to apply to a population that is diverse in age, culture and capacity.

It is acknowledged that developing a new ophthalmic methodology will be challenging, but not impossible. As the NDIS is progressively rolled out across Australia it is critical that clinicians are active in the development of this methodology to ensure NDIS funding provides reasonable and adequate support to people with vision impairment.

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