VISION 2020
THE RIGHT TO SIGHT
AUSTRALIA

Response to the draft National Disability Insurance Scheme Bill 2012

January 2013

National body working in partnership to prevent avoidable blindness and improve vision care

Contents

1 Introduction **1**

2 Members of Vision 2020 Australia Low Vision and Rehabilitation Committee **2**

3 Executive Summary **4**

4 Recommendations **5**
4.1 Recommendation 1 5
4.2 Recommendation 2 6
4.3 Recommendation 3 8
4.4 Recommendation 4 10

5 Conclusion **12**

6 Contact details **12**

1 Introduction

Established in October 2000, Vision 2020 Australia is part of VISION 2020: *The Right to Sight*, a global initiative of the World Health Organisation and the International Agency for the Prevention of Blindness.

The organisation's vision is the elimination of avoidable blindness and vision loss by the year 2020 and ensuring that blindness and vision impairment are no longer barriers to full participation in the community.

Over 60 organisations are members of Vision 2020 Australia and are involved in; local and global eye care, health promotion, low vision support, vision rehabilitation, eye research, professional assistance and community support.

Members come together to collaborate, advocate and raise awareness of eye health and vision care in Australia and in our region.

Recognising the transformative opportunity of the National Disability Insurance Scheme (NDIS), Vision 2020 Australia and its member organisations have come together to provide a united voice to the Senate Standing Committee on Community Affairs (the Committee) to ensure that the draft NDIS Bill 2012 maximises positive outcomes for people who are blind or have functional vision loss when the NDIS sites are launched on 1 July 2013. This response has been produced in collaboration with members of the Low Vision and Rehabilitation Committee of Vision 2020 Australia. We appreciate the opportunity to provide feedback to this critical element in the NDIS policy, and as this response represents the expert advice of Australia's leading organisations in vision related sensory disability, that the Committee accept and progress the recommendations.

2 Members of Vision 2020 Australia Low Vision and Rehabilitation Committee

(Alphabetical order)

Association for the Blind WA

Australian College of Optometry

Blind Citizens Australia

Brien Holden Vision Institute

CanDo4Kids - Townsend House

Centre for Eye Research Australia

Guide Dogs NSW/ACT

Guide Dogs QLD

Guide Dogs SA.NT

Guide Dogs Victoria

Keratoconus Australia Inc

Macular Degeneration Foundation

Optometrists Association Australia

Queensland Vision Initiative Inc

Retina Australia

Royal Guide Dogs Tasmania

Royal Institute for Deaf and Blind Children

Vision Australia

Association for the Blind WA

Australian College of Optometry

Blind Citizens Australia

Brien Holden Vision Institute

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Optometrists Association Australia

Queensland Vision Initiative Inc

Retina Australia

Royal Guide Dogs Tasmania

Royal Institute for Deaf and Blind Children

Vision Australia

3 Executive Summary

Vision 2020 Australia and its member organisations are strong supporters of the National Disability Insurance Scheme (NDIS). Only a major reform on the scale of Medicare is the answer to fixing the lottery that currently exists in the provision of disability support in Australia, and we remain committed and engaged in the process of turning theory into practice as the NDIS becomes a reality. The undersigned members and Vision 2020 Australia recognise the opportunity before us, and we come together with a united voice to provide advice at this critical time in the development of the NDIS.

Vision 2020 Australia is encouraged by the release of the draft NDIS Bill 2012 for public comment, and draw some comfort from the recognition of the functional impact of visual sensory disability. Vision 2020 Australia remains concerned however, that people aged 65 years or over may be excluded from equitable disability services on the basis of their age. We also seek assurances from the NDIS Rules that a person's functional need will not be determined by a medical diagnosis of legal blindness or clinical assessment alone. Finally, we propose the consideration of an independent middle path (such as a Disability Services Commission) to review decisions and resolve complaints in a way that is truly independent and accessible.

As Australia's leaders in the blindness and low vision sector, we have drawn upon our unique position to gather together and present with one voice, the perspectives of what is important to consumers and the real life support profiles of people who are blind or have functional vision loss. As we move closer to the introduction of the NDIS in the five launch sites on 1 July 2013, now more than ever is the time to understand fully the landscape of support that is the everyday for people who are blind or have functional vision loss around Australia. It is our hope that this will assist the Committee in understanding our perspective inherent in our recommendations in response to the Bill and positively guide the detail that is still to come.

4 Recommendations

4.1 Recommendation 1

4.1.1 Age criteria - s.21.2(b), (c) and s.22.1(a)

Vision 2020 Australia rejects the exclusion to the NDIS for people aged 65 years or over, under s.22, and seeks guarantees that mechanisms will be established ensuring that all people who are blind or have functional vision loss will have access to equitable disability services and support and will not be disadvantaged on the basis of their age.

Explanation

The 65 age is likely to create a situation of 'have and have nots' purely on the basis of age. Put simply, whilst a person aged 64 might be able to access the scheme and the supports they need, another person aged over 65 years would not, even where both have exactly the same conditions and needs.

Additionally, Vision 2020 Australia is unable to support s.22 as there are no specific comparable supports or measures provided by the aged care and health services sectors for the provision of disability related services and supports for people who are blind or have functional vision loss and are 65 years and over. Considering the impact of vision related disability on an individual, where the social, attitudinal and environmental barriers remain present regardless of one's age, this arbitrary cut off fails the equity and fairness test prescribed in the National Disability Strategy.

Figures from *Access Economics* indicate that over 70% of people who currently experience vision loss are aged 70 and above, with macular degeneration the leading cause of blindness and vision impairment[1].

Without any change to the proposed age criteria, people who are blind or who have functional vision loss will fall through the cracks. Vision 2020 Australia therefore asks that the Committee include within its report a strong recommendation to Parliament to change s.22 that people aged 65 years or over are eligible for the NDIS, or have guaranteed equitable access to publically funded support and services.

[1] Access Economics (2010) *Clear Focus - The economic impact of vision loss in Australia in 2009,* Canberra, Australia www.vision2020australia.org.au/resources.cfm

4.2 Recommendation 2

4.2.1 Grandfathering provision – s.21.2

Vision 2020 Australia seeks amendment to the grandfathering provision of s.21.2(B) that enables the continuation of services for applicants receiving services who aged 65 years or over, to be extended to applicants with a condition diagnosed within the prescribed period but who have not accessed services.

Explanation

The grandfathering provision under s.21.2 (b) allows for an applicant aged 65 years or over who does not meet the age requirements of s.22.1 (a) at the time of application, to be eligible to participate if the applicant can demonstrate that they have been in receipt of prescribed supports at a prescribed time or within a prescribed period as set out in the NDIS Rules. This provision recognises the importance for individuals to continue to receive supports where they have an ongoing need, and acknowledges that it is not reasonable to create a barrier to access solely based on an individual's age.

Notwithstanding our strong assertions under Recommendation 1, Vision 2020 Australia considers that this same intent be extended to applicants who have been diagnosed with an eligible condition and who meet the other access requirements for disability or early intervention under s.24 and s.25, but are yet to access supports. This is a reasonable adjustment given that the grandfathering provision already recognises that it is unfair to enforce the age restriction where an individual was already accessing services, and the same rationale is valid for someone whose condition has increased in severity over time or they had simply not engaged support within the prescribed timeframe. It would seem unfair to penalise an individual because their pre-diagnosed condition had not manifested a required functional impact within a prescribed timeframe. And as with the current provision, this amendment would still be time limited to a period prescribed by the NDIS Rules, which Vision 2020 Australia suggests should be no less than 24 months prior to the launch on 1 July 2013.

Hypothetical examples

The following hypothetical examples are provided to demonstrate how the current proposed approach, if left unchanged, may unfairly impact individuals living with blindness.

Case 1 – Existing grandfathering provision

'Lucy' is a 68 year old former primary school teacher living in Geelong. She has late onset retinitis pigmentosa and has utilised a range of services following significant decline in her vision over the previous 15 years. When her vision loss first started significantly impacting on her ability to read and navigate around the community, she accessed adaptive technology training to learn how to use screen magnification

software on her computer and a hand held portable magnifier, and had orientation and mobility training to maximise her use of residual vision and adopted the use of an ID cane when out at the shops so that people in the community were aware of her functional low vision. However, over the last 5 years with a rapid decline in vision, she has needed to transfer to using screen reading technologies, the use of a long cane, occupational therapies to keep up her love of cooking and to learn techniques for cleaning around the home. Although Lucy does not meet the age criteria, it is possible with her history of service access, that her application to participate in the NDIS will be approved and she will have ongoing access to disability services to assist her independent day to day living.

Case 2 – Inclusion of diagnosis (Our Recommendation)

'Luke' is a 69 year old carpenter who has his own home maintenance and minor renovations business with his two sons in Newcastle. While he continues to engage with his work, in 2011 he was diagnosed with macular degeneration and is now starting to have significant difficulties with fine detail in his work, reading and depth perception on construction sites, and moving around the community. Luke has never accessed functional low vision rehabilitation services before and he is unsure about what is available in terms of training and aids and equipment to assist him maintain his independence and continue working in his business. Early intervention at this crucial time of transition will be a significant factor in whether Luke is able to maximise his contribution in his business, and engage with his current lifestyle moving forward. Should diagnosis not be included in section 21.2(b), Luke **WOULD NOT** be eligible to receive the rehabilitation and early intervention services he needs for the short and long term.

Both Lucy and Luke have had to adapt to changing situations due to their vision loss but as it stands, only Lucy's needs would be counted. Should Luke's functional impact have manifested earlier and should he have accessed a range of rehabilitation services and supports, the current grandfathering provision would likely have included his access to the NDIS.

Vision 2020 Australia considers that the extension of s.22.1 (b) to include a provision of diagnosis under the same statutory requirements set out in the NDIS Rules, would:

- be consistent with the intent of the current provision,
- not undermine the integrity of the scheme due to its time limited nature; and
- promote the social and economic engagement purpose that the NDIS is seeking to achieve.

4.3 Recommendation 3

4.3.1 Disability requirements s.s22 and early intervention s.25

Vision 2020 Australia seeks assurances that the translation of s.24 and s.25 in the NDIS Rules will adequately include the needs of people who are blind and people who have functional vision loss without an arbitrary medical diagnosis of legal blindness.

Explanation

The Bill's high level statements in s.24 and s.25 provide an encouraging indication that legal blindness will not be the only determinant for participation and that functional vision loss (low vision) will be included in the NDIS. However without further detail on the assessment process, certainty cannot be guaranteed.

Vision 2020 Australia highlights the point that the severity of a medical diagnosis of vision related disability, the interventions, supports and services have varying levels of intensity, but the functional impact on an individual remains comparable.

In 2009 the Australian Government supported the World Health Assembly (WHA) *Action Plan for the Prevention of Avoidable Blindness and Visual Impairment* (WHA Action Plan). The WHA Action Plan sets out a host of challenges for member states and is set to be revised for the period 2014 – 2019. The vision of the *Zero draft Universal Access to Eye Health: Global Action Plan, 2014-19* states 'A world in which no one is needlessly visually impaired, where those with unavoidable vision loss can achieve their full potential, and there is universal access to eye care services'. To ensure this vision is achieved, it is imperative that functional vision loss, be included, in addition to legal blindness and not rely solely on a medical diagnosis within the NDIS.

It is important the NDIS recognises the incidence of disability can be directly influenced by a system providing timely, meaningful and effective intervention and treatment/rehabilitation measures. For example, front end loading eye health interventions can reduce the further incidence of disabling eye conditions and vision loss. This in turn can affect the broader health system such as reducing early hospitalisation and access to the mental health system.

The following principles further describe and provide evidence on functionality and cost of varying levels of vision loss.

Same outcomes for less cost

Service profiles typically indicate that more vision means less cost, less intensity and less frequent support. It is estimated that an indicative ratio of 1:4 between people who have low vision and those who are blind can be used across all three measurements[2]. Therefore, positive outcomes can be met for people with functional vision loss at a reduced premium.

[2] Centrelink FOI request by Vision Australia, October 2011.

Proportionally small numbers

It is difficult to accurately determine the prevalence of blindness and functional vision loss in the Australian community. However, there are several different sources that could be drawn upon to assert prevalence. The Productivity Commission has drawn upon data from the ABS 2009 Survey of Disability Ageing and Carers (SDAC), however, this data does not provide an accurate representation of prevalence for blindness and low vision. The 2009 SDAC estimates the number of people who are blind in Australia to only be around 16,200, which is in contrast to Centrelink data showing some 26,532 persons are currently recipients of a Disability Support Pension (DSP) or Aged pension and are blind[3].

To overcome this deficiency, population prevalence modelling has been performed which extrapolates data from the 2003 SDAC across the 2011 census data[4]. This analysis uses the proportional prevalence by age, blindness and low vision from the 2003 SDAC and applies it to corresponding population data derived from the 2011 Australian census. This modelling estimates that there are likely to be around 333,000 people in Australia who are blind or have low vision that cannot be corrected by spectacles or contact lenses.

Should the NDIS budget proper only be concerned with people aged under 65 years, the modelling estimates that there are only 13,000 people who are blind and 129,000 people with low vision aged under 65 years within the broader group. However, from market projections based on real service data, it is anticipated that less than 30 per cent or 3,900 people who are blind and 10 per cent or 12,900 people who have low vision will seek to access NDIS funded support in any given year. This represents only 4 per cent of all those who will be funded by the NDIS[5].

Fiscally Responsible

Based on this market segmentation and drawing upon anticipated corresponding cost profiles in the Productivity Commission's report, the total cost to the NDIS budget for vision related disability would be a maximum of $250 million or less than 2 per cent of the NDIS operating budget. This is using the exaggerated cost profile of $15,000 for each and every person, even though real life profiles indicate most people with low vision will seek to use less than $4,000 in any given year. If the anticipated 1:4 cost ratio plays out, the actual total cost is likely to be closer to $110 million or less than 1 per cent[6].

The right social investment

Social investment is recognition that there are consequences stemming from social spending that flow back to the community in different ways, similar to how spending on infrastructure has a myriad of positive community consequences. Social spending is not dead money, but is dynamic in terms of the flow on effects it generates.

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[3] Ibid

[4] Vision Australia's figures are based on information from the ABS (Australian Bureau of Statistics): (1) from the latest general population census (2011) and: (2) from the 2003 Survey of Disability Aging and Carers (SDAC).

[5] Ibid

[6] Productivity Commission (2011), Chapter 16 in 'Disability Care and Support', Report no. 54, Canberra.

There are many different approaches to measuring social investment. The Social Return on Investment (SROI) methodology has been used to calculate the monetary return to the community for each dollar spent on a range of services, and useful indicators have been quantified. This analysis reveals that substantial returns to the community are derived from each dollar spent on blindness and low vision services, with a minimum of $1.85 returned by Orientation and Mobility training, $8.58 from disability employment services, and $12.40 from children and family services[7]. These examples of returns exist despite limitations accurately quantifying social returns across the spectrum of community interactions and projecting these gains long term. Despite these shortcomings quantifying the full extent of returns, providing access to services and supports to all those that need them, does make good financial sense and is the right social capital investment.

Therefore, Vision 2020 Australia strongly recommends that the Senate Committee's report articulate the need to include access provisions for people with functional vision loss according to the World Health Organisation's designation of 6/18 for low vision[8].

4.4 Recommendation 4

4.4.1 Review of decisions s.99 and appeals s.103

Vision 2020 Australia recommends consideration of an independent middle path (such as a Disability Services Commission) to review decisions and resolve complaints in a way that is truly independent and accessible.

Explanation

Vision 2020 Australia feels the internal review process of s.99 is not a transparent review mechanism that holds sufficient independence to provide assurance to persons seeking a review of decisions. The proposed next step of going to the Administrative Appeals Tribunal (AAT) does not provide reasonable ease of access without undue burden on complainants. Vision 2020 Australia believes a review body completely independent from the funding agency is essential.

A middle path is not without precedent (i.e. Victoria has a Disability Services Commissioner, or other appropriate model) and may provide a faster and more efficient review mechanism that is less arduous on complainants and as it would be disability service specific for the NDIS, would provide some assurance of decisions having due respect to the nuance of disability issues.

The National Disability and Carer Alliance conducted a series of consultations involving over 2,000 people with disabilities, families and carers and service providers in the second half of 2012. A summary report was provided outlining the issues raised and a

[7] Ibid

[8] These criteria are based upon testing of vision with the Snellen chart. With the standard Snellen chart, vision is tested at a distance of 6 meters or 20 feet. 'Normal' visual acuity is 6/6 or 20/20.

section on Reviews and Complaints outlined that the reviews and complaints system must focus on individual issues, needs and outcomes[9]. Further, the review process should:

- Consist of a review body completely independent from the funding agency.
- Address issues in a timely manner.
- Allow the opportunity to involve independent support persons, perhaps including a system of lay advocates.
- Have the ability to enforce its rulings.
- At no cost, without lawyers, be welcoming with a variety of venues for hearings. The process and results need to be widely publicised.
- Require a defined framework including: *how to use it* and *what to expect*.
- Include a process to ensure systems modification based on feedback for all parties from reviews and complaints data.

[9] National Disability and Carer Alliance (2013), *Summary Report-Key Issues Raised in the Alliance NDIS Community Engagement Project*

5 Conclusion

Vision 2020 Australia supports the creation of a National Disability Insurance Scheme. It is a significant social and economic reform, long overdue.

We are encouraged by the release of the draft NDIS Bill 2012 for public comment, however in order to provide reassurance that the NDIS will fully meet the needs of people who are blind or who have functional low vision, the NDIS must address Vision 2020 Australia's concerns around age restrictions, eligibility to participate in the scheme and an independent disability specific appeals process.

Vision 2020 Australia's recommendations support the notion of inclusion, economic independence and contribution to society, need and equity, on which the scheme is built.

6 Contact details

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