



Submission to the parliamentary inquiry into NDIS Workforce

Joint Standing Committee on the NDIS –
NDIS Workforce

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SUMMARY OF RECOMMENDATIONS

Recommendation 1. Undertake research to determine current unmet need across all service types for NDIS participants with deafblindness

Recommendation 2. (this recommendation is Recommendation 14. from Prain (2019)). Workforce development is needed to train more interpreters and communication guides to work with people with deafblindness, and to upskill allied health professionals in the area of deafblindness.

Recommendation 3. Research is needed to determine the key factors which are leading to the lack of supply of all professionals, with a specific focus on interpreters and communication guides, to better know how to address these shortages

Recommendation 4. (consistent with recommendation 2 from Prain (2019)). NDIA to appoint a full time Deafblind Consultant in each State to:

- Improve coordination of service provision to individuals with deafblindness
- Improve service provision of generic disability service providers to ensure they are meeting the unique and specific needs of individuals with deafblindness
- Support and coordinate training and professional development of State based services providers in deafblind awareness

Recommendation 5. That medium to long term (5 – 10yr) funding is available through the Information, Linkages and Capacity Building grants to develop the workforce of people with deafblindness which will both build capacity and economic participation of people with deafblindness and help address current workforce shortfalls.

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 envisaged that the National Disability Insurance Scheme will to some extent address current issues experienced by people with deafblindness, unless systemic changes are made to approaches to workforce development relating specifically to the needs of this diverse group, it is likely their needs 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, use of communication guides trained specifically to work with people with deafblindness, and deafblindness consultants to provide input to service providers and community facilities to ensure the access needs of the person with deafblindness are fully understood and addressed. 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.

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, potentially through cross departmental initiatives, if the needs of people with deafblindness are to be addressed effectively.

The need for workforce development to address the needs of service users with deafblindness is not an issue solely faced by the NDIA, but also in education, health, transport and aged care, so there are opportunities for initiatives specifically focused on development of staff working with people with deafblindness to have broad reaching impacts.

BACKGROUND

Introduction to deafblindness

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

People with deafblindness will ALL require the provision of hearing services at some stage in their lives, though services for those with the single sensory impairment often do not fully address the needs of, or remain inaccessible to people with deafblindness.

Prevalence and causes of deafblindness

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). 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. All individuals with Usher syndrome will fulfil the criteria for acceptance into the National Disability Insurance Scheme given they are born with a hearing impairment and have a progressive vision condition which will significantly impact on their functioning well before the age of 65 years.

CHARGE syndrome also results in combined vision and hearing impairment. 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)

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 (Kiana and Miller, 2010).

RESPONSE TO TERMS OF REFERENE

- a. the current size and composition of the NDIS workforce and projections at full scheme

For NDIS participants with deafblindness, there are certain professionals which most will require services from at some point, if not continuously throughout the duration of their NDIS participation. These include:

- Auslan interpreters (See Appendix A),
- Communication Guides (support workers trained and skilled at working with people with deafblindness)
- Deafblind Consultant (funded under multi-disciplinary therapy, or specialist support coordination, See Appendix B)
- Orientation and Mobility Specialist
- Orthoptist
- Occupational Therapist
- Speech Pathologist
- Assistive technology trainer
- Social Worker
- Psychologist

Some will also require 1:1 Auslan and / or braille training.

Senses Australia in Western Australia is currently the only services which provides the full complement of services listed above (apart from Auslan interpreting) by professionals trained and experienced in the needs of clients of all ages with deafblindness.

Some data is available regarding supply of and demand for Auslan interpreting services, however this data is lacking for other services.

Currently there is only training for communication guides in Perth, Melbourne, Adelaide and Newcastle, however the training is only run regularly in Perth and Melbourne where it is not currently dependent on grant funding. In other areas, people with deafblindness need to train their support staff on the job which can be slow, challenging and insufficient.

Also, mainstream service providers who employ support workers are typically not aware of the range of competencies required by communication guides and do not pursue training for staff, or use targeted recruitment strategies to find staff with at

least some of the skills required to provide adequate support to participants with deafblindness. Training to these staff would best be provided by both deafblind consultants and trainers with deafblindness.

Given the nature of deafblindness consistently impacting on an individuals' ability to effectively communicate with those in all environments and to orient and move about safely and independently in all environments, all individuals with deafblindness require the support of communication guides to some extent. With communication guides being funded as core supports for typically 6 – 20 hours per week and Dyke's (2013) estimated 13,700 people with deafblindness under the age of 60, it is clear that there is a current under supply of communication guides, nationally, but even more so in those regions where no training is available.

Regarding supply and demand of Auslan interpreters:

"The Auslan user survey indicates that there were around 110,000 occasions over the past

year where a professional Auslan interpreter was required in the key service areas. On

68,000 (61%) of these occasions, a professional Auslan interpreter was provided.

Estimates calculated from responses to the Auslan user survey of professional

interpreting provision across key service areas are broadly in line with the estimates based on data submitted by Auslan interpreting service providers. For example, 66% of the occasions on which users said that interpreting services had been supplied related to education/employment. As discussed in Chapter III.C, Auslan interpreting service provider data indicated that education and employment together accounted for

59% of the total expenditure on Auslan interpreting services in 2002-03 (see (Department of Health and Community Services, 2004, p.59)

And

"The Deaf Auslan user survey found that the vast majority (between 80% and 87%) of

Deaf Auslan users who attended a medical consultation (e.g. a doctor's appointment, hospital, dentist, etc) in the last 12 months considered that they needed an interpreter.

However:

- 66% of those who needed an interpreter at doctors' appointments (general

practitioners or specialists) were not always able to get one;

- 34% of those who needed an interpreter at a public hospital were not always able to

get one;

- 41% of those who needed an interpreter at a private hospital were not always able to get one; and
- 63% of those who needed an interpreter at a consultation with a health professional

(other than a general practitioner or specialist) were not always able to get one.”

Department of Social Services (2004, p.70)

It is recognised these figures are quite old now, however with the increase of funding available for interpreters resulting from the NDIS, there is significantly increased demand with no initiatives to change supply.

Also, it must be noted that these figures are for Auslan generally and do not take into account the issues associated with sourcing Auslan interpreters for bookings with people with deafblindness. Auslan interpreters require an additional skill set for working with people with deafblindness and many are not skilled or confident in working with this population, thus reducing supply further.

As acknowledged the data outlined above is relatively old, however the key issues stated appear to be persisting as evident in a more recent survey undertaken by Dillon & Heuston (2018).

Their findings indicated that:

“Demand for interpreting service hours are trending upwards with employers predicting that they will be more severely strained over the next three years.”

Interpreters report that the following issues contribute to them leaving or considering leaving the profession, or reducing their commitment and availability:

- unreliable, insufficient, and casualised work;
- less than desirable remuneration (including out of pocket expenses);
- lack of structured professional support;
- feelings of isolation, not being valued, and lack of connectedness with peers;
- unaddressed WHS hazards (both physical and psychological), and
- affordable and accessible Professional Development.”

(Dillon & Heuston, 2018)

In summary, across all regions and service types, there is a lack of trained, skilled, experienced service providers to meet current demand of NDIS participants with deafblindness. With no systemic processes to address this undersupply, it will only worsen as the scheme is fully rolled out.

In order to develop systemic approaches to address supply, more accurate data regarding demand is needed.

Recommendation 1. Undertake research to determine current unmet need across all service types for NDIS participants with deafblindness

Recommendation 2. (this recommendation is Recommendation 14. From Prain (2019)). Work force development is needed to train more interpreters and communication guides to work with people with deafblindness, and to upskill allied health professionals in the area of deafblindness.

- b. challenges in attracting and retaining the NDIS workforce, particularly in regional and remote communities;

It is known that people with deafblindness and their families are currently experiencing difficulty finding professionals to support them in addressing their stated NDIS goals, however it is unclear to what extent this reflects a lack of professionals with the necessary skills and experience in deafblindness or a lack of professionals available at all.

People with deafblindness living in rural and remote areas are at increased risk of under servicing, particularly as telepractice is less viable with this group due to the tactile nature of learning and communication.

Recommendation 3. Research is needed to determine the key factors which are leading to the lack of supply of all professionals, with a specific focus on interpreters and communication guides, to better know how to address these shortages

- c. the role of Commonwealth Government policy in influencing the remuneration, conditions, working environment (including Workplace Health and Safety), career mobility and training needs of the NDIS workforce;

The key requirements of Commonwealth Government policy in positively influencing workforce development to improve quantity and quality of services for NDIS participants with deafblindness are;

- recognition of deafblindness as a unique and isolating disability required specifically trained and skilled professionals including communication guides and deafblind consultants.
- recognition of the need for nationally accredited training programs in deafblindness (as exist in other countries e.g. George Brown College, see <https://www.georgebrown.ca/C108-2011-2012/>)
- Appointment of State based deafblind consultants to:
 - o Improve coordination of service provision to individuals with deafblindness
 - o Improve service provision of generic disability service providers to ensure they are meeting the unique and specific needs of individuals with deafblindness
 - o Support and coordinate training and professional development of State based services providers in deafblind awareness

Recommendation 4. (consistent with recommendation 2 from Prain (2019)). NDIA to appoint a full time Deafblind Consultant in each State to:

- Improve coordination of service provision to individuals with deafblindness
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d. the role of State, Territory, Commonwealth Governments in providing and implementing a coordinated strategic workforce development plan for the NDIS workforce;

See section c. and recommendation 4.

e. the interaction of NDIS workforce needs with employment in adjacent sectors including health and aged care;

By employing deafblind consultants in each State, with local knowledge, support of professionals working with people with deafblindness across the lifespan and across sectors such as disability, education, health, and aged care. Allied health professionals and others working in one sector would take awareness of needs of people with deafblindness across sectors if changing employment. For example, an Occupational Therapist who has learnt about the communication and education needs of a child with deafblindness, will be able to apply these principles if they move to aged care where they are highly likely to encounter some older adults with deafblindness, thus more readily and appropriately meeting their needs.

See recommendation 4.

f. the opportunities available to, and challenges experienced by, people with disability currently employed, or wanting to be employed, within the NDIS workforce

People with deafblindness have a central role in educating and being involved in formal training of NDIS staff and service providers regarding the needs of people with deafblindness.

There are currently people with deafblindness working as Local Area Coordinators, and communication trainers, however more opportunities exist for people with deafblindness to undertake capacity building roles with regard to teaching technology, braille and a variety of communication techniques including Auslan.

People with deafblindness across all sectors experience challenges in employment, and would benefit from approaches such as that taken by Blind Citizen's Australia to promote positive examples of people with disabilities in employment and offering opportunities for mentoring. Considerable time and effort are required to build the confidence and skills of people with deafblindness to effectively participate in the

workforce, but more funding for projects such as Able Australia's Deafblind Employability project will help further increase the confidence and skill set required. Current short term funding through ILC grants is insufficient to allow time for confidence and skill development.

Recommendation 5. That medium to long term (5 – 10yr) funding is available through the Information, Linkages and Capacity Building grants to develop the workforce of people with deafblindness which will both build capacity and economic participation of people with deafblindness and help address current workforce shortfalls.

g. any other matters

Senses Australia, recognising the widespread need for capacity building of the existing workforce of allied health professionals to be better able to meet the needs of Australians with deafblindness have initiated monthly national peer supervision sessions via videoconference.

Similarly, Able Australia through the Centre of Excellence – Deafblind are coordinating collaboration between all those currently running training for communication guides to develop a nationally agreed upon set of competencies and training modules to address these.

These activities currently receive no funding and so are at risk of discontinuation or incompleteness. These are core activities which would be addressed by recommendation 4, having a National team of deafblind consultants to work on both local capacity building and National systemic projects to improve consistency and quality of service provision.

See recommendation 4.

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