



**Response to the 2020 review of the Disability
Standards for Education 2005**

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Acknowledgements

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Background

Deafblind Australia (DBA) is the peak body for people with deafblindness, and their family members, service providers and support networks in Australia.

DBA promotes the rights of all people with deafblindness to live full and rewarding lives, engaging in all aspects of civic life.

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.

Causes of deafblindness and prevalence

The below background information is given regarding prevalence and causes of deafblindness to support recommendations made throughout this submission. While exact prevalence of deafblindness is not known, it was estimated that in 2013, there were 13,700 Australian's with deafblindness under 60 years old (Dyke, 2013).

There are a number of syndromes and other causes which result in hearing impairment combined with vision impairment (deafblindness). 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).

Norrie disease is an inherited eye disorder resulting in blindness in male infants at birth or soon after birth. Additional symptoms occur in some cases, however this varies from case to case. Most individuals with Norrie disease develop sensorineural hearing loss and many exhibit cognitive abnormalities such as developmental delay, and behavioural issues including psychotic-like behaviours. Treatment focuses on the specific symptoms present in each individual. The coordinated efforts of a team of specialists, including paediatricians, ophthalmologists, and audiologists are typically needed. Early intervention and special education services are important to ensure that children with Norrie disease reach their full potential. (National Centre for Advancing Translational Sciences, 2016)

2020 review of the Disability Standards for Education (DSE) 2005

This DBA response to the 2020 DSE review refers specifically to students with deafblindness. The DBA response is a synthesis of responses compiled during a consultation period with members. We have also drawn from the submission made to this review from the South Pacific Educators of the Vision Impaired (SPEVI), and reiterated their points where relevant to students with deafblindness.

Supporting students

How have you appropriately supported students with disability during their education? This includes the student being able to access supports, including specialist resources.

Services for students with deafblindness are fragmented. Typically, they receive services from a Visiting Teacher of the Blind or a Visiting Teacher of the Deaf, or both, but neither usually fully understands the implications of the dual sensory impairment. Students with deafblindness often have very unique and individualised needs which are typically poorly addressed and which contribute to feelings of isolation and lack of belonging.

Students with deafblindness, their parents and educators all experience a sense of isolation as typically none have met another student or family experiencing deafblindness, so even if they do know their rights, it is hard to have them addressed or know where to go for assistance.

Specialist Teachers (VI and Deaf) support students in the following nine areas of the Expanded Core Curriculum:

- Technology, including mainstream and assistive technology and optical and hearing devices,
- Compensatory skills such as sign language, braille and handwriting skills,
- Sensory efficiency, including tactile, auditory or visual perceptual skills,
- Orientation and mobility, including safe and efficient travel between home and school and within the school,

- Social interaction skills, which are predictors of personal life and future employment,
- Career education, including types of careers and specific skills required,
- Recreation and leisure skills, including what recreation options are available and how to access them safely,
- Independent living skills, such as cooking, dressing and organisational skills, and
- Self-determination and empowerment skills, including self-advocacy, problem solving and independent responsibility.

The variability in quality and quantity of services and programs for students with deafblindness directly impacts on the students' educational outcomes. Variability can be found in (i) education sector policies and standards, (ii) funding provision for optical and assistive devices, technology and alternative formats (braille, large print, digital, audio), (iii) levels of student access to specialist teaching support due to geographical location (urban, rural, remote), and (iv) attitudes, policies and practices of school leaders and staff.

It is not uncommon for parents and allied health professionals to need to advocate strongly for the provision of essential services and equipment for students with deafblindness to fully access the curriculum.

Appropriate supports for students with deafblindness throughout their education include:

Plans and Profiles:

- Individual Curriculum Plans
- Individual Education Plans
- Individual Student Support Plans
- Personalised Learning Plans
- Classroom Level Support Plans
- Communication Profile
- Learning Media Profile

Education and therapy supports:

- Specialist Teachers of the Vision Impaired
- Specialist Teachers of the Deaf
- Speech and Language Pathologist, Occupational Therapist (OT), Physiotherapist, Orientation and Mobility Specialist, Psychologist, Creative Arts Therapist (music, art, dance and drama), Deafblind Consultant.
- Auslan language models
- Adjustments and accommodations to the Australian curriculum, pedagogy and/or learning environment
- Adjustments and accommodations for health and personal care, safety, social emotional wellbeing, or communication

- Individualised English and Mathematics goals created and progressed each semester
- Assistive listening technologies
- Alternative Augmentative Communication (AAC) systems (e.g. Proloquo2Go, tactile signing systems)
- Roadmap of Communicative Competence (ROCC)
- Multi-sensory room for students with severe disabilities
- “Engine room” for students requiring emotion regulation and/or physical movement supports.

Transitions

Tell us about your experience assisting a student with disability to transition from one education sector to another; for example, from school to further education.

Transitions between preschool and school, and school to tertiary education or other post-school options, are multi-faceted and often challenging for students with deafblindness and their families.

The following are recommended to support students with deafblindness when undergoing education transitions:

- Emphasis on development of social skills, including emotion regulation, and problem solving skills, in order to establish new friendships and a sense of belonging in the new school community.
- Emphasis on supporting students to orient themselves to the new physical environment and independently managing home to school transport options when possible
- Collaboration and support for classroom teachers and teacher assistants in learning how to create accessible books and learning materials, and inclusive teaching strategies. This support includes provision of training sessions during student-free days or staff meetings.
- Participation in transition or education teams, together with the transitioning student and family, key school staff and supporting professionals.
- Advocating for parents and caregivers to be included as equal partners in the transition process, to ensure a holistic, “team around the child” approach in which a clear understanding of the capabilities and needs of the individual student are communicated to staff in the new educational setting.
- Emphasis on proactive, student-centred approaches to school transitions.

COVID-19

Has COVID-19 impacted the experience of your students with disability in participating in education? Have their experiences ever been impacted by other major events, such as natural disasters?

Online learning has presented both opportunities and challenges for different students with deafblindness. For some students, working online has increased access and participation. In traditional classrooms, the majority of work is visual, displayed on a whiteboard or classroom noticeboards, and to be completed within the time constraints of specific lessons. For students with deafblindness who are skilled in the independent use of technology, the combination of home-based online learning, accessible curriculum content, more flexible work completion times, and often quieter environments to work in, enables students to participate in education and meet curriculum outcomes. In these instances, teachers and parents have reported that students with deafblindness have effective access to online learning activities and resources.

However, in situations where schools have hurriedly transitioned from school to home education delivery in accordance with government and requirements, schools have had to quickly adapt to online learning with no training for school staff or time to review the accessibility levels of online platforms. Communication between specialist and class teachers was limited during the rapidly changing school contexts, and the provision of accessible learning materials for individual students was overlooked. Examples of inaccessible online materials for students with deafblindness include scanned pictures, maps and diagrams with no provision of alternative text (Alt Text) descriptions. Educational resources that are scanned and saved as pictures are not accessible to students using screen readers or electronic braille notetakers. Some apps and programs selected by schools for information sharing are also not accessible, or only certain elements are accessible.

For students who require tactile interaction for learning significant challenges have been experienced by both educators and families.

Access and participation

Do you think the Standards help students with disability to access and participate in education and training on the same basis as students without disability? Why, or why not?

The Standards guide teachers and other school staff towards creating more inclusive learning environments for all students. The Standards serve as a framework for how disability-focused education should take place, but lack in providing explicit examples and thorough explanations of how to best cater for students with diverse learning needs.

Explicit examples are needed of what the Standards look like within the classroom context. And how curriculum access for individual students should be created.

However, the following issues remain:

- Awareness – not all parents and caregivers are aware of the Standards.
- Understanding - not all teachers and parents understand the Standards as a whole, and there is no plain English version.
- Interpretation - terms such as reasonable adjustments and financial hardship may not be interpreted correctly.
- Training – not all States/territories and education sectors provide mandatory initial or yearly training in the Standards for regular and specialist teachers.
- Accountability – who is responsible for making reasonable adjustments?
- Auditing – who is ensuring the standards are being upheld?

While the Disability Standards for Education have been in place for fifteen years now, services, supports and strategies for students with deafblindness to access and participate in all aspects of school life, remain fragmented, inconsistent, and in many instances completely lacking.

Aboriginal and Torres Strait Islander students with disability

What would you change to make the Standards work better for Aboriginal and Torres Strait Islander students with disability and their families and carers?

Education of Aboriginal and Torres Strait Islander students with deafblindness is particularly poorly understood and poorly addressed. Due to higher incidence of trachoma and otitis media in ATSI Communities, there is a higher incidence of vision and hearing impairment, so education of ATSI students is of particular concern.

Guidelines are needed on how to better support Aboriginal and Torres Strait Islander (ATSI) students with deafblindness. Emphasis should be placed on the particular cultural contexts within such guidelines, for example, students from ATSI background, and students from other cultural or ethnic groups.

Clear communication about the Standards with ATSI families, needs to be improved, and educators need to be encouraged to apply the Standards equally for all families in the school community, with respect and appreciation for diversity.

Educators should familiarise themselves with the supports available to Aboriginal and Torres Strait Islander students, including where to find and how to access specialised supports.

The DSE review process should include liaison with Aboriginal and Torres Strait Islander elders to hear the issues and problems experienced by families and their children

disabilities. SMART goals should be set to address any issues and recommendations raised by the elders.

Comprehensive professional learning should be provided in how the Standards intersect with Indigenous history and culture.

Closing comments

While pockets of good practice in the education of students with deafblindness exist, for the most part the access and inclusion of these students in education systems remains inadequately addressed.

Given the always complex and individual nature of the learning needs of student with deafblindness, a systematic and coordinated integration of education, therapy, assistive technology and other relevant supports is required.

All students with deafblindness can learn and participate when provided adequate and appropriate supports, and it is hoped that in reviewing the Disability Standards for Education, good practices will increase to address the variability across regions and States, and that accountability is improved so the rights of all students with deafblindness are upheld.

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