Transcript

# Congenital Deafblindness: Overview of services and strategies

Welcome to Deafblind Information Australia’s fourth webinar in our introductory series.

I acknowledge the traditional custodians of the land on which I am presenting today, the Whadjuk people of the Noogar nation. I also wish to acknowledge the people of all the other lands from which our participants are dialing in today. I pay my respects to their Elders past, present and emerging and our community members with deafblindness.

This training series was made possible by an NDIS Information, Linkages and Capacity Building, or ILC, Grant. My name is Melanie Robartson. This module is titled Congenital Deafblindness: Overview of services and strategies.

# Project Team

It was developed by myself and Emily McDonald, project officers and Deafblind Consultants. I am a practicing Speech Pathologist and Emily a practicing Occupational Therapist. This project is managed by Meredith Prain.

# Training Modules

This presentation is part of the introductory series, following on from Introduction - Deaf, deaf and hard of hearing, Introduction to Vision Impairment and Introduction to Congenital Deafblindness.

# Module Overview

The module will explore the evidence base for interventions in congenital deafblindness, services in Australia, assessment tips and provide an overview of intervention strategies.

# Evidence base: Where are we at?

Best Practice Intervention

Ferrell and colleagues in 2014 made a number of recommendations for supports, services and interventions for students with deafblindness. They concluded it was insufficient to have team members with expertise only in visual impairment or only in deafness, as compensatory strategies in deafness often rely on full vision and vice versa, strategies for vision impairment often rely on full hearing, so many of these strategies are not helpful in deafblindness.

Strategies from the field of blindness and low vision and strategies from the field of deafness may, at times, be useful for someone with deafblindness, however, two single sensory mindsets cannot be added together to come up with deafblind interventions and strategies. Therefore, the recommendation is that deafblind specialist services are needed to support service team members and in addition to this, within each team, at least one regular member is needed who has knowledge of the impact of deafblindness and of deafblind communication methods and teaching approaches.

The report’s second recommendation addresses the diversity of the deafblind population which creates a need for considerable time and resources to be put into developing descriptive documentation about the individual and the individualized approach to their needs and skill and concept development.

Thirdly, in teaching environments, student groups must be small enough to allow the person with deafblindness to access information, engage in the lesson and receive feedback about their responses. Even for those with quite functional hearing and/or vision, small groups facilitate more effective communication. For example, locating the person communicating is less difficult in a small group, communication distance is reduced, as is background noise and visual clutter. Those who rely on touch for access to the environment, learning and communication may need one on one support for most of their day.

Evidence based practice

The level of evidence for these best practice recommendations is at an emerging level and there is still a need for research. Predominantly, professional literature written by experts in the field who have classroom, therapeutic and administrative experience, is used as evidence to support these practices until research has been conducted that can provide additional guidance or suggest different practices.

Communication is one of the more developed areas of research in the field of deafblindness. There is a rapidly growing body of evidence that communication partners can improve the responsiveness and turn-taking of children and adults with congenital deafblindness.

The congenitally deafblind population is small, but within it, there is also great variety. People with congenital deafblindness are all different, they have different degrees of hearing and vision, they use these and their other senses in different ways, they have all different causative diagnoses, often have a range of medical conditions and other disability and all develop at different rates and in different ways.

This is challenging when trying to apply research findings to guide any individual’s intervention strategies. This is also a challenge for researchers, who should be mindful of providing detailed descriptions of their research participants so that practitioners will better be able to determine if the findings are relevant to the people with deafblindness they are providing services to.

# Services: Requirements and supports

Deafblind specialist supports

What does this mean for any service providers? In addition to a generalist allied health, medical or education team, provision of the following will ensure a tailored approach to the deafblind specific needs of the individual: -

* Consultant in deafblindness – In Australia, this person has an allied health or teaching qualification and has either worked and/or studied over a number of years in the specialised area of deafblindness. They have knowledge of sensory impairment, deafblind communication, orientation and mobility, assistive technology, counselling and advocacy. They will work with professional in these different areas to achieve deafblind specific solutions that are appropriate for each individual.
* Communication guides are support workers with training to develop specialist skills to support someone with deafblindness in daily life, including guiding someone safely to where they want to go, helping them access environmental and other information and facilitating successful interaction and communication. Some may be more familiar with the term Intervenor, which is a term used more in the Americas and Europe. Intervenors may also have training in developing early communication and social interaction skills which is a skill set that is often required when working with someone with congenital deafblindness.
* Specialist teachers in deafblindness are teachers with extra qualifications in sensory impairment and have undergone further training in deafblindness. They consult with a child’s education team to ensure the school environment and information is accessible and help teachers develop an individual curriculum and assist with provision of customised resources and technology for this. The education team is also likely to work with the deafblind consultant to ensure consistency with home and community life.
* On a day-to-day basis, those providing services to people with deafblindness, and liaise closely with a consultant in deafblindness should also have some deafblind awareness training and knowledge. \*These may include
	+ an orthoptist
	+ an audiologist
	+ an orientation and mobility specialist
	+ an allied health team
	+ a medical team
	+ a sign language interpreter

More information about these roles can be found under the Services Menu of the Deafblind Information Australia website. The image on the right of the screen is a screen shot of the Services available to people with deafblindness under the NDIS page of the [www.deafblindinformation.org.au](http://www.deafblindinformation.org.au) website. It includes an image from the Deafblind Consultant video, of two consultants in deafblindness sitting side by side in dark navy tops. To the right of them is an Auslan interpreter framed against a dark background.

# Assessment

Assessment

This section of the presentation guides your thinking about how you may need to adjust your assessment approach when trying to gather information about someone with congenital deafblindness and help you self-analyse whether your existing approach to assessing in your field will provide helpful information or guide you in developing helpful solutions or outcomes.

Assessment is more often pre-linguistic, which means you may not be able to ask questions or give instructions to the person. Information is gathered by observing the person in familiar environments, and also doing familiar things and interacting with familiar people. Descriptive information is also gathered from these people through interview and questionnaires.

Standardised assessments are often not helpful in guiding you to valid conclusions or useful intervention strategies.

While observing the person with deafblindness is important, equally important are the actions and interaction of the communication partner and the characteristics of the environment such as the lighting, visual and acoustic characteristics and the layout of the space).

For representative function

In addition to these considerations, to get a broader perspective of the skill set and development of a person with deafblindness the following are some suggestions of situations to observe the person in.

* alone
* with a familiar person
* with a familiar object
* with a familiar person and familiar object
* in a familiar routine

According to your profession

You can think about

* what skills and functions are present?
* is this a familiar enough situation for the person to demonstrate their skills and knowledge
* if using standardized assessment, how much does each test item depend on hearing and vision?
* How much does your interpretation of responses and behaviour come from a socially normative, sighted/hearing perspective?

For example, if someone mouths objects for prolonged periods, does this indicate low sensitivity in the mouth and sensory seeking behaviour or does it represent a very valid way of determining an object’s size, texture, density, taste, smell, sound or vibration characteristics when you can’t see or hear it particularly well? If someone stares at something for a long time or spends a long time visually exploring something, do we question their need to look? Why then would we question someone’s need to explore something in ways that don’t rely on hearing and vision?

If a congenitally deafblind person doesn’t turn to locate a sound, is this because they haven’t heard it or is this because turning to the sound gives them no further information as they can’t see the source of the sound? Sometimes we may not discover precise answers to our assessment questions, however during the course of observation it is important to explore whether no response or an unusual response is telling us the same thing as the standardised assessment tells us about a person with hearing and/or vision.

Let’s now look at some cited case examples in literature on congenital deafblindness. These examples come from the 2013 resource by Damen & Worm on congenital deafblindness.

This next slide with the title

What is happening?

shows a man sitting in a ball pit, filled coloured plastic balls, which are about the size of tennis balls. He holds a red ball on his cheek. It sits just below his left eye, and rests against his nose.

What if this man repeatedly picked up balls and held them against his cheek and nose? What if this man seemed to look around him and you had previously seen him find his way into the ball pit? How would you interpret his behaviour with the balls? What if you didn’t know he had a vision impairment? What if you didn’t know his level of hearing? What conclusions might you make?

Gerard – case example

Next there is Gerard who is completely deaf and blind. He communicates through signs and tactile symbols. When Gerard is sitting alone on the couch, he is always busy feeling something: the sole of his shoe, the light switch behind him or his stomach and torso. When caregivers tap him to encourage him to do something, like drink his tea, he will often bite hard on his thumb​. When drinking tea, he clamps his cup in his mouth, leans his head back and blows.

This is the deafblind consultant’s interpretation of these actions. When Gerard is left alone, he requires information and stimulation. The constant touching provides this. He can find out a lot about where he is in space and what is around him by doing this.

The thumb biting is not explored in this example as it is quite a complex behaviour. My own preliminary questions might be something like this:

* What are people’s thoughts about Gerard’s emotional state before, during and after thumb biting?
* Does he know or understand the social significance of biting himself? Can we automatically assume anger, extreme distress or a desire to hurt oneself, if he has no social norm to guide this behaviour?
* How useful has thumb biting been to him in the past? Has it gained him attention, interaction, food, or resulted in others providing him pleasant experiences?
* Is there any neurological or historical information to suggest Gerard does or does not experience pain or react to pain in a typical manner?
* Does Gerard bite his thumb because the carer’s touch is not communicating anything specific and until he knows what is happening, will he bite his thumb until he feels more relaxed or sure about what is happening?
* Are there other situations during which Gerard bites his thumb?

With regard to Gerard biting and blowing into his cup, by copying this behaviour, the team around him found that this was not stereotypical behaviour but rather functional. Blowing produces air circulation and tells you how much liquid is still in the cup and how hot it is, without having to stick your fingers in it.

The next case is example is Els who is a 43-year-old woman with a severe vision impairment. Caregivers call all residents to dinner and during the week Els responds to this, but on the weekend does not. On the weekend she has to be collected by a caregiver.

Observation of Els at mealtimes during the week and on the weekend revealed that her appetite does not change. However, there is no one sitting next to her on the couch on the weekend because the person who normally sits next to her spends weekends at his parents’ house. This means that on the weekend Els has no way of knowing it is time to get up and go to the dining room. Els, unlike the other residents, cannot benefit from auditory information because of her deafness. Els’s limited vision also means that she cannot observe the behaviour of others at a distance. Close by, she can see and also feel the movement of the person sitting next to her on the couch. This experiential knowledge combined with other indications, like the smell of food and the order of events, lets Els understand that it is time for dinner when she sees and feels the resident next to her get up. When that person is not there, this final bit of information, is unavailable.

The final example is Bianca, a deaf and partially sighted woman who went shopping with her caregiver. She can see large gestures and is responsive to touch signals. Bianca is pushing the trolley while shopping. The caregiver accidently bumps the trolley​ and Bianca turns to exit with the trolley. Caregiver signs "no wait"​. Bianca starts hitting her head. The shift notes on that day read, Bianca was not interested in shopping today. ​

Here is another interpretation of the same event. Bianca held tight to the shopping trolley while the caregiver fetched a product from a low shelf. While doing so, the caregiver bumped into the trolley. Bianca understood this as a signal to return to the community home and started walking back with the trolley. The caregiver stopped her and made a gesture in front of her face: “No, wait”. This message conflicted with the touch information she had received (the bump against the trolley, time to go home). Bianca began to panic and started hitting her head.

# Strategies

Overview

This overview provides not specific solutions, but rather a process to guide your thinking about the world knowledge and skill development of someone with congenital deafblindness.

Safety, security, wellbeing

Firstly, to provide safety, a feeling of security and support wellbeing we must firstly spend time thinking about the health and potential sources of pain in that person’s life. Take courage to engage the child’s doctors in conversation about your concerns and share your perspective. So often people with congenital deafblindness come into the world with medical and neurological complications, with health and comfort sometimes taking a long time to achieve.

A person, even a very young child, must be given the opportunity to be a part of what is around them and this takes thought and planning, as usually we would be relying on that person gaining this information by looking and listening. With limited or fragmented hearing and vision, this is much harder to achieve, and carers need to be more mindful of how experiences we would usually look at or hear can be adapted or brought into the learning space of the person with congenital deafblindness. Touch becomes a more significant learning tool and may remain an important avenue for gaining information for the duration of their life.

Routines because of their predictability can provide a sense of security about where someone is, what time of day it is and what is happening next. This can be useful when memory and or communication is limited, however routines should be used as aid to, but not a substitute for communication and interaction with a person.

There are many forms of deafblind communication and the process of determining the most appropriate for an individual can sometimes be a long one with many not reaching the stage of achieving formal language such as signed, spoken or tactile language forms. The foundations of communication are important to establish and are often overlooked in the hurray to develop or introduce some form of language.

Whereas an infant with full vision and hearing will engage a caregiver with their eye gaze, facial expression and the sounds they make with their voice, an infant with deafblindness may for example be more reliant on body movement and a caregiver responding to this with touch and a body movement of their own.

Establish interaction

The interaction partner first task is to pause and observe the whole body of the person with deafblindness. Pausing not only provides a good opportunity for observation, the person with deafblindness also has a chance to settle, think and initiate some action or sound. Learning they can do something that captures the attention of another is an important early communication skill.

Once you have identified an action to respond to, then you must think about how you can imitate that action back to the person with deafblindness, to let them know you have noticed them and noticed what they are doing. This is the equivalent of, for example, making eye contact, nodding your head to acknowledge someone, returning a smile or cooing back to an infant who is making noises with their voice. This also teaches the idea that what they do has an effect on others, other notice this and notice them and respond.

The imitation of action can be matched or be imitated in various ways and could include any or all of the following; the strength or pressure of the action, the speed of the action, the rhythm of the action. These concepts may seem a little abstract at first but trying them out and experimenting will help your understanding of them and help you observe through the lens of congenital deafblindness.

Facilitate concept development

Once you have established a way of sharing experiences and developing these conversation-like interactions of movement, you have an avenue to add in experiences and information from the world around the person. This is extremely important if the person with deafblindness is going to develop an understanding of the world beyond their own body, the world beyond their fingertips.

Facilitating concept development is dependent on the person with congenital deafblindness accessing a range of experiences and the environment in which they occur, having opportunity to use their senses other than vision and hearing and having the opportunity to make the most of any functional vision and hearing they have.

Engage the other senses

When we think about an everyday experience, we also spend time thinking about not only how that experience looks or sounds, but how it feels on the body, temperature, pressure, texture, what the movement and body position feels like.

Can we incorporate these opportunities into experiences that are traditionally visual or auditory experiences? For example, when you enter a room that a congenitally deafblind person is in can you use the sense of touch to let them know you are there and to let them know exactly who you are? What about if you move them to a different place, how can you let them know where they are, do different places or things feel different, or smell different? Have you set situations and environments to be recognisably different in these ways? Perhaps they are naturally different, and we just need to recognise this ourselves, so we understand what the person with congenital deafblindness might be using to recognise the difference.

Is there any way to let them know where the smells in a space are coming from or can time be spent exploring smell as an alternative to the missing senses?

Is adding a taste aspect to the experience helpful or meaningful. Are they seeking these experiences and being allowed to explore in this way?

Support residual vision and hearing

Where possible do you know what the level of functional vision and hearing are and how you can support these through modifying the environment and materials and use of assistive technology? Professionals with expertise in these areas in conjunction with the deafblind consultant can help you determine the answers to these questions.

Let’s consider a common daily experience of a young child’s bath time and think about all the aspects of this experience we take for granted because we can see and hear them?

How does that child develop any concept of where the bathroom is?

How will they know how big the bathroom or the bathtub is?

How will they learn that a bathtub needs to be filled with water and that water comes from a tap and can be different temperatures?

How will they learn where the sweet smell and lather comes from?

Will they have the opportunity to learn how to lather the soap and rinse it off themselves?

How will they learn that if they kick in the bath, the water goes all over the floor and the person helping with the bath gets really wet? How might you facilitate this learning?

If the child can sit in the bath by themselves, how will they know that you are still there?

How will they know bath time is over, or how will you know they have had enough?

How will they learn how the water gets out of the bath?

How do they know where the towel is kept and where it goes after they are dry?

What’s important is that we start thinking through day-to-day experiences and identify opportunities for developing world knowledge and understanding of events that surround them. Rather than life being a series of events that just happen or that people do to them, how can they be informed about these life experiences and how can they be an active part of them?

Introduce language

The last slide in this presentation is titled Introduce language. It shows a young girl with deafblindness and her teacher playing with a blue fan, The girl's left hand lays over the teacher's hand to follow the movements of playing with the fan. The girl's right hand lays over the teacher's other hand so she can feel the teacher's sign language.

Decisions about communication methods and forms of language will also need to be made. While many people with congenital deafblindness may rely on others to understand their body movements, facial expression and vocalisation to determine what the person might be thinking, feeling or experiencing, there are other methods that can be used to take this development further. Often the first of these to be used are touch cues, which are signals made onto the body or are felt on the body to indicate something is about to happen. For example, tapping the hip bones might indicate “time for a nappy change”, a tap on the shoulder might indicate “someone is here”, a tap on the pram that is felt as vibration in the body indicates “were going to move from here now”. This helps build understanding, prepare someone for an event and build comprehension and thinking skills that enable them to establish links and recognise patterns between different sorts of touch cue and their respective outcomes.

Objects presented for the person to feel and possibly look at, give the person a clue that some event or activity associated with that object is going to occur. For example, presenting a towel might indicate, we’re going to go for a bath now. Conversely, the person with deafblindness presenting the towel to the caregiver might be a way of communicating they want a bath. Repetition and consistent use of touch cues and objects builds this understanding and the ability to recognise the patterns and links.

Sign languages and gesture can be used in different forms, depending on vision levels, and can be accessed by seeing them, or seeing them but with modifications such as distance away or what background the signs are set against. If functional vision is not sufficient, signs may be offered via touch. There are a few forms of signing involving touch. The convention here is not to control the hands, but rather have the person with deafblindness lay their hands over the signer’s hands to feel the movement, location and handshapes.

A person may have a degree of functional hearing and vision that allows them to use lip reading to access speech. They may have enough hearing, well suited hearing technologies and adequate movement and cognitive skills to facilitate speech development. With adequate vision or the right sorts of modifications, pictures and other symbols can be used to represent words and language.

That concludes this module.

# References

References for this presentation can be found on the following five slides.

A word document of the references will also accompany this video on the Deafblind Information Australia website which is located at [www.deafblindinformation.org.au](http://www.deafblindinformation.org.au)

Project officers can be reached by email at info@deafblindinformation.org.au

We will now open up to audience questions. If you prefer to ask your question in Auslan, please type in the chat, “I need my camera” and this will be turned on and for those who need it, your question will be interpreted into English.

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