Transcript

# Congenital Deafblindness: Overview of services and strategies, Question and Answer session

>>  Would it be possible to get the journal article sighted about best practice interventions?

>> So any resources that I referred to in the presentation are listed at the end of the presentation but also in a Word document that will be on our website.  So once this webinar has been edited, it will be put up on our website and the references will be there.

If you can't wait that long, please email me at info@deafblindinformation.org.au, with your question or request for specific references and I can email you the whole document or the reference that you're after.

>>  The next question, is there a resource available that outlines examples of touch cues?  For example, double tap on hip bone for nappy changes?

>> Not really.  Because we're often talking about quite unique individuals, it often starts from scratch about where the person has sensitivity for those things, how their nappy change routine proceeds, where they can tolerate touch on their body and where potentially they could reach on their body.

If they were going to imitate those cues but they couldn't reach a certain part of their body, then we might modify.  So each case is unique.  Having said that, there are some resources that particular places have developed, that might outline some signs that they use, say in a classroom, but the general approach is this need to be individual and the deafblind team can help you think through those solutions and come up with that person's unique system.

>>  I'm just having another thought on that.  I can't recall the resources off the top of my head, but there's a Scottish Lee McWilliams or something like that.  If you're looking for ideas and inspiration, I would maybe use something like that to guide you, but I would think about each example and how it applies to the individual that you want to use it with.  Not just take it as a formula that you apply to everyone.

If you want some of those resources, please email me and I will put up a list.  I guess I see so many, I can't remember the specific names and authors.

>>  Carol would like to sign her question, so I will spotlight her so everyone can see.

>>  The PowerPoint and everything I read through it and that was really fantastic.  It gave me a good idea, so I'm excited to share that and read through it.  I can look at that later possibly if I don't have much time.

That was a really great resource.  I will definitely keep hold of that and look through it.  I think there's some good information on deafblindness.  It's good to keep a record as well of that information.  Possibly things we can add to it as well would be great.  Yeah, I'd love to get a copy of that and put in my notes.

>>  Okay.  If you would like the slides in particular, you could email me and I could send you a copy of the slides.

>> Yes, please, I will do that, absolutely, thank you.

>>  The webinar will be put up on our website under the congenital deafblind section.

>>  I'm wanting to clarify the email address as well for that.  What was the email address?

>> Info@deafblindinformation.org.au.

>>  Perfect.  Excellent.  That's easy to remember.  Thank you very much.  I will email you.

>>  Thanks, Carol.

>>  Another question.  This was very profound to me.  Routine should be used as an aid and not a substitute for communication and interaction.  Can you explain more?

>> I thought that might spark a bit of controversy.  So I'm definitely valuing the use of routines, particularly I said because they are a great memory aid and they are a real source of someone to orient to the place that they're in, to the people that they're with, to the time of day.

Sometimes they see that's all that person needs.  We've got their routine, so they can just be - we can just guide them through that routine, but there's no conversation, there's no turn taking, there's no back and forth interaction, there's no commenting on the things that might be different about the routine on that day.  So sometimes I just feel like the routine is relied on too much at the expense of interaction and communication.

They know what's happening, they understand what's happening, so there is no need to provide anything around that experience.  That was really the point I was trying to make there.

>>  We have had a couple of other people ask for resources for tactile Auslan, different touch use.

>>  There was one that was in development about a tactile Auslan dictionary for people with congenital deafblindness, but people's ability to move, to receive on different parts of their body, the control that they have with their hands, the kinds of concepts that you need to communicate to them are going to be different each time.  So if you use a dictionary or a standardised dictionary, you need to check each sign's appropriateness for the individual.

This was in development and I never heard where it got to.  I will refer to some of the people in the audience because I think they might know that, the source of this resource better than I.

We will just wait to see if anything comes up in chat there about that.

People around the world have tempted those things.  You just need to be mindful of how you use them.

>>  We have a deafblind currently communicating through sign language students with progressive neuropathy causing loss of touch sensitivity.  Do you have any other suggestions for communicating with this student?

>> They're tricky ones.  I would suggest you keep pursuing those avenues until you're certain they don't make sense any more and I would be thinking, I would be engaging an occupational therapist to help you try and understand how that person is perceiving the input, and maybe I would be thinking about making some of those signs or movements bigger.

So that the person is perceiving the movement, not just the touch, that they're getting - when you're perceiving tactile signs you have the handshake, which is a detailed perception.  You're feeling the space where that sign is located.  So is it up high, down low, in front, to the side, two hands, is it one hand.  That is probably something that could be retained, so that large movement and sense of space around the person.

Also how big the moments are.  If you're doing more, which is potentially a smallish movement, then maybe you exaggerate that movement a little bit or start to exaggerate it, so there's more input and more time to process that sign.  Apart from that, I don't have any ideas off the top of my head, but I have an OT sitting next to me and wonder it she has something to add.

>>  My suggestions are similar, working out what the rest of the body is perceiving when the person is experiencing that sign, if they could somehow experience the sign as more of a movement than as a touch.  That's probably more likely to be retained as the condition progresses.  Then that feeling of touch on the skin.  So lots of assessment and lots of observation over time.

>>  So we had about the tactile sign question.  There's an app called adapting signs that can be used for documenting signs as you establish them, and then if possible try to relate them to Auslan as much as you can, so they're more likely to be understood by people who use standardised Auslan, enabling better communication in the community.

>>  That adapting signs app is a lovely little resource that you can download onto a tablet and you can record your own videos of the person who is developing sign and has their own sort of unique communication methods.  You can record in and make that American's own dictionary.  That app is released by Next Sense who some of you might know as RIDBC children.

Which is the Royal Institute for Deaf and Blind Children.  They have just renamed and rebranded.  You can get the information about the app on their website.  It is also available on the app store and Google play.  I'm pretty sure it's both platforms.

That really just provides you an avenue to record and document an individual's communication.  It doesn't really guide you about what that is going to be.  So if you're looking for ideas and a preexisting dictionary, if you find something, I would always try and consult someone with expertise in deafblindness about your choices there.

We have hit the one-hour mark.  So thank you, everyone for your questions.  I will let you know about some training that's coming up that is run by myself and our project manager, Meredith Prain, in conjunction with Deafblind International.  It is a webinar for families although if we don't fill all the spots with families, it will be opened up to professionals and people in a deafblind work role.  It is about developing social interaction and early communication skills for people with congenital deafblindness.  The details of that should be released on our Facebook page and the details will also go up into the new section on our website very shortly.  That is being run on 27 April.  I can't remember the exact time.  It is different around the country.  11am Perth time.  It will be in the afternoon in the Eastern States.  It's open to the Asia-Pacific area.

So, I will finish up there.  Thank you to our interpreters and our captioner and thank you all for coming.  We look forward to seeing you hopefully in future webinars.

**Transcribed March 2021**

End of document