[Recording in progress].

>> So, welcome to this month's CVI for the TVI and other professionals.

Today is September 29th, and my name is Mary Zatta, director of professional development at Perkins school for the blind. Today's presentation cortical visual impairment of dep-blindness will begin in just a moment. The webinars are presented throughout the year on a monthly basis. You may register to attend live at no fee, or a few recorded webinars at a time and place that suits your schedule.

The webinar series is just one of the offerings in our professional development program.

Which includes publications, e-newsletters, online classes and self-paced study.

You can see our entire listings at our website. Explore Perkins CVI for families and those who support them at Perkins.org/CVI-now. For those interested in professional development points, this webinar will also be available in a tutorial format.

Information will be available on this webinar's page with more detail.

Before we get started, I'd like to review a couple of things about this technology.

To keep noise levels in control, we have muted your lines. There is a question-and-answer space available at the bottom of your screen as well as a chat box.

We encourage you to post your questions as they occur to you during the webinar and we will address them at the end during the Q&A.

Hover your mouse at the bottom of the screen to open the tool bar, and chat in Q&A are both provided there.

You may decide to keep them open on your screen.

We are using this virtual meeting room for audio. You have individual control over your audio level.

Make sure your volume is on, and turned up.

External speakers or personal headphones might give the best audio.

Captions are available by locating the closed captioned and full transcript toggle on your bottom menu within Zoom. This event is being recorded, and will be available on the Perkins website.

It will include also a download of the live presentation as well as a transcript.

Thank you for joining us for this event. We appreciate your feedback and your topic suggestions.

And now, it is my pleasure to introduce -- here we go -- Chris Russell.

And I should have this memorized by now. Because we get to work with Chris so very often.

Chris Russell is the project coordinator for the New York deaf-blind collaborative and has experience as a classroom teacher and a teacher of the visually impaired. He's worked with children who has visual impairment and other disabilities as well as deaf-blindness. Chris presents widely in New York and nationally on educational of deaf-blindness, cortical visual impairment, and communication development for children with pre-symbolic communication.

He has the Perkins CVI range endorsement and serves as co-instructor with Dr. Roman on the Perkins e-learning, CVI and CVI phase 3 courses.

And without further ado, I say welcome, Chris.

>> Chris: Hi, this is Chris. Thank you so much, Mary, for the introduction. And thanks, Mary and Robin for putting this together, along with the CVI for the TVI coordinating group.

To which it's been a real pleasure for me to join recently. I'm happy to see so many people here today as well as a handful of familiar names and colleagues who I've worked with directly.

I'm just going to get started, because as usual, I probably have twice as much information in front of me than we have time to cover.

That said, this is sort of a part 1 of a two-part series.

The next one will get a date and more information to you in the chat box, or, by the end of the session.

But the first part I'm really going to talk today, I'm really going to talk in-depth about CVI and deaf-blindness and kind of lay a foundation for understanding the unique impact of CVI on students who also have additional hearing loss or are deaf-blind.

And what this population looks like, as well as some of the unique considerations from the field of deaf-blindness that need to be incorporated into anything that you're already doing, and know about from the field of CVI.

So it's sort of an attempt to integrate those two things.

Which I think there's a real need for. And I think hopefully you'll agree.

And then the second part, for part 2, is going to be much more into the unique approaches including communication techniques, and adaptation strategies for students kind of more broadly who have multiple disabilities.

What I like to say working in the field of deaf-blindness is any of the content that we talk about that comes out of the field of deaf-blindness is totally appropriate to kids who have multiple disabilities, including visual impairments more generally, right?

So when we talk about the communication principles, the adaptation techniques, and then the considerations around things like availability for learning, which I'll talk a little bit about here, and concept development and social skills development, all of those things when we talk about them from the perspective of deaf-blindness are applicable to kids with multiple disabilities more broadly.

Even if you don't work with a child who is deaf-blind or have a child who is deaf-blind, hopefully you'll get some information and some ideas here that will be meaningful to your work with kids more generally who have CVI and additional disabilities.

Okay. So, again, as Mary said, the chat box is open. Q&A is also open.

I'm monitoring the chat box, so if you have quick comments or questions to clarify things right when we're talking about it, I'm happy to answer that as we go.

If you have more general questions or questions about specific -- very specific scenarios, throw them in the Q&A, and I will address those by the end at some point.

Okay. Feel free to interrupt me with those questions and comments, too.

So just to set the stage, I want to introduce you to some of the data that has been collected. This is just in the past few years.

But we've been collecting this data in the deaf-blind projects for a very long time. Since before I was around in part of this.

And we can see the trends in the actual population percentages, demographics, and then what I find most interesting is the identification of kids.

And our own skills in identifying and referring those kids.

So the national center on deaf-blindness or NCDB, you can go to national DB.org and there's a link down at the bottom of it, of the slide. National center and deaf blindness keeps track of data and organizes and, you know, makes sense of the data that is collected by all of the various state deaf-blind projects in the U.S.

In the U.S., every state has a deaf-blind project which is funded by the office of special education programs at the federal level, through the U.S. Department of Education. I work for the New York deaf-blind project.

One of the things we do in addition to all of the other work we're doing to support kids, families and teams, is we also collect demographic data, or census data to get a picture of what the national child count of kids who are deaf-blind is.

So NCDB collected all the that data from the various states and they can give us some percentages.

And they found that in the last, the most recently published national child count, this is around 10,000 kids who are deaf-blind total, in total around the country.

And we estimate that based on underidentification, and even misidentification, and underreferral, there's probably twice that many who have not yet been identified.

So out of the 10,000 kids that we have identified, the average is per state around 29% of deaf-blind students, first through 21, also identified as having CVI. We always talk about CVI as the leading cause of childhood visual impairment of children in the U.S. and in other countries that have access to quality neonatal healthcare.

But I don't think that we're talking nearly enough about within certain populations.

This is also the largest percentage of primary condition causing visual impairment in kids who are deaf-blind as well.

We may see maybe a different percentage in looking at the broader, you know, data on kids with cerebral palsy or with certain syndromes or certain chromosomeal disorders.

But this is a very high percentage, about 30% of deaf-blind students also have CVI, and that's their primary visual condition. That looks like a big percentage.

But also, an additional 55% of those kids, of those 10,000 kids, are unknown as to whether or not they have CVI.

So what that means is that only about 20% of all of those 10,000 students who are deaf-blind do we know that they don't have CVI.

So within that 55% unknown, there's probably a good percentage more who have CVI and just haven't been diagnosed formally or identified. So this to me illuminates a pretty big need. If you're in a deaf-blind project, I think this is something important that we need to be looking at.

The other thing about this population data is that we see an extremely wide variance per state.

About what percentage each state is reporting, what percentage of kids they have with CVI. The lowest is 4%, one state is representing 4% of their population have CVI. Another state says it's 66% of their population has CVI.

So that's very hard to be able to get any strong indication of what percentage we expect do have CVI. This is similar to the issues that we have from the American printing house for the blind's data, the APH data. It's really just an estimate. The current estimate is that 60% to 80%, somewhere between 60 to 80% of kids with visual impairments have multiple disabilities.

So any way you look at it, we have two things. We have a large percentage of kids, so that designates a need for focus. But we also have an issue in underidentification and data that's not really TRA strong.

So we've got some charges here as to what we should be doing and spending some of our time on, if you work in this area of the field.

All right. So to get some shared definitions, what is deaf-blindness in general. When you hear that term deaf-blind, you probably think of someone who is totally deaf and profoundly -- profoundly deaf and totally blind.

But that is not the overwhelming majority of the population. When we refer to that term deaf-blindness, we're talking about individuals who have some combination of vision and hearing loss.

And the majority of the students that we work with, birth through 21, children and young adults, have some vision, some residual vision and some residual hearing. It is the exception who has no vision and no hearing.

Sarah is asking is there a higher correlation with auditory and visual processes? Absolutely yes. We're going to talk about that in a little bit. But we don't have data to back that up.

I'm saying absolutely yes, based on my observations in working with this population. But I think definitely true.

So this is in New York, for the New York deaf-blind collaborative. We developed an eligibility form for who is referred to services with us. You can see in the chart

on the left side in the columns, we're looking at hearing loss ranging from 0DB to 91 and greater profound deafness. Across in the -- in the columns, sorry, across the top, we're looking at vision loss from normal visual acuity to light perception. We realized several years ago

as we incorporated more information about kids with CVI that this was not a fair way to be inclusive of the students who have CVI. We also said that kids who are identified with CVI we're automatically referring them over to serve them. Kids already identified as being in phase 3, we want to take a closer look at,

because we want to be sure it is really CVI and hasn't been some other visual processing disorder or learning disability which could be misidentified as CVI.

Kids in phase 1 or phase 2 are kids who clearly have CVI, and the visual behaviors are not subtle.

Okay. Prevalence of additional disabilities in kids who are deaf-blind. We have around 10,000, sometimes a little less year-to-year, kids who are deaf-blind around the country. About 87% of those kids have one or more additional disabilities as of the 2019 child count. That's a high number, almost 90% of kids who are deaf-blind have additional disabilities on top of deaf-PLINDness.

The most common speech language, cognitive and orthopedic and complex healthcare needs. Complex healthcare needs is a very high percentage. Those could be anything from physical to, you know, neurological, et cetera.

But what's really alarming is the recent change and increase in students with very significant multiple disabilities.

In 2005, about 13% of the students who are deaf-blind were identified as having four or more additional disabilities on top of deaf-blindness which already seems like a big percentage, but by 2019, 42% had four or more. That's a dramatic increase in a population of kids with more complex multiple disabilities.

My opinion this is probably happening because of basically improvements in the medical field, and in particular, in survival rate of low-weight, early preterm infants. This is the exact same cause that we can identify for the increased percentage of students with CVI.

So there's an overlap in these populations, and I think that's what we're seeing, and that's why CVI has become such an important area of focus in the communities of professionals serving kids with multiple disabilities, and in the deaf-blind world.

Okay. It's interesting to point out, too, that about 12% of those students have no additional disabilities. And that's been increasing, too.

So it's really the students in the middle who, you know, the two ends are kind of increasing.

So let's get into like the real functional implications. I wanted to touch on the population, so that you have an understanding of what this prevalence looks like and maybe some of the reasons for that.

But I want to spend most of the time on functional impact. Deaf-blindness is primarily a disability of access.

Of course, all of the additional disabilities, if students have multiple disabilities on top of deaf-blindness, come with their own implications.

But deaf-blindness itself, reduced access to vision and hearing, is primarily a disability of access.

And access to what? Access to the distance senses. You can see in the image on the left here, separating out the distance senses versus the near senses.

Distance senses is a way of describing sensory input that is acquired from senses that you can access beyond arm's reach.

That includes vision and hearing obviously, but it also does include smell to some degree, versus the near senses where you can access information only when in physical contact, or in some kind of vibrational environmental contact.

Which I don't think we think about enough.

So those include proprioceptive sense, vestibular, taste, of course, touch being really our primary way of accessing information at near.

Vibration, which, you know, impacts vestibular proprioceptive and touch.

And then I haven't -- of course, in the middle there you see the word "pain" written as a near sense. Pain is not a sense or sensory channel, but I think it's important to consider that kids who have early childhood experiences, extensive early childhood experiences with -- within medical systems, lots of early surgeries, maybe spent the first few months of their life in the NICU without access to comforting touch,

and direct physical contact that was calm and comforting, those kids have often a different interaction and a different ongoing connection with pain.

Whether that's a low or high threshold for pain. They may experience painful tactile input in a different way.

Whether or not they have central nervous system disorders.

About 90% of the information that we acquire throughout our life is through distance senses.

Most of that's through vision. If we are sighted and hearing. We get some additional background information through hearing, of course. We're going to talk about this from a developmental perspective soon.

If a student cannot clearly hear or see what's going on around them, they're going to miss out on a lot of other important information, and especially in an educational context, but of course, in social context, in the community context and throughout development.

I think a more specific way to think about this, and this is one of the slides that, you know, if you've ever really dug into any training on deaf-PLINDness on childhood impact of deaf-blindness of development, you've probably seen this slide, or this concept I've adapted from a few other people.

What we're looking at here is the impact of deaf-blindness on incidental learning. Incidental learning is another way of describing observational learning. The child psychologist, Alfred Bendura looking at atypical childhood development.

Mostly he was looking at typical. And thinking about how most of the early concepts and the way that we understand the world are based on observation alone, in the first few years of life.

So most of your early childhood concept developments is from just looking around, and listening. It's from access to those distance senses.

It's not from explicit teaching, or deliberate instruction of any kind. It's just from watching the world, and listening.

So the pyramid on the left, the yellow pyramid face-up, you can estimate around 85% of early concept development comes from incidental learning alone.

Just from observing the world and watching people interact with objects, with environments, with each other.

And that's how we've learned those early concepts. About the next 10 to 12% of early childhood concept development comes from what's called secondary learning, and that would be somebody explaining it to you.

So kind of like teaching or modeling.

And it's only the tip of that pyramid on the left there, the last little 1% to 3% that comes from direct hands-on instruction.

And I don't mean direct instruction in the way that it's talked about as like a, you know, a term that's used for an approach

to teaching students with autism.

I mean, hands-on tactile contact.

So that last little 1% to 3% is learning from someone physically taking the child's hands and showing them how to do something.

And that early hands-on learning really only occurs -- primarily occurs in order to teach fine motor skills and access to objects and materials. So for example, somebody took the -- you take a child's hands and show them how to pull a lid to open a jar, or how to turn a handle to open a door or turn on a sink.

And it's really fine motor instruction.

So what you can see already is that on the right side, that pyramid is turned upside down for kids who are congenitally deaf-blind. I would argue kids with disabilities on top of that, congenital impairment and any additional challenges.

Because there's limited access to incidental learning, learning through observation, very little information comes from that.

There are very few opportunities, and they usually have to be facilitated in order to observe the world and explore.

And get information from observation.

The overwhelming percentage of instruction and early childhood learning comes from hands-on direct tactile contact.

And we know this, we who work with kids with visual disabilities and impairments, we know we'll have a lot of hands-on contact with kids way more than we would ever have with a child who is sighted and does not have multiple disabilities.

The question we want to ask ourselves and the majority of the rest of what I'm going to discuss today and in the part 2 is, given that hands-on direct instruction, given that we're going to have to do the hands-on direct instruction, what is it going to look like.

And how deliberate is it going to be. How responsive is it going to be, how compassionate is it going to be, how patient or intuitive is it going to be.

And one of the things I'll frequently say in doing training on some of these techniques we're going to go through, is you cannot train someone to be responsive, intuitive or patient, but you can train someone to count to 10 before they touch a kid again, before they add another physical prompt.

You can train someone how to use specific hand techniques, so that they're not being intrusive.

You can train someone to use certain communication cues so they're giving kids information to anticipate what's happening next, rather than just coming out of nowhere and yanking them around, and moving them through the world without anticipation.

So that's what we're talking about with all of the techniques, approaches and strategies around direct instruction for kids with deaf-blindness. I think this applies to kids with multiple disabilities in general. Especially if they have a visual impairment.

Okay. So I'm going to step off my soapbox, and impact on development. Concept development. Concepts are mental representations of images and ideas. In typical sensory access, concept development, again, comes primarily from incidental learning. It comes mostly from sensory perceptions from interactions, and then later on, after you've got your initial concepts, you learn those more specific concepts, like matching, comparing, classifying, grouping.

And those are more higher order processing skills that are connected with language and structure.

Now, we're going to see how this relates to kids with CVI very specifically when we look at some of the measurement for kids with CVI that we use, like if you've done some training on CVI, in late phase 2 and phase 3, we can look at can the child identify, recognize, and discriminate 3D and then later 2D targets.

Now, that's obviously connected with concept development. And one of the issues we come up against in kids with CVI who don't have expressive language, who are pre-linguistic or pre-symbolic, is how can you do those things, especially identification and discrimination, how can you have those skills if you don't have expressive language.

So maybe you can do them visually in your processing, but does that visual processing also rely on the higher order concept development and language skills? Is it possible to have a child who's in phase 3, but doesn't have language?

Or is the child stuck in phase 2, because phase 3 relies on language?

And this is an issue that I don't think that we've adequately tackled in our field yet. And I think there's still lots of different opinions, and experiences with that.

So we can get into that later if it's something you guys want to talk about.

Of course, the quality and quantity of the experiences that are available to kids is probably the major factor determining what concepts the student gets. Because with kids who don't have access to incidental information, they are reliant on responsive communication partners to create opportunities for exploration and concept development.

And communication development.

Just breaking down different concepts that are important to develop in kids who are deaf-blind, including those who have CVI, we're going to talk about the impact of CVI in these things, too, how the world works, routines, what things are, and are used for, cause-and-effect. Some of these basic concept development skills that we always talk about.

Orientation and mobility concepts, how the physical environment is ARPGed and how to navigate it. Where things come from.

The natural world and its cycles and laws. Now, that I think impacts kids with visual impairments greatly, because very often things just come out of nowhere and are suddenly right in front of the child with a visual impairment.

Where did the milk come from? I don't know, it just appeared on my desk in front of me. Before that, where did it come from? Oh, it came from a container that was in the fridge. But before that, where did it come from. It came from the grocery store. Before that, where did it come from. So connecting to the real concepts of the natural world.

It requires a great deal of stepping back and having concrete meaningful experiences.

It can't just be explained, it has to be experienced.

Time concepts, like sequence, order of activities, before or after, that kind of thing. Self-concepts. And social concepts.

A lot of this stuff comes from some really great articles from Barbara Miles and Barbara McClatchy on deaf-blindness. That's an article I've been working with some colleagues with in Vermont, which will include some stuff about concept developments with kids with CVI.

Social and self-concepts include these. I won't go through all of them. But lots of different social and self-concepts. If you think of any of these, how could lack of access to incidental information as a result of CVI impact the ways that kids learn some of these concepts.

And again, I'm not going to read through all of these, but I'm making the slides available, too. So if you want to read through these, you're welcome to. I just want to throw it out here, the variety of different things we should be considering.

Okay. So we've got all of this stuff on impact of deaf-blindness which I think is pretty similar to the impact of multiple disabilities of kids who have sensory deficits, visual impairments, et cetera. As a result of those sensory deficits, kids tend to have a lack of or reduced quality of social experiences.

There may be some processing delays. Kids often develop unconventional forms of communication because they don't have the access to observing conventional forms, like waving hi, nodding head yes or no, conventional gestures.

And language.

I think kids with multiple disabilities in general tend to have a history of others doing things for them, instead of with them.

We want to really shift that narrative and think about working to do things with the child, to develop self-determination and a feeling of agency and, I can do this, rather than things only happen when someone else, when an adult is involved and facilitating.

So that's a problem of communication partners' attitudes and behaviors. Also, a history of negative experiences with touch. I don't mean to say people are intentional touching children in a negative way, it's that if you're having tactile input,

if you're touching kids without proper anticipation and without responsive techniques that we're going to look at, like hand under hand as opposed to hand over hand, it's alarming, stressful, and is ultimately a negative experience for the child.

That whole sequence of negative interactions and deficits, at its worst case scenario, leads to stress behaviors and ultimately to learned helplessness which is the opposite of self-determination.

Learned helplessness is the feeling of, I can't do things independently, or my communication, or my, you know, my initiations are not understood by people, and so I'm just going to stop trying to communicate.

And shut down.

Okay. If you haven't heard of this term yet, again, I'm not going to read all of this in front of you, but I wanted this as a resource, an intervenor, in Canada they use an OR at the end, interveneor, and in some other countries. But an intervenor is essentially a one-to-one paraprofessional with specific training in deaf-blindness and in the child's needs specifically who basically acts as a bridge for that child

to communicate with other people, and to access information throughout the school day.

And one of the things that I've really advocated for in working with children who are deaf-blind who have CVI is that part of that training and skill-set needs to be in CVI, if the child has CVI. It's not just about getting training in deaf-blindness, it's also about getting training in the unique child's specific impairment and specific hearing loss.

So an intervenor for a child who's deaf-blind with CVI should have plenty of training and expertise in understanding and adapting for the child specific to their CVI.

Intervenor is not a mandated position in most states, in the U.S. It is in Utah, Minnesota, and I believe in Texas there's a strong development towards -- I think we've got someone from the Texas deaf-blind project. I know it Texas you guys have done awesome work around developing interveneer training. I don't know if it's recognized yet by the department of Ed. All of the deaf-blind projects have been pushing for a role in a more national level. For that to happen it would hav indiv

disabilities act. It's widely accepted this is a best practice for supporting kids with deaf-blindness.

Let's take a step back now and think, we've got all of this sort of overview and foundation about the impact of deaf-blindness, what is unique about kids with CVI? And deaf-blindness?

Obviously, take everything you know about CVI and add a lack of access to auditory information, or processes. We're going to look at that specifically.

There's also a large percentage of the population with CVI and deaf-blindness, has additional complex healthcare needs and complex communication needs.

That's an interesting aspect for all the experiences I've had in my work, because the overwhelming majority of kids whom I work with do have complex multiple adaptive needs.

And I'm not sure how representative that is of the total population of kids with CVI. But a lot of the kids we're working with who have CVI and deaf-blindness have multiple complex needs that require adaptation and support.

That impacts things like availability for learning, which I'm going to dig way deep into.

Pre-intentional and unconventional communication, which I'll go through a little bit.

Development of symbolism, and multi-modal AAC, August men TA tiff and alternative communication. I'll talk a little bit about that, too.

I think what we're really talking about in CVI and deaf-blindness is how do we apply the unique practices and approaches that come out of the field of deaf-blindness much more deliberately and specifically to kids with CVI. There isn't necessarily a direct fit. There's an adaptation in applying what we know from the field of deaf-blindness to this population.

Some general updates I think you would all be aware based on whatever perspective you're coming from, that our understanding of CVI is constantly evolving.

So you have to keep up on current practices and trends, because this is a relatively new field. You know, it's a field with a nice strong history, but it's a relatively new field and there's still a lot we need to do and find out and work on.

And I like to say to folks who I'm working with, professionals I'm working with, if you're really passionate about CVI,

there's a lot of room for you to innovate. If there's something else that you know a lot about, like let's say you're an expert in the Wilson reading program,

well, we need more information about how to adapt the Wilson reading program to kids with CVI, so go for it. Go forth and do that work.

and there's a lot of space in the field for that.

If there's some other interest that you have, that you can combine with CVI, based on your experience and the kids you're working with, go and do it and share that information with the field, because we need it.

There's research and implementation of what I really want to highlight as promising practices.

And that's a term that I took from Dr. Susan Bruce, a great expert in the field of deaf-blindness who pointed out that in our field,

low incidence disability field, we don't really have a lot of evidence-based practices, because the population isn't big enough to have that data, and that research.

We have promising practices. Let's kind of talk about it that way and also give ourselves the charge to do more work. You know, to do this work.

Also, many more parent organizations, and etiology specific organizations are getting involved. Like the CDKL5 foundation, also deaf-blind parent groups around the country are getting more involved in the conversation around CVI.

So let's collaborate and communicate with each other, and grow as a field in that way.

Advocacy on a local, state, regional, national, international level. If there's any updates that people have about that, I would be really eager to find out. The most recent one that I saw was a senate bill from the Louisiana State Senate that called for, which is still pending in their State Senate, that called for the development of a CVI task force

in their department Of Health. That's an exciting idea. I would like to see that replicated around the country.

All right. Since we're not going to do any, like background overview stuff on CVI, and understanding CVI and the characteristics, because that exists in plenty of places, including recordings from the CVI for the TVI group,

I do want to say that I've developed a two-page fact sheet kind of explaining CVI basics. What is it, how is it different from other visual impairments, how is it diagnosed, what are the characteristics,

what are the phases, and why is this unique, and then the second page is sort of some answers to frequently asked questions. For families and professionals. As well as links to additional resources.

And you might see some familiar ones in there.

If you want a copy of that, I'm sure -- actually, you can find it on paths to literacy.org. In the chat box.

You can just look up CVI fact sheet, or look up my name or whatever.

Okay. So hearing loss and CVI specifically. There's a major problem of identification and diagnosis of potential auditory processing disorders. Sarah asked earlier about the correlation between auditory and processes disorders. I would suspect this is probably the primary cause of hearing loss in children with CVI, but there's really no data to show that.

I think we just haven't looked at that data, or it doesn't exist.

But I also think that one of the major issues at the core of this is in the diagnosis of auditory processing disorders. Oh, thank you, Jeanie, I appreciate it. Most assessments or tools or exams for diagnosing auditory processing disorders involve language.

So a child needs to have expressive language in order to give good information about their auditory processes.

In the audiology field there are many different ways to diagnose hearing loss. You can take a typical audiogram, there's play audiometry, and other ways to get information about whether auditory signals are going to the brain or not.

As well as functionally how a child is hearing. But auditory processing disorders, there's two major types or categories.

There's central auditory processing disorder, CAPD, or there are what's called auditory neuropathy spectrum disorders. Of course, there's an acronym for everything, ANSD.

And if I'm correct, don't quote me on this, because I'm really not a total expert in this area of the field, so I'll just say one of those can be tested essentially with auditory brain stem response. So you can get a yes or no, the signal is or isn't going to the brain.

I believe that is auditory neuropathy spectrum disorders. And the other I believe central auditory processing disorder can only be tested with a functional exam that involves language.

Which basically is the child, or the individual puts on headphones, and in each ear a different word is being read at the same time.

And they're rhyming words. So in the right ear, the word rat and in the left ear the word cat. At the same time. Simultaneously.

And the child is supposed to state back all the words that they're hearing.

Okay? And basically a child who does not have auditory processing disorder will get about half from each ear correct.

They'll kind of switch back and forth, half from each ear. A child who does have an auditory processing disorder will either get 100% of the words from one ear, and nothing from the other, because basically

similar to what we see in kids with CVI, the information that's too much and too complex just shuts down. So that's too much to deal with, so I'm not going to listen to the information over here, I'm only going to focus on the information from my right ear.

Or it's just too overwhelming or overstimulating and the child gets nothing, no words from either ear.

That's closer to what we see in kids with CVI visually. But the problem is, you can't diagnose that if you don't have language and can't complete that XRAM. So I think that we're missing a lot of kids who have auditory processing disorders, because

the testing requires language.

If you want more information about that, I can send it to you. Also, on national center for deaf-blindness website, they do have links to explaining the difference between different auditory processing disorders.

So it is important to know whether the child has -- what type of hearing loss the child has.

However, I think it's very probable that a lot of kids with CVI also have an auditory processing disorder of some kind, whether or not it's identified.

And we know that kids with CVI have issues with sensory complexity, right? We'll talk about this a lot more in the next session. But sensory complexity impacts basically the ability for the child to use their vision while they're also getting information from another channel.

Whether it's auditory, tactile, vestibular, et cetera.

So if a child is getting a lot of auditory input, their visual skills, their visual functioning may be reduced, and maybe the other way around, too. That in itself, even if it's not a clinical processing disorder, it is a functional processing issue. In that way I think we could treat a lot more kids with CVI as if they have processing issues.

Of course, we need to know about the unique role of hearing assistive technology with kids with CVI and how that might help, or hinder the child's access to information. Especially visual information.

Also environmental modifications that are relevant to kids with hearing loss.

Let's talk about that a little bit, too. I'm not going to spend a ton of time going through the different types of hearing loss.

But I want to have that information, again, available to you.

It's very important to know which type of hearing loss a child has, because each type of hearing loss has different implications as well as different possible accommodations that might be helpful, whether it's sensory neural hearing loss.

And here's some more information about that. Or conductive hearing loss. Conductive hearing loss you can basically simulate by plugging your ears. It means sound is not sufficiently going from RT outer ear canal into the eardrum, into the middle ear.

So that basically sounds like a muffling, or reduction in sound, depending how severe it is.

Next hearing loss is conductive and sensory neural.

And then the auditory processing.

One of the ways that I've heard the auditory processing piece is a child with an auditory processing disorder is not able to distinguish the important sounds from the unimportant sounds, or the background or ambient sounds.

For example, you might have a child in a class circle attending to a read-aloud from the teacher. The child with an auditory processing disorder cannot distinguish, or prioritize the primary speaker, the teacher, from the background noises, like the buzzing of the fluorescent light bulb in the room, or the sound of people walking by in the hallway,

or the air conditioning unit, or the fan, right? So the ambient background noises may take over. And as a result, a lot of those kids with auditory processing disorders get misdiagnosed as having autism, having attention deficit disorder, or learning disabilities.

It sounds similar to CVI, right? It sounds similar to an auditory version of CVI.

Actually, the project coordinator of the California deaf-blind project, Maurice Belote, and his colleague at the project, Julie Meyer, have written and done a little bit of work around auditory processing disorders as the auditory version of CVI.

We've had some conversations about that. I think there's some definite similarities. And there's a tendency for people to really misinterpret those behaviors.

So what if a child has both of those things, right? I'm giving you some links to different hearing loss simulations. We won't go into this or spend time on it, but these are two really good ones that give you a good simulation to see what it would be like to have different kinds of hearing loss.

So just like it's important to have simulations of visual conditions, if you work with a team or on a team, it would be good to -- for everyone to experience that.

So they have a better understanding of what's going on with the child.

Again, I'm not going to get deep into audiology, and, you know, hearing loss specifically, but just to note that the child's audiogram, if they have a neural hearing loss is really important to have an understanding of, especially so you can see what specific speech sounds may be inaccessible to that child.

This is a whole other deeper look into it, but it is important to have a functional audiogram as well.

Most of the speech occurs in this particular region between these frequencies and this decibel range.

Okay. Now, what about our kids which is the majority of the kids that I'm working with who have CVI and hearing loss, or may have hearing loss who really can't take any of those standardized audiology tests.

We just can't get the information from a clinical audiologist. The Texas School For the Blind in collaboration with that deaf-blind project, the Texas deaf-blind project, has developed this really excellent tool called the informal functional hearing evaluation, or the IFHE. Hey, it's Chris Montgomery. How is it going, my friend. Which Chris and aAM and some of their friends over there in Texas developed.

And I think that this is really the best thing that we have, and congrats to you guys on that, for getting a functional collection of information about what our kids are hearing, and I believe, and I think in New York,

we've been able to register kids with our de-blind project based on their functional hearing results. Even if we can't get something clinical saying that this child has a hearing loss, as they're presenting as missing out on, misinterpreting or not having functional access to significant amount of auditory information throughout the day, then

they may be considered to be deaf-blind. And I do think that where we see that the most in kids with CVI is in the intersection of sensory channels related to that multi-sensory complexity characteristic. Kids with CVI have difficulty regulating which sensory channel they're getting information from.

And you may see reduced vision when the child is trying to listen. The child is looking away or light gazing when they're trying to listen to someone, or when they're looking at something, it's too much to process the auditory information at the same time. And that becomes overstimulating, and then the auditory component is lost.

So I would really strongly recommend downloading this form from their website, and checking it out and adding it to your tool kit.

In terms of auditory support and hearing assistive technology for kids with CVI -- and I know we have about five minutes left. I'll cover a little bit more and then show you what I'm going to talk about in part 2.

So you have an idea where this is going.

In terms of auditory support for kids with CVI and hearing assistive technology, sometimes headphones or FM units, even if the child doesn't have hearing aids and isn't getting it through the boot in the hearing aid, they actually may be able to access an FM unit

through headphones. With the FM unit, it's basically taking away all the background ambient noise and giving a direct connection to the primary speaker. To that teacher in the read-aloud.

That may be very helpful. But you want to be very deliberate in providing access to that, because you really want to figure out, when are we expecting visual information, when are we expecting auditory information.

And I'm sure that if any of you have used FM units, you've had that awkward experience where you forgot to turn off the FM unit and take it off. The student is still listening to everything that you're saying, or, you know, going and flushing the toilet in the bathroom, the student is listening to that.

So if we're using FM units or other hearing assistive tech, it should be with purpose and with a deliberate plan that everyone is comfortable with.

Sound walls and environmental supports are typically recommended for kids with hearing loss. May be very helpful to kids with CVI whether or not they are actually deaf-blind.

But simply to add a layer of control to the impact of multi-sensory complexity. I've definitely seen this be very functional. The ones you see in the picture on the bottom right, are the ones you can get through like Lake Shore, one of those educational materials catalogs.

There's a great resource called School Matters that you can find through the ASHA website that really breaks down hearing assistive tech.

And general recommendations for educational team members and communication partners in, you know, providing accommodations, and integrating those things into teaching strategies for kids with hearing loss. So now just apply this to CVI.

I'm glad we got to this. This is the last thing I really wanted to get to today, is visual and tactile modifications to sign language for kids with CVI specifically.

This is an area that we probably need to do a lot more work on. But myself and my colleague Jen Willis, the coordinator of the Maryland deaf-blind project have developed some of this work together with support from my project director SUZie Morrow in New York. It's looking at adaptations to sign language, modifications to sign language receptively, depending what phase the kids are in.

Kids in phase 1 are really tactile sign communicators, who need hand-under-hand modeling. No visual access to sign language in phase 1.

In phase 2, depending on whether the child's in early or late phase 2 of CVI, we may be looking at the beginning of access to visual sign at near, but there are still tactile supports that are needed and the child may still reach for your hand to get tactile support to narrow in on what they're looking at.

There may be field preferences we need to look at for that, complexity to background, and more than that.

Here's a picture of exactly that. A child kind of guiding the teacher's hands to be able to control the visual space for observing visual sign language. Tactile support.

Phase 3, we are increasing the distance, we may still need some tactile modifications for complex or novel environments.

There's more information here on just phases in general.

All of that stuff is discussed in-depth in this new tool that Jen and I developed called the August the AAC matrix. I can give you access to that, too. We're a minute away from being out of time so I'm going to stop sharing.

I just want to say in the next session, we're going to dig into adapting strategies specifically by phase. I'll share a lot of, you know, hands-on approaches, now that we have a foundation.

Thanks. I think we're -- we've got one minute to go. I'll turn it over to Mary.

>> Thank you, Chris. As always, just such rich information. I'm sure that everyone really enjoyed this presentation.

We have one question here from Sarah who says, I wonder if infant massage is practiced routinely in the NICU? It's proven to help with social and emotional development. I wonder if it's become a common practice. I don't actually know the answer to that. But do you, Chris?

>> Chris: I've definitely seen that as a practice in some of the NICUs in the follow-up clinics I've seen. A lot of the stuff we talked about in terms of early interaction with touch, you know, we've definitely seen the responsive tactile access and experiences of the NICU are important to development.

>> Yeah, absolutely, no question. Someone's looking for your e-mail. Can you put it in the chat?

>> Chris: Yeah, I did. I put it in the chat. It's Christopher.Russell@qc.cuny.edu

I'll put it in again. It looks like people are typing in the chat.

>> There's not a certificate with this webinar. We will create a tutorial, if people are interested in earning credits.

But we don't provide certificates for our free webinars.

Let's see. And when is part 2, and how do we access your slides? The slides will be up on the Perkins website with the recording, once we have it posted, which will be in a few days.

And when is part 2? Do you have that date in front of you, Chris? Because I do not.

>> Chris: I think I do. Oh, yeah, there it is. October 12th. Tuesday, October 12th.

>> Great. Thank you. And yes, there will be an invite sent out for the second webinar. So keep an eye out for that.

Any other final questions?

Okay.

Someone asked a question that I will try to answer. Why does Perkins CVI now use cerebral? Perkins is using the term cortical/cerebral, because like many others in the field, both in the United States and also in Europe,

there is a -- I believe that more than the cortical part of the brain is involved, and that it's more reflective. So we don't use cerebral, we use -- by itself, we say cortical/cerebral.

>> Chris: The only thing I would want to add to that is in this presentation, and in my work, I use the word cortical because I'm talking about an approach to assessment and intervention for these students which is based on the 10 characteristics associated with the CVI range.

That's sort of like the deliberate use of the word cortical to talk about that approach.

>> Thanks for that clarification, Chris.

And then someone is asking, was that a new communication matrix?

>> Chris: That is a new tool that we developed, which we basically do as an intersection of the communication matrix, with the CVI range. So it's putting communication assessment and CVI range assessment together to look at recommendations for AAC kids with CVI, depending what phase they're in,

and how they score on the communication matrix.

>> And where do I find that? You can just Google -- oh, your tool, I'm sorry. Where do you find that, Chris?

>> Chris: Let me see. Can I drag tools into there? I guess I can't drag a file in. I was going to try to drag a file into the chat box. If you e-mail me, I can send it to you.

>> And we can put it on the website, too.

>> Chris: Okay.

>> With the webinar.

And then the other question -- any tips on assessment tools for preschoolers?

>> Chris: Good question. It depends on what you're trying to assess. The one thing I would say is a lot of the vision assessment tools that are specifically geared towards preschoolers are not appropriate for kids with CVI. Like the Oregon assessment or the Hawaii assessment.

Because they look primarily at visual skills that occur in kids with ocular visual impairment, they don't look at CVI. I don't know of any specific tools that are geared towards kids in preschool age who have CVI,

but the CVI range is appropriate for kids who are in preschool as well. If you're looking at communication assessment, the communication matrix is appropriate for kids in preschool, including those who have visual impairments and CVI.

Yeah, depends on what you're assessing.

But definitely the main answer is to be cautious of applying tools from ocular fields to CVI.

>> And then a question, what website will this be on? It will be on Perkinselearning.org.

I'm checking up on one new -- lots of thank yous.

Lots of good comments. Thank you. Great info.

All right, with that, I would like to thank on behalf of the audience and also Perkins elearning, I would like to thank Chris, for your time today. I would like to thank our audience for joining us, and participating in today's webinar.

As you know, it's been recorded and it will be available on our website.

Wishing you a great rest of your day.

>> Chris: Thank you so much. Thanks again to Mary and Robin and to our captionist, and thanks to you all for being here. Looking forward to part 2 with you.