**9.12 CVI for the TVI\_What's My Vibe Webinar**

CATHERINE SMYTH: Welcome. Today is September 12, 2022, and my name is Dr. Cathy Smyth. Today's presentation, "What's My ViBe? Visual Behaviors in Autism Spectrum Disorder" will begin in just a moment.

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Today, we're talking about visual behaviors and autism spectrum disorder. And now, it's my pleasure to introduce today's speaker, Dr. Rachel Pilling, who's a pediatric ophthalmologist and a professor of ophthalmology and special needs and learning disability eye care at the University of Bradford in the United Kingdom.

She's been involved with learning disability eye care for over 10 years. She is published widely on aspects of eye care for learning disability, special school visual assessment, cataract surgery, and diabetic retinal screening in adults with learning disability.

Her current areas of research are in cerebral visual impairment and brain-related visual problems, including visual behaviors associated with autism spectrum disorder. And I'm pleased to say that I've had the opportunity to discuss some of her current projects with her as we begin to implement them in Anchor Center for Blind Children. So take it away, Dr. Pilling.

RACHEL PILLING: Well, thank you very much for inviting me to contribute to what's a really incredible resource of things about CVI and vision in children. I feel very grateful to be invited. So I'll talk about visual behaviors, or what we call "ViBes," for short, in children with autistic spectrum disorder-- or we may refer to that as ASD for short.

So I'll offer you a summary of the traditional visual performance in ASD-- what's published in the literature about how children with ASD use their vision-- perhaps introduce you to two models of visual perception in ASD, which may help us to understand a bit better how children with autism use their vision.

I'll offer you a couple of questions that you might want to ask yourself in clinic or when interacting with a child in the classroom or when speaking to a parent that might help you draw out some of these visual problems, and then offer you two essential examination tools, things that we've been developing that have really helped us understand how to help children with visual impairment and vision problems in autism to draw those out and help get some solutions to the children.

So this is the playground question. So do autistic children have vision problems? This is what people in the playground at my daughter's school would come up and ask me. They have a cousin or nephew are someone with autism-- do they have vision problems?

Well, the best answer I have to this is from a young man called Luke Jackson, who's got Asperger's. And he's published a great book. And he says, "Autism is an umbrella term-- except some people get rained on more than others."

So we all know the spectrum nature of autism. But what Luke's trying to get at is that some people will have a very different impact of their vision problems or their sensory problems in autism.

So on the basic level, do children with autism have reduced vision? Well, in terms of visual acuity-- how many letters on chart they can read-- how good their near vision is-- actually, no more than the background population.

Do they have problems with seeing? That's a slightly different question, isn't it? We know that around 1 in 10 will have some sort of squint, strabismus, that they'll have problems with their accommodation-- that is, shifting their focus from distance to near, a bit like you need reading glasses when you get into your late 40s, 50s. They'll have a difficulty with that.

They may have astigmatism, a type of requirement for glasses. But interestingly, and we'll come back to this-- they have problems with their saccades. They offer fast eye movements that help you accurately shift from place to place and person to person and, indeed, when reading words along a page. So yes-- they do have problems with seeing.

But what I encourage you to think is-- stop assessing what the child can see, how small it is and what size the text needs to be, and start thinking a bit more-- how does the child see? How does this child use their vision to access their world?

So atypical visual processing in early life may be the underlying cause of social communication problems. And that's the spectrum under which ASD sits. There's a lot of discussion about lack of eye contact.

It's been said many years ago to be one of the cardinal features of ASD. I don't think that's thought any more. But certainly, this difficulty of the child connecting with their parent, not really looking them in the eye-- and this may be because they find understanding faces difficult.

If we're to understand who we are as a person, we learn how who we are in the world and we interact with the people. We realize that people don't always think exactly the same as us-- or how we understand how someone else feels.

Well, actually, without understanding parts of your vision, that's very difficult. And there is almost certainly an overlap between cerebral visual impairment, autistic spectrum disorder, and the children who are premature, with cerebral palsy, developmental delay, and, of course, ocular visual impairment. But quite what this overlap looks like-- we don't really know.

So if there's one thing that you take away from this talk, it's that you don't see with your eyes. You see with your brain. What our eye does is collect lots of little LEGO bricks. It collects all the visual information. And then it somehow assembles it into these beautiful structures.

So I often say it's a bit like having all these gray LEGO bricks, and somehow your brain turns into a 3D model of the Death Star from Star Wars. It's just this incredible assembly thing that we don't really understand properly how it does it. So it's not seeing the individual bricks. It's assembling it into a 3D model of your world that is so incredible that your brain does.

We're just going to take a few steps back and think about vision processing at its most basic level. So when you are born, you aren't really aware of a vision. Your vision isn't very switched on. And you may have short periods where you are aware of light and dark or when you're aware that something passes across your vision. But actually, you're not really tuned into it, and it's a bit hit and miss.

You then develop visual attention around-- within the first 2 to 6 weeks of life, where your vision is switched on more. You're able to look at objects for more than a couple of seconds at a time. If you've ever played peekaboo with your child, you know they'll play with you for a few seconds, and then they'll just look away and look over their shoulder. But it's just a bit much. And then they'll come back to you again.

Children then develop this idea of detection, where it doesn't have to be right smack in front of them for them to see something. They learn to look around the room to search out objects to learn more about their world.

And then they learn to identify what things are in order to match it to learn. They think, oh, I've seen that before, and I know what that's for. I know what that's called. And we attach meaning to the objects we're seeing. And then we know what to do about it.

So this is all many steps back from how many letters can a child see. But if we start to attach this model when we are looking at a child and how they interact with their environment, that helps us understand a bit more-- create a picture in our head of how is this child using their vision.

And so, having spent a lot of time in special schools with children with autism, I began to notice four groups of vision processors. Now, it's worth saying that children don't fall neatly into one category.

So a child may have any combination of these. They may be one combination in a busy environment and a different combination in a quieter environment. And you'll discover that they contradict each other-- many of these. So there's the central processors, peripheral processors, position processors, and single-channel processors.

And the second framework that we'll talk about is Dunn's sensory processing framework. And Dunn spoke about these two axes. So the one going up and down-- the children who are hyposensitive. So something needs to be really massive and in their face for them to be able to notice it.

And the ones who are hypersensitive-- the ones who just feel a bit overwhelmed with everything all the time and they are hyper-alert. And then going sideways-- those who are passive-- so they just tend to be in the room and they don't really pay attention to stuff very much. They can just be quiet. And the ones who constantly have to be on the move.

And she described these four different-- across this cross-section, four different ways that children access their sensory information. And we'll talk about these each in a moment.

So first of all, we need to think about the sensitivity. What do we mean by that? Well, that's the child's threshold for noticing something. And self-regulation-- that's the child's ability to move their sensory mixing desk-- to turn up vision and down sound or turn up sound and turn down vision and manage to completely suppress the feel of their clothes on their skin. We'll all recognize these patterns in children with autism, as some children seem very upset by things that we just don't notice.

So the first group-- sensation seekers. These are the seekers. This is the child who has to touch everything. They walk into your room, and they have to do a bit of a tour. They have to touch every surface and lay their hand on everything, often not looking straight at it. And you feel you want that child-- just stop. Just stop that. Just sit down. Stop it. Stop it.

But they need to be on the move all the time. They look like they lack focus. We think they've got good vision. We're not worrying about them. They like to see. They're seeking things out. They're like wheels spinning, and they are on all the time. These are the children who are full of energy.

The second group are the avoiders. These are the children who will deliberately look away. You may recognize this. You're trying to show them a vision target, and they are deliberately looking in the other direction. You know they've seen it because they react in opposition to what it is want them to do.

These children might get stuck on something they like to see. I've seen it described on vertical blinds in a window. They just can't seem to turn-- tear themselves away. Or a child who had this bottle of drink that was bright yellow, and they just had to keep looking at it. They might have specific colors they like. They are certainly the people who light gaze.

And they might be what I call the flappers and chewers, these children who seem to have to flick something in front of their face in order to control or regulate themselves. Or they chew on their hand and they rock. They're using other sensory stimulus to just turn their vision off. They just need to switch their vision off. It's just too much.

There's then the sensory sensitive group. These are the children who become overwhelmed with sensory stimulus. They are easily distracted. They seem to see everything. They're scattering about. They've been picking one thing up and then seeing something else. It feels like they can see too much.

So in children who are able to describe it, they say, well, when I look at a page of text, it's as if every single letter on the page is trying to come into my face at one time, a bit like hearing the whole of a symphony as a single sound.

They see every detail. They read every word. They may need to either look or hear. They might find it difficult to do both because they're so overwhelmed with the amount of information coming at them.

And the final group are what I call the bystanders. These are the very passive children. They need things pointing out to them. They don't seek things out. They sort of lack interest a little bit.

You need to work with them. They may perhaps be shy. They're quite easygoing and drifters. But they are approaching vision in a way that they are almost dismissive or disregarding of it.

And if we contrast this now with the other visual behavior matrix that we're trying to put together, we need to think a little bit more about how vision works, so the teeny, teeny, tiny bit of vision science coming in here.

When we describe vision, we talk about the two areas. Central vision-- we can all imagine our central vision, the bit we use for reading, almost our binocular type vision, the bit in the center that's detailed. And then the bit around the edge-- our peripheral vision. And they come from different parts of the way our brain is wired called the parvocellular and the magnocellular.

And you can immediately forget those terms. But it's pointing out that this is not new. We're just looking at it in a different way-- the neuroanatomy. This is well, well established. The wiring networks between our eyes and the vision part of our brain has long been understood, but just not applied to autism.

So our central vision is our what? What is this thing I'm seeing? And yes-- we need to know what the acuity is, the sharpness of the vision. And it gives us our color vision and our very good 3D spatial discrimination. That's what the central bit of the vision does.

But the peripheral helps us know where something is. It's our visual field. It's important for light detection. It's what gives us our night vision-- is our peripheral field. And it's very good at movement. It's very good at spotting that saber-tooth tiger that's about to run at us and try and eat us.

That's what our peripheral vision is for. And most of the time, we are flicking between these two. We're able to integrate them-- tune one up, tune one down, depending on what the task is in hand, how relaxed we are.

But for some children with autism, they can't seem to do this mixing desk. And they may find themselves stuck in one area. So for central processors, these children have good acuity. They can see tiniest letters. But they may only be able to see one part of the page at a time.

They perhaps can't integrate images they've seen. So that means they can't put things into context. And I'll show you a photograph in a minute with what I mean about that. They may seem to be clumsy and trip over things because they are using that central bit of their vision.

And that means they are just walking through big objects on the floor because they've seen that blue LEGO brick over there-- that is what they're going for. And they may be particularly sensitive to flicker, to strip lights in the ceiling-- that-- you and I can't see this tiny flicker, but for them, it's too much.

So I mentioned a moment ago-- these children can perhaps only see one part of the page at a time. So imagine this. This is what the child has looked at. And they're given a photograph or a picture and they said-- how many children-- how many people are in this photograph? And they see somebody there.

And now they see this, and they think, oh-- that looked like this-- maybe that's a planet. Maybe that's a rocket going into space. And now they see this. I'm not really sure what that is. It to be some triangles, or maybe that's some smoke. I don't understand what that is.

Oh, and now they found another person. All right. So there's two people on this page. Whereas actually-- there are four people.

But the way the child is using their vision means there's some plane-- a small section at a time. And they can't tell you that this is a beach scene because they've not seen all of the context.

These children may appear to not see things unless they're right under their nose. I talked about the problems with strip lights. And they may miss whole sections out of a page. If they have a list of, perhaps, maths puzzles, they're only seeing the left-hand strip. They're not seeing the right-hand strip. They just might miss whole sections of tasks out.

So in contrast, I'm now going to contradict everything I said and talk to you about children who are predominantly or prefer to be peripheral processors. These children may not be able to use their sharp central vision, not because it hasn't developed, but because it overloads the amount of information they're being asked to process.

Or we talked about being able to balance and flick between central and peripheral vision, to tune up and down. They may just not be able to turn off their peripheral vision in order to get to their central vision.

So this is the difference between having a 3D HDTV flat screen and, for those of you who are old enough to remember, a black and white, analog, fuzzy screen. Your peripheral vision is much more like an old-fashioned black and white, low-intensity television, and your central vision is like your 3D HGTV.

So what do these children do and what do they look like? So this picture here is great from an article I've referenced at the bottom, where they may turn their head to the side because they're then using their peripheral vision. It gives them lower-quality input and means they can access it better. It may reduce their sensitivity to that light flicker.

It may be that they can't use information from two eyes at once. That's just too much. And so they turn their head to choose one eye they're going to use for and don't use their stereo vision. And it might mean they have an eye that drifts out because they're choosing one eye.

And here's an example of a little boy who, when doing the vision task, would start with his head slightly on a tilt and then would tilt it back more and then tilt it back so you almost think he's got his eyes shut. But what he's doing is reducing the amount of peripheral information so he can just get to the central stuff because he can't integrate.

He can't shut between them. And so the only way that he can get to his central vision is to tilt his head further and further back to make this tiny little letterbox that he looks through.

So thinking-- does this child seem easily distracted by objects in the corner of their eye? Are they the one who's constantly looking over their shoulder for somebody moving in the room? They are now looking at them. Or they turn their head from side on.

We're now going to talk about position processors. And this is a different concept altogether. One of the functions of our vision is to understand where we are in the world, to know how far away objects are, to be able to walk into a room and instantly map out how big it is, what objects are in there, where they are relative to us.

Now, these children, again, may have a normal acuity, may be able to see as many tiny letters on a chart as you like. But they can't use their vision to understand where they are in space. And that means they can't use their vision to learn new motor skills. They may find it difficult to copy somebody brushing their teeth. They may find it difficult to catch a ball or see things.

These are the children who, when they walk around, trail their hand against the wall. They stand in this capital A position with their arms slightly out from their side. They may bump into people. They're being told off. They're not paying attention. They're told off for not observing an appropriate space between people, or some too close.

They may be completely disoriented by a new room. To them, it's a frightening, terrifying space that anything could be in it. And they may be the rockers or spinners. Some children use this movement of the spinning round to help them work out where they are in space.

So they walk along with their hands away from their body or trail against a wall. They explore the environment by walking in and touching every surface, mapping out a room. And again, they may flicker their hand in front of their face to help them feel where they are.

And finally, the single-channel processors-- and this probably applies to all the groups of children we've spoken about so far. We're all aware of these people who are a "one thing at a time" person. But this is even more extreme in a child with autism and vision problems. They are hypersensitive to multiple sensory inputs.

We talked about this mixing desk. They can't slide things up and down to be able to feel what they need and really pay attention to the bit that we as adults think is the most important. They might have very strong color likes or dislikes, texture likes or dislikes, clothing likes or dislikes because it just helps them have one less thing to think about or process.

So quite often, when I am using my PC at home, this little message pops up, "High CPU Usage." And I thought, oh, what is that? So I decided to be totally distracted and Google. Your CPU, for those of you who don't know, is your central processing unit. This is the brain of your computer.

And what your computer's doing is-- whenever you've got apps open or functions open, it is constantly flicking between them to keep them all working. And it does it seamlessly so that we don't really notice it happening, except sometimes when you've got too many tabs open and too many things going on-- my computer would say, too much, too much. I can't do all this. You need to basically close some tabs down.

Now, we can all see this happening in children. You can see that when their bandwidth just becomes not enough for what they're dealing with. One teenager explained it to me beautifully. She said it's a bit like-- normally when you're streaming Netflix, it's fine.

But just sometimes, your connection is not very good. And so the screen will freeze, but you'll still hear the sound. Or the screen will pixelate. Or maybe the sound will go, but the screen will keep going. The pictures will keep going.

And then at other times, it just goes into this buffer and it just stops altogether. That's what it's like for me, she said. For no reason at all, suddenly, I'll feel like I can't see, whereas a minute ago, I was seeing perfectly.

Now, for a child who has difficulty expressing themselves, how do you describe that to someone else? How do you explain? And when you don't realize that not everyone else's vision is doing the same as your vision-- you don't realize that everyone else can see normally all the time, can see well all the time. They don't have these periods of freeze or flicker.

So how can we help children shut down some of the processing they're having to do? Is it the sound of the fan on the computer in the corner? Is it this flicker from a light? Is it something as simple as the shadow from a tree flickering on the desk?

Is it people moving around the classroom? Is it the carpet? Is it the feel of the chair? What is it that is overloading your system that means you can't get to your vision?

So think-- what is this child experiencing? What are they seeing, hearing, feeling in this moment? How can we reduce some of that overload?

And you can see, really, here where the overlap is with cerebral visual impairments, where we talk about clutter, visual clutter being a problem. Well, if all sensory clutter is their problem, how can we support that child?

So these children may look away when someone's speaking. They may turn away from a visual stimulus. They're trying to isolate what they're trying for-- what they perceive as the most important thing.

Now, I spoke early on in the course, in the talk, about our saccades. Saccades are these fast-flicking eye movements that we use to look from one object to another. They're not the nice smooth-tracking ones. They flick, flick, and we use them to move along the words on a page or to look around the picture when we're trying to isolate things.

And we know that half of all children with autistic spectrum disorder have either slow or inaccurate saccades. But what does that really mean in life?

Well, when most of us read, we move our eyes along the page about 7 or 8 characters at a time. So when we're reading, we read this line of text as "once upon," and our eyes move, "at a time," and then our eyes move, "there was"-- and we're moving along the text in a quite efficient fashion.

But for a child with problems with these saccades, they might not move properly. So they've read "once upon." And they've not moved far enough, so they've read the word "upon" twice. And so now what they're hearing is "once upon upon a."

They move on. They don't move far enough again. So they've read "once upon upon a a time." And now they've made an overcorrection. So now they've missed a word out together. So they're reading "was a."

And they flicked back. So now they've read "once upon upon a a time was a time the" because they've only seen half of the word. So you can see how utterly frustrating and exhausting and lacking any sort of sense reading might be for a child who has difficulty accurately moving their eyes across a page.

And that is before we've added in the problems they may have with integrating sensory and-- all the different senses-- integrating peripheral and central vision before we've understood about the page. It may be on poor contrast, or it may be on textured paper, or all those other things. Reading is one of the most effortful things that we ask a child to do. We need to think how we can make it easier.

So we've introduced these two models. The one about the different types of processing that a child with autism might have just looking at their vision-- do they use their central vision?

Do they prefer to use their peripheral vision? Do they have difficulty mapping where they are, having to feel and touch the room? And how they deal with more than one sensory channel at once.

And then we talked about Dunn's sensory model. So these are children who either sensation-seek-- they're on the go all the time. They're go, go, go, go, go. But they might miss something important because they're on the tiny things. They may avoid, and they deliberately look away from things because they just can't deal with all the information.

They may be sensitive. They may find-- get themselves very overwhelmed with things. They might get stuck on visual problems. They might get stuck on a single thing that they just can't stop looking. Or they may be low registration, the children who are bystanders, who just seem very passive and in the corner and watch the world go past them.

So I mentioned I'd talk about two essential examination tools or things that you can do to try and draw this out. And the tools are look and listen. You need to look at what the child is doing. You need to watch them in the classroom.

You need to watch how they access materials, be that screens or be that written materials-- be that pictures-- be that toys. How do they move around the classroom? How do they interact with other children? Just watch and think-- are they using central or peripheral? Are they having problems mapping where they are? Are they overwhelmed by sensory information?

And then listen. Listen to what the parent is telling you about what they enjoy and what they find difficult, about the circumstances around when they might have an episode where they need some time out or they seem to decompensate it-- or the term we would use in the UK is a "meltdown," but I know we all have different terms for these things.

One, where does that happen? What else has been going on? Because if we can spot when that's coming, if we can help the child when they're trying to communicate to us-- enough is enough. Too much. This is too much for me. We can intervene before it gets to that stage, and the child can function comfortably for longer.

So my question is-- does the child integrate vision and other senses? Just watch them. And do they integrate their central and their peripheral vision, or are they choosing one over the other? Because that will help you understand how and where to present information for them.

Now, a visual assessment in autism does need a what-- what we call in the UK "reasonable adjustments," things to think about before you start. And I'm not talking necessarily about a formal visual assessment, like me doing an eye clinic. I'm really thinking about anything, if you're just observing the child or you're trying to work out how they need to use their vision.

Before you begin, watch the child's head position and body position. Notice what works best for them, rather than what you as a teacher might feel-- oh, we need to sit nice and straight in the chair with our back straight. What works for the child? Because that might not be what helps them use their vision best.

Allow lots of time. Wait for 8. 8 seconds is a really, really long time. But we sometimes need a nap time to help the child regulate, to integrate, to work out which bit of their vision they want to get to. Can they, with effort, suppress some peripheral stuff so they can get to their central vision?

Enable "breakouts." I had one child who I vividly remember. We were trying to examine him in eye clinic. And he would get closer and closer to me and have his hands on my knees and be really leaning in. And then he'd suddenly spring back and he'd spin round three times, and then he'd sit down.

And then-- give him 3 or 4 seconds, and then he'd be up again and he'd be ready to be examined. And we just let this cycle go on because he was presenting himself to me for me to examine absolutely beautifully, but just in five-second chunks. But that's OK. Rather than "no, sit down, stop it, you mustn't"-- no, no. Let the child do what they need to do to get to their vision.

And then things I'm sure you already know-- simple instruction, softly repeated. I try and discourage the parents from encouraging the children. Ooh, will you look? No, hold your head still. Ooh, have you just seen? Ooh, is it a frog? Is it a frog? No, no, no, just less. Very, very quiet-- perhaps three or four words of instruction, softly repeated, helping the child get to their vision.

And thinking about the amount of noise, thinking about the overhead lighting, thinking about your own clothing. Is that brightly patterned? Is that in itself a stimulus for the child?

And finally, something that vision specialists need to think of-- we know that one of the problems that children with autism may have is translating objects from 2D drawings to 3D pictures, or understanding that a duck doesn't always look like a duck in this picture, or an apple isn't always orange and green. It may be a different color.

And so if you're setting a child's vision using line drawings, these may bear absolutely no resemblance to the pictures that the child has in their head of what a fish or a cup or a shoe looks like. We need to think carefully about that.

Think about text. The child learns to read on printed fonts-- they may not be able to read handwriting. Or there may be a particular font they can read. And so if you change the font, to them, it's like a foreign language again.

And so, finally, I'll introduce you to the VIBE8. We said that ViBes are sort of visual behaviors, and we found eight questions that can help to draw out some of the visual behaviors that a child might have.

And we did an assessment with a team from Ireland looking at-- do parents and clinician reports of these behaviors match? So is a parent spotting the same things at home that a clinician spots in clinic? And what we found is there were no significant differences between what a parent reported they've seen at home and what a clinician spotted in clinic.

And here are those eight questions. And that's with the CVI5 that you may be familiar with. The parent is asked to comment-- do you see these things? Do you see them never, sometimes, often, or always? So which of these things?

So does the child become visually stuck on an object? Does your child turn their heads to look out of the corner of their eye? Does your child become distracted by moving objects, things alongside them or in the edges of their vision?

Do they trail their hand along a wall when walking? Do they flap their hand in front of their face, or do they rock in their chair? Do they look away when they're speaking or when someone is speaking to them?

Might they be more engaged with sensory activities that aren't vision, for instance, chewing? And is vision on their terms? This is a term that perhaps it’s vision on his or her terms. Deliberately look away-- and we call this visual avoidance.

And so this is trying to encapsulate the most commonly seen visual behaviors. And what a parent may have said is-- oh, it's just how he is. That's just how he is all the time. Oh-- not really thinking that this is not normal visual behaviors.

But if the parent can understand why the child is doing it, we can then begin to provide an environment that means the child can access the vision more easily. And as we said, maybe not reach those limits of their sensory burden-- we might be able to prevent them having these episodes where they just feel they can't cope anymore.

So I'd encourage you to think about some ViBe statements when you're watching the child. Do you notice-- can they integrate sensors? Or are they actively using their vision? Or their vision seems on all the time and they're integrating central and peripheral vision.

Or are you noticing the child has deliberate visual avoidance? Are you noticing they use touch rather than vision when they're finding things? Do you notice they're using their peripheral vision rather than their central? Or do they just seem to switch their vision off, disengage, daydream most of the time?

Or are you noticing that the child walks over things to go and get what he wants or engages with very specific visual input and uses their central more than their peripheral? So thinking about some statements that you could work in and ask yourself when you're watching the child in the classroom.

Thank you very much for asking me to speak to you. I'm very happy to answer any questions that there might be. And my email's at the bottom of the slides. And I hope it's been useful for you.

CATHERINE SMYTH: Thank you for sharing your knowledge on this important topic. We really appreciate it.