This session is being recorded and if you give me just a moment I am about to start that recording. I have minimized so many of my windows. I can't find the button.

>> Recording in progress.

>> Good morning. Welcome to CVI for the TVI and other professionals. Today is Wednesday. It is June 9th, 2021.

My name is Robin Sitten. I am the program manager for Perkins e-Learning at Perkins School for the Blind who host these monthly meetings for the CVI for the TVI committee.

Today's presentation on visual fatigue will begin in just a moment.

Perkins e-Learning webinars are presented throughout the year on a monthly base. You may register to attend live at no fee or view or recorded webinars at a time and place that suits your schedule.

CVI for the TVI and other professionals is just one of the offerings in our professional development program which includes publications, e-newsletters, online classes, customized training and self-paced study.

You can see our entire listings at our website, Perkins e-Learning.org. And you can look at CVI resources for families at our page CVI Now, which is www.Perkins.org/CVI Now. Speaking that carefully so the captioner can get that as well.

For those interested in professional development points this webinar will be available in a tutorial format. And information will be provided on the webinar page with more detail. And I also send it out to all of you who have registered for this event.

So before we get started let me just review a couple of things about the technology. We have muted your lines. That helps us keep noise levels in control.

You may choose to use the chat space for questions. If your question is more of a private nature, feel free to use the question and answer box. Both of those are available at the bottom of your screen.

And we encourage you to post your questions as they occur to you during the webinar.

I'm going to address them at the end during the Q&A section and we'll try to consolidate some of them so that we can get to as many as possible. Chat and Q&A are both found at the bottom of your Zoom screen with the tool bar and you may choose to keep them open.

As you figured out, we're 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 and personal headphones can give you the best audio.

Captioning is available through Texas caption center, and you can find that by locating closed captioning and full transcript toggle on your bottom menu within Zoom.

This event is being recorded, as I mentioned. It will be available on our website. Including a downloadable of the presentation that Rachel is making today and a transcript.

If you want to earn credits you will register for an online assessment and there is a 55-dollar fee for those credits.

thank you Rachel for indulging me in those morning announcements.

Rachel Bennett is the content and community manager for CVI Now at Perkins School for the Blind. She is also a CVI mom. Rachel intimately knows the struggles, fears, joys and precious moments of hope that come with raising a child with a complex visual impairment and other needs.

A lifelong learner about CVI and neuroscience, Rachel is committed to advocating for better outcomes for kids with CVI. In 2019 Rachel completed the University of Massachusetts, Boston CVI certificate program. Prior to joining Perkins she was a special educator and a curriculum specialist for Montgomery county public schools in Maryland.

Rachel, I'm going to turn off my camera so that you have our full attention. Thank you for joining us today.

>> Rachel: Thank you, Robin, for that warm welcome.

It's so exciting to be here. I'm going to share my

Here I am on Zoom sharing my screen!

Thank you all for joining me today and to talk about visual fatigue. This is a really important topic to me and it's really exciting to be here on CVI for the TVI. I'm having a bit of a fan girl moment because I remember when CVI for the TVI began a few years ago and just as a CVI parent, to be able to learn from a wide range of professionals,

to be able to hear multiple perspectives it really broadened my knowledge and showed this is a gathering place for ideas. So I'm so excited to be here.

Visual fatigue, it's a really big topic in the CVI community and I want to share with you my learning journey of how I got to where I am today. Of course it begins with my son Henry. He's eight years old. He has CVI and ocular visual impairments including severe vertical miss stag must, myopia, intermittent exotropia. He has delays in motor

skills, speech skills and other needs.

Of all the needs that I have to deal with on a daily basis with him, visual fatigue is right at the top. It's constant. I always have to calibrate the day, I always have to be worried about fatigue with Henry.

And when I learned of Henry's CVI when he was five years old, I of course dove into the foundational text and envision the brain and talk about visual fatigue in relation to dorsal stream dysfunction. It shows in individuals more at the end of the day. Dr. Roman lancecy talks about fatigue in relation to the latency scope.

I saw how being tired being affects visual attention and visual skills with children with CVI.

In reading cerebral impairment in children, this is definitely something medical in the medical perspective, they don't talk directly about visual fatigue, but they often talk about visual search and the time it talks for visual search and how that effects the ocular motor system. They have this one example of a study where they have a picture

and this one here B shows all the different eye tracking movements and then these examples of C and D are individuals with CVI and all the different individual search patterns.

So they talk about how really the visual search isn't as efficient.

And then we have Dr. Merabet's work and Chris Bennett's work and Dr. Karina's work in the lab for neuroplasticity and they have toy box crowding and even a virtual hallway. And with increased visual demand, with increased visual load they saw increased visual search and the impact on the visual system.

And then we have Matt Tijen’s work in what's the complexity framework. He brought visual fatigue to the forefront of what we need to know about CVI.

It was such a pivotal point in my learning when I took his course in 2018. He really talks about how to create an accessible school day so we can keep the CVI battery charmed, not red like this, but green all through the day.

And what accessibility looks like for kids with CVI and how to make sure fatigue doesn't set in so melt downs don't set in.

And at the end of February I believe I developed a three-part series on visual fatigue for CVI Now and this first part is one of our top three most visited pages on CVI Now.

So it goes to show how this is becoming a really big topic in the CVI community.

I want to dive in to a statement from an individual with CVI. As much as I can today I want to elevate the voices of individuals with CVI.

She says when I'm rested and happy I see clearly except for the visual field loss. My acuity is fine, but when I have visual fatigue it's like looking through a straw. I have an extremely limited visual field. It gets all fuzzy. I'm also not able to recognize what I was just looking at. Touch helps me recognize it again. I get almost blind

when I am tired.

Right? So we have a lot to talk about and a lot to unpack here when it comes to visual fatigue with CVI.

Visual fatigue is likely one of the most common shared experiences among individuals with CVI.

So today we're going to explore the science behind visual fatigue, what research is telling us about the neural network of the CVI brain. We're going to talk about what visual fatigue looks like and feels like. We're going to hear from individuals with CVI and families of children with CVI.

And then we're going to scratch the surface, but thinking about accessibility much more broadly for our kids with CVI and a multi-sensory approach to help reduce visual fatigue and ensure access to learning and environment throughout the day.

Okay. So let's of course start with the research and science. There's a neurological and physiological reason why individuals with CVI become so easily fatigued.

Let's talk about the brain for a second. Here on the left we have the brain, the occipital lobe, the frontal lobe, the parietal lobe. We have the ventral stream identified from the occipital lobe to the temporal lobe. We have the dorsal stream identified. And the dorsal stream actually ends in the frontal lobe. So our visual system is highly

efficient of processing every aspect of a visual world for those with average processing abilities.

Our life experiences feed our visual memory, which then shapes perception and allow us to come up with a plan of action. So all of our experiences, all of our multi-sensory experiences help us perceive what's in front of us at any given moment.

And we have a visual template that we are constantly using to match what we see.

But it's a delicate balancing act, right? This is where a visual system allows us to do, visually search for targets among competing distracters. Attend to this target while ignoring other sometimely. And then match that target to our visual library to support the speed and efficiency of recognition. And then make a plan for action.

So when searching for an object, it's not just about where to look, but also about where not to look. The brain has to keep track of what it's looking for and ignore information that is not relevant.

But we have limits. There is a perception actual limit in terms of how much information the visual brain can handle in any given situation or moment. So I want to do a really simple simulation example using M&Ms. This is an idea from Dr. Merabet. I'm going to show you a few slides with different amount of M&Ms on them and I'm only going to show

you them for about two seconds. I just want you to note how many M&Ms you see. Okay? Ready?

Here we go.

Okay. We'll go back to the beginning here. Now, there might have been a moment where you realized I don't know how many are on there. I need more time to count. I can't instantly know the amount.

This time I will show you again and I want you to note which slide you are not able to perceive instantly the amount of M&Ms on it, okay?

Here we go.

Okay. Going back to the beginning. Sorry, fast slides moving.

Okay. So Robin, I'm going to go through the slides again. I want you to tell me which slide you were like oh, couldn't perceive it right away.

>> I am ready. I should just tell you at which slide?

>> Rachel: Tell me when to stop. We have one M&M here. Three, got it.

>> Five, simple.

>> Rachel: You got that one. I was a little tripped up on this, but good.

>> I did. And I actually got the seven, mostly by the way that they were laid out except now that I see there are eight.

>> Rachel: There's eight here.

>> [Laughter]. So both times I added seven. I think the pink did not stand out to me.

>> Rachel: I was trying to show if you had to count them in your hands. Interesting. And then this last slide.

>> This last slide I needed to count and there wasn't enough time.

>> Rachel: Interesting.

>> On this slide both times I saw that as seven and I think it must have been the pink didn't --

>> Rachel: How interesting. That's awesome.

Well, thank you for sharing.

So now I want everyone, before we go to count that last slide, I want us to try to count and really grind it out, but with competing distracters, okay?

Everybody ready?

How many M&Ms do you see? Count it out. How many do you see? How many are there?

>> Do you want me to tell you?

>> Rachel: How many were there?

>> Saw 12.

>> Rachel: Yeah, I think there's 12, yeah.

So that very sample when competing distracters were there, what was it like? What do you notice?

>> Well, I couldn't -- I was certainly distracted by the moving human factor because I kept thinking -- am I supposed to be attention to that, is that coming into play? The noise was again a momentary distraction mostly because as the host of this event I thought oh no, what's happening, but then I remembered your presentation.

So so I was actually able to put that out of my head pretty quickly.

I think, for example, if that noise had been somebody counting or even a list or something, something that -- it was just sort of indistinct noise as our captioner writes.

So I think if it had been words that I was trying to pay attention to that might have been even more complicated.

>> Rachel: Yeah. This is a very example with the M&Ms.

I really wanted to grab them off the screen and CO2 them. That's what I wanted to do with all of this stuff. I need some other sensory input to support me here.

Yeah, thank you. Thank you for that. And hopefully other folks just had a little noticing there.

So what is this? It's been called the set-size effect. There's been a lot of research on this. It's a capacity limitation in vision whereby the time needed to find a target increases in the presence of distracters, inputs from multiple objects interfere with each other.

So this is our perceptual limit. We all have this.

Let's give you another example. This is a famous example from Matt Teitjen's work. I can't each look at this because I've seen it so many times that I'm having a visual reaction because I know how hard it is to look at. I know it's not accessible.

This is definitely crazy above my perceptual limit. I need access to this and that's what it looks like. We have spacing, color coding, grouping, folding. So many supports here and design tools to make this accessible to me, somebody with average processing, visual processing abilities.

Okay. We all have accessibility needs. Vote just happens to be designed and therefore accessible to those with "Typical" visual processing abilities.

Individuals with CVI have a right to accessibility, something that many of us use every moment of everyday.

It's not extra, it's access as the famous CVI parent advocate Rebecca Davis said.

I just want us to keep us in our soul as we go through this presentation.

So why is the set-size effect important to talk about in relation to CVI?

Dr. Merabet says that these examples demonstrate that there's a perceptual limit in terms of how much information the visual brain can handle in a given situation.

In fact, this upper limit may be lower in the case of CVI or show more variability depending on the nature of task demands.

The neuro network of a CVI brain is fundamentally different. Our kids are neuro diverse. It can be a more sensitive network, it's a network that's not as flexible. And so having to respond to increased demands, whether a visual demands, whether sensory demands, whether it's too hot, too cold, whether it's something unexpected, it will

be very, very challenging and our kids need access.

With increased individual load, individuals with CVI have to kind it out as opposed to have an instantaneous capture of information that we see with a really efficient visual system.

A simple example with the M&Ms at the end we had to grind it out. We had to go and count each M&M one by one.

Imagine having to do with a much more complex task all day every day. You get really tired.

So this grinding it out is called serial processing. Scrutinizing one piece of information at that time when there is more sensory information to take in. Serial processing is less efficient form of visual search.

And this is as opposed to parallel processing. Many elements of a visual scene can be processed at the same time instantaneously.

So early research is showing in Dr. Merabet's lab, learning about what's happening with the frontal eye field with kids with CVI. So the frontal eye field, FEF, FEF, is in the frontal lobe, which controls the movement and visual attention, is more active in the presence of CVI.

So why is this important? Let's look at this image on the left. We have two images of an FMRI imaging brain. Here we have the control and you see big swaths and patches of yellow here and activation. You see back in the cortex, the motion processing. You have a nice thick track from the primary visual cortex to the inferior temporal cortex

that makes up the ventral stream. You have a nice swath from the occipital lobe to the parietal lobe for our dorsal stream. And then you see the FEF lit up in the frontal lobe.

In the CVI brain here, you see the yellow, but it's much more patchy, it shows less connectivity in the primary visual cortex, in the ventral stream, within the dorsal stream, but you also see the FEF. It is lit up and it is big.

So what this graph shows in the middle is even more visual stimuli is presented the FEF is already engaged versus the control FEF is engaged when visual stimuli is presented.

So why is this important to know? Why is this important to kind of begin thinking about and discussing?

Dr. Merabet says it seems that the frontal cortex has to work harder to make up for the fact that early visual areas are not doing their part, so to speak, in visual processing. And this may be related to why kids with CVI are so much more fatigued with increased attention demands. So if the early and higher-order visual areas are not processing

visual information as easily, the frontal cortex has to take on the load and work harder. And because the frontal cortex is also interconnected with many other areas in the brain, including attention and emotion, things can break down easily with excessive fatigue.

A lot of kids with CVI we work with tell us about the frustration they experience, the sensitivity to clutter and how exhausted they are at the end of the day.

We think this is because their visual system is not as efficient as it should be. The brains of individuals with CVI have to work harder to carry out visual tasks that may be very simple to somebody else.

And so let's now talk about what does visual fatigue look like?

And we're going to start with an adult with CVI. This adult just started a new blog called the CVI perspective. They wrote an open letter to the CVI community. It really is incredible, very powerful and vulnerable. I suggest all of you go and look at it and read it.

The first time I met another adult with CVI we spent eight hours straight, swapping techniques that we both use to pass as sighted. Not tips on how to see things better. We both agreed that even during our strongest visual years, trying to use our eyesight had always been exhausting, confusing, frightening, and straight up traumatic.

Exhausting, confusing, frightening and straight up traumatic.

Now, I know that CVI manifests, you know, differently in individuals, but to hear what it was like to try to use their visual system really hit me. They go on. We swapped tips on how we used other senses so we could fool people into thinking we were seeing things.

We learned how to hold on to a million other pieces of data and how to do constant mental math, moment by moment, so we could calculate everything and all the pieces would add up to the illusion of seeing.

Constantly running extra algorithms behind the scenes, carrying a heavy cognitive load, operating delicately under a thick blanket of anxiety, sewn with the threads of what if I miss judge where I thought I heard that foot step was and my foot lands in a hole or a crack instead?

When Fi eyes are pointing in the wrong direction? What if a ball hits me in the face again? When we talk about visual fatigue we're also talking about what it's like with individuals who try to exist in the world that is expecting them to be sighted because not many people fully understand CVI and the profound impact CVI can have on access.

Wherever the individual is on the CVI continuum or the CVI mixing board, it's going to have a profound impact on access.

They continue, when you have CVI, seeing is not passive. Anything sight-related is active work. Relentless, grueling work, tons of effort, very little payoff. It is always a big deal.

We saw that in research. Using vision with a less efficient system is going to be active work.

So some examples of signs of visual fatigue that both families and professionals have shared. Resting head in hands, looking away. Pushing all items out of view. Asking for a snack or preferred activity. Running away. Walking into the corner of the room.

Closing eyes and appear to be sleeping. Head down, goes to sleep. Talks, sings or tells jokes to change the interaction to an auditory event.

Fidgets and plays with other objects that are near. Yells, grabs or shows other outward behaviors.

My Henry has shown all of these signs of fatigue. This isn't just one, it's a lot of ways our kids try to communicate that it's too much. That their visual system is shutting down.

I asked some parents of children with CVI what does visual fatigue look like in your child? And here are some examples of their responses.

Visual fatigue occurs most often for my son with multi-sensory input. For example, as he's physically exerting himself the school gym is loud with lots of people and items moving quickly. His vision essentially turns off for a period of time.

Learning has to happen in 10 to 15 minute bursts. Anything more than that and my daughter can't physically hold herself together.

Visual fatigue can have a whole body hold being affect.

My daughter's fatigue always shows as behaviors, melt downs and aggression. She will also look away from everything and often puts blankets on top of her head. Henry does this too.

And this last one is me about Henry.

After school Henry doesn't want to engage. He doesn't have the energy to respond to me. I can tell when he's tired that his nystagmus is going wild more than unusual. There are times that I can see that across the room.

His fatigue accumulates throughout the week, so by Thursday or Friday he has a hard time with challenging tasks at school or even meals at home. Now it's been so hot here in Boston and I've had to recalibrate him in the heat. The heat is really exhausting for him. I've heard from many individuals with CVI that with excessive heat they're not

able to use their vision.

From Dagbjort, the adult with CVI we heard at the beginning of this presentation, she shares: I had a moment today during my rehearsal as the lead role in an operetta show. In the last few practice sessions had been doing choreography. Today while doing a as I remember dance I had this five minute break down that I associated with CVI. I realized

that if I have to use all my senses at the compatibility same time I will have to back off. With CVI it is always the vision. Using my whole body dancing, using her ears to listen to the microdetails in the music, remembering my next lyrics or dialogue line, looking at closely as I can as I dance, not to bump into anybody, remember to start singing

in the exact nanosecond. Plus in my case lack of motor skills, which makes me think even harder about what I'm doing. Something has to back off.

And as parents we've heard it all about our kids. And Henry's former school system I've heard this, all of these.

Lazy, inattentive, task avoider, not available for learning, doesn't show any interest, can't sit still, easily distracted, can't follow directions, always angry and frustrated, has a sear bear problem.

-- severe behavior problem. All words that blame the child rather than seeing fatigue as a visual contributor to difficulties associated with CVI.

So it's really important to know the signs of your students and the kids you work with, the individuals you work with.

Individuals with CVI show fatigue in a myriad of ways, in a lot of different ways. The signs are unique to the individual. So talk with your student, talk with your student's family about the signs of visual fatigue they observe every day in their child. The compounding effects of visual fatigue. What is needed once visual fatigue

has set in. And how to support the child to get through the rest of the day.

What helps to reduce visual fatigue over the course of the day. And if anything, the key take-away you want from this presentation is go talk to the individuals you work with, go talk to their families about visual fatigue to better understand how to create a much more accessible day.

So now let's think about accessibility. And when I think about access with CVI using a multi-sensory approach and how to ensure that they have access to their learning at all points throughout the day.

So of course it starts with the foundations to create any accessible education program, right? We need a whole child assessment approach. A functional vision assessment for ocular issues.

Many kids with CVI have co-occurring ocular issues so we need to understand those and how they impact access.

The CVI assessments available. The Roman CVI range, Dutton's inventory. Henry's included what's the complexity framework in his vision report and it added such incredible insights and observational data to support recommendations to his IEP team.

The learning media assessment. That is really important for kids with CVI. Can't emphasize this enough. Kids with CVI need a learning media assessment. They need to know what things will be accessible and how they're contingencies their world.

Yes, we know there is an expectation for improvements in some kids with CVI in terms of vision, but we also know and I see this with Henry that he uses other sensory inputs as a bridge to vision use, as a bridge to visual attention recognition.

For example, he is an incredibly tactile kid. When his tactile system is warm up often times he has to be holding on to something he is better able to visually attend and visually recognize.

So the learning media assessment really showed his CVI and his school team all the ways that he uses the sensory inputs to make sense of his world.

So using that information to then create a multi-sensory approach to learning that incorporates visual access, but also incorporates other multi-sensory approaches to ensure that there's access to education throughout the entire day.

No matter how CVI manifests there will be points throughout date that vision is not available. It could be a huge swath of the day, could be little moments and we need to ensure that there's access at all times to their education.

O&M assessments are partner. AT evaluation, OT, PT, speech and others all to establish present line baseline data. It is really important that we have this current baseline data. We can't use assessments from five years ago. The brain is ever changing, our kids grow. We have to have current data in order to create an accessible educational

program.

Of course, consider the CVI behaviors at every turn and their impact on access and the barriers that come up. And how you think about access throughout the day as I just mentioned, targeted supports, accommodations, adaptations that support both visual access and multi-sensory access to help reduce visual fatigue and allow for more accessible day.

I want to highlight Matt Teitjen's what's the complexity framework here. It's such a great tool to really look at the day, your student's day in a very eval la active day. How to create balanced activities, how to keep the CVI battery charged includes proactive breaks and multi-sensory approaches and looking at the learning materials.

Making sure that -- that you know from all the assessments from the learning media assessments that you always continue to is ask what's the crowding like, is it unfamiliar, what are the multi-sensory inputs, what are the visual motor demands, what distance is appropriate? And always evaluating the environment. This is at every time.

What's visual clutter like, what are the acceptsry inputs. Is there distracting movement. What's the impact of lighting. Is it unfamiliar? What needs to be addressed for the student to have access to their learning?

So let me talk about just a few ideas. I'm sure this either affirms what you're already doing or gives you some points of inspiration, but I want to talk about predictability and routine. We all take advantage of this. We all need predictability and routine during our way. Imagine waking up every day and everything is unexpected. That would

be exhausting. But for many of the kids with CVI if they don't understand what's going on, if they don't understand the schedule, they don't have access to the participatory cues, the incidental learning that tells them what's coming next.

So our kids with CVI have a right to really understand what's going on in their day and calendar systems are a huge support for this. This isn't new for many of us who work in the visually impaired world, work in the deafblind world.

Calendar systems build context, memory, expectation to support perception and understanding.

Robin was just telling me how she has this elaborate color coding system on her calendar to support all that she needs to do during the week.

We all need these supports to keep us going and to keep us perceiving the world -- to keep us perceiving and understanding the world that we need to.

So here's some examples. Here are Henry's calendar. Here's a school calendar on the left and his home calendar. It's a tactile calendar. I started with a visual calendar, but it was not okay with him. Just because two dimensional edges are still a task for him.

So his TVI said let's take try a tactile calendar. I wanted him to access this at all points in the day. No matter what he's feeling, no matter what his vision is like. It's been two years now and it's just been a game changer.

He has so much more calm, so much more rooted and anchored. He has so much more autonomy and his calendar system has been such a great foundation his literacy, for going from 3D to 2D. And time is so abstract for many of kids with CVI, so often times they ask me to do something and I'm at home, doing, trying to run a household. I'll be like,

I'll be there in two minutes, five minutes. And he flips out on the floor because what does that mean to him? He has no idea when I'm going to be there.

So I've tried to use this visual timer with a highly familiar photograph of the washing machine. He loves laundry. It works sometimes, but trying to put in the supports and tools to keep him going.

Here's another example by the incredible Barbara. She's a CVI parent and her beautiful son Logan. She says: Our calendar system has evolved. This is what we're using now. We present three activities at a time. Work from top to bottom.

We recently added time for an activity like lunch at 12.

Knowing what to expect during his day has been really helpful for Logan. It has reduced his anxiety dramatically. Since he started recognizing numbers and counting, Logan is much more relaxed during activities. He now understands what three more and last one means.

We are working on him reading a digital clock. That's an app. I think it helps him feel more in control during his day.

So wonderful. Thanks for sharing that, Barbara.

Some other examples, here's Sharon a CVI parent. She wrote this great post about going from 3D to T2 for a child with CVI and she used the calendar system. And this is an example of an object calendar with actual real objects.

This is another example from a parent that they used the first then visual schedule that has different types of options for display and you click on the icon for recording.

Here is an example of a high schooler with CVI. He uses color coding to support his visual access and to understand what's going on throughout the day, throughout the week.

And so predictability and routine can be incorporated in so many different areas throughout the day. Placement of items, where to find, where to put away, order of tasks within an activity. Clearly lay out the end game.

Henry if he's doing a really challenging task like math. He hates math. But he needs to know what he's not going to be doing this forever, right? So a lot of prompts to say this, this and then we're done to support that okay, he can get through this.

And then a natural everyday routine of movement breaks and reseniorityive and snack time. They're part of the daily schedule that the kid can CVI with know they can rely on this.

And all this to continuously develop ton context and memory. We use this to support access -- to support access, to reduce anxiety and increase motivation.

I asked parents with CVI what helps reduce fatigue and support access for your child with CVI?

And at first they have an interesting pattern. Movement helps my child reset so he loves to ride his bike for 10 to 15 minutes.

Time on task can only happen in short five to eight minute bursts. After that he needs a movement break.

My son's visual breaks involve gross motor activities using his scooter or taking a walk.

Movement, movement, movement is a reset. Movement is not a distracting behavior or a defiant behavior. It's required for access for our kids with CVI. For survival.

Lots of sensory input during rest breaks. Deep pressure, swinging, help her pull her body back together.

Reduce the amount of competing inputs such as background noise. Allow him to look away when he's listening. And then look when he's ready.

He also benefits from some short breaks throughout the day when he can listen to an audio book or music.

Henry's just gotten into music and it's so funny. He just started singing like random songs out of the blue so it might be a calming technique. Another great support.

Another great quote from a parent with CVI. School is extremely tiring for my 16-year-old son. Since being home because of COVID and getting to take many visual breaks and physical movement breaks, he is not so tired and is now doing better at school more than ever.

He needs to move and be in a visually quiet environment. Another example of when we give our kids autonomy, when we allow them to be experts of their own brain and what they need for access, a lot of incredible things can happen.

So I want to talk a little bit about a multi-sensory and flexible approach for our kids with CVI. We need to help our kids build their toolbox for access. So we need to provide them multiple tools for them to use and figure out what best works for them.

There is no one-size-fits-all.

When vision is not reliable 24/7 it's important to build our kids' toolbox to ensure access.

Here are just some really brief examples, incredible for kid with CVI, he is doing some letter work but notice that he's sitting on a scooter and he's sitting in an interesting position. Again, our kids naturally adapt to their vision.

The parent also shared that during sight word learning and work he was on the couch kind of spinning around and upside down or lying on his belly, but was able to do really well with recognizing the words.

So really take the cues from our kids, you know?

This parent also did a great multi-sensory approach to learning letters. You know, connecting them with real life objects in the house, using Play-Doh for that kinesthetic tactile work. The writing wizard app has become a popular one in the CVI community to support writing and using that use of light.

Here's Henry with the muffin tin. I love this. I got this idea from his TVI. I think he's doing a graphing exercise.

So I want to go through what kind of learning activity might look like for Henry. This is an actual objective from his math goal.

So given various math tools, Henry will combine two add ends with sums to 10 in isolation and within the context of a word problem given three out of five opportunities.

I know with Henry he needs a tactile warmup to support vision use and access. Here are is muffin tin and trays. And using this he can play around with them, put them in different cups. And then from there he goes to visually challenging work. Prairie here are images of an instapot. He loves home appliances so this image of an instant pot is

really familiar because he's had a full life experience with it. Because he's been able to touch it and talk about it and see how it works and listen to it it supports his visual access here.

And the color coding of the red and blue is purposeful. And then after this challenging visual task, asking how many, counting how many, how many are two more, three more, less. Go back to the tactile work. And can -- now that he has a group of five, take all the blues how, how many do you have? Take out the reds. How many do you have? Two

plus three equals five. You can go through that whole sequence.

Bringing back the visual work. This is on the magnet board. These are 3D foam magnet numbers. Now he sees the equation and connecting all the work he's done previously to this equation three plus two equals five.

From here if this is kind of a little too much for him, if he's kind of giving little crazy eyes, which I see a lot, you can move to a kinesthetic movement. Movement. He loves movement also. And presenting a word problem with these big cardboard box and having him still work towards this objective, this goal. So work towards understanding this

equation and these numbers and developing this number sense.

And then now bringing it back to identifying the numbers with the amounts and such. This is just a quick example, but how you can incorporate different multi-sensory approaches with one activity to still support access to education, still incorporate visual access, but again not doing it in such a way that he's going to be toast for the rest of

the day.

Here's an example of a worksheet. I could get on my soapbox about worksheets. I hate them. But I'm not going to. Maybe I just went on my soapbox.

Anyway, this was sent by another CVI parent. This is a worksheet from handwriting without tears.

So I really want to take a look at this and break apart.

Worksheets are used so often to first of all teach the concept and then to assess the child bass able to apply that knowledge. And then that worksheet is taking into report and then to grades and progress monitoring.

So we really have to realize that if that's going to be the teaching tool and not accessible to kids we need to think deeply about this.

So more so than just getting rid of extra clutter or doing a little color highlighting, we need to think deeply about what's the goal. So what's the goal of this worksheet? It's to teach kids how to write the letter K.

And what are the skills need, the concepts that need to be understood? We need visual motor skills. And the concept here and we're really going to break this down, because our kids with CVI, because kids with visual impairments in general have limited access to incidental learning a lot of these concepts that are just naturally learned through

observation need to be directly taught.

And they always have to be thought about inner learning activity for our kids.

So we have here down burp the line as a way to teach the straight line. That's an abstract thing. Maybe Henry knows how to bump into things, but what does it mean to bump this line down here?

Okay. I know, right? Black on White abstract 2 D of course is not acceptable for most of our kids with CVI. But the whole idea of the kick is going to help you understand how to write this diagonal here I'm having a hard time too with this.

So first of all, it's important that the child has a felt experience with what is like to kick their leg and some of our kids with motor challenges may not.

Then our kids need to have access to biological motion. Seeing somebody do a kick and then processing the shape of the body of a kick to then translate that to this how to write this part of the K.

A lot of concepts that need to be understood.

And it doesn't mean that our kids can't do it, right?

They need access in a different way to understand how to write this part.

And then slide away. A lot of kids understand slide, but it's abstract to bring this experience to writing this diagonal line. Do you see where I'm going here? There's a lot to think about.

And K for kangaroo, this parent sent this great picture of her son looking at a real picture. This helps many of our kids with CVI, of a kangaroo and he said oh, it's a dinosaur. So K for dinosaur? A lot of things that impact access here.

So let's think about some multi-sensory and flexible approach. What are some ideas to support access to concepts and skill developments, visual motor skills, visual recognition, the spatial configuration of the letter K, the spatial configuration concepts that need to be learned, elements of shape, short, long, angle, diagonal, real world connections

to letter and sound.

Bring out the Wheatley board. I love Henry's Wheatley board. His sister loves the Wheatley board. But this is a great way to take apart the components of the K and have a multi-sensory experience of understanding all the different components of K. You can even do it with pipe cleaners.

Bring in familiar objects that begin with K, stories about these objects, real world stories of these objects.

Practice the visual motor skills using a shaving cream tray or gel and Ziploc on a light box or the writing wizard iPad app.

Support the student developing their own concepts of what we'll have to remember how to write the letter. That kick and that slide may just not be accessible, but they have their own concepts. They have their own ways of doing things and we need to respect that and empower them to trust their instincts and trust their expertise and brilliance.

This parent also shared how she does it for her son she uses color coding to help support the writing of these nice red markers and where to start. So use of color, tactile markers. Dirt writing utensils. Use of a whiteboard, maybe gross motor is more accessible. Keyboards, speech to text which my son use. He has a hard time with

sign motor.

But all of these things create much more access and multiple access point to understanding this concept that can be easily built on throughout their educational career.

And so when we think about accessibility for all learning activities for kids with CVI, we need to think about what's the learning goal? We need to think about what skills are needed? What are the students' strengths. All kids with CVI have strengths and abilities that can be capitalized on.

What concepts need to be understood. Really thinking about what's the incidental learning that should have access it and didn't because of their visual impairment. And so what concepts need to be directly taught to really unlock that potential in learning.

How can we incorporate experiential learning to build memory and context. We know how powerful memory and context is to build visual access, to build perception and understanding.

What are the CVI supports and adaptations for visual access.

What are the multi-sensory approaches, tactile, auditory, kinesthetic, olfactory, matched to the unique needs of the student that support access to learning and be a bridge to perception and understanding. How are we building their toolbox?

And it's different for all kids with CVI. Tactile might not be available, but they might have incredible auditory skills. Or vision might be the strongest but they need a lot of modified overvisual reports for access throughout the day. You've got to know your kids. You have to talk with families and you've got to assess really deeply.

And how will the students show their learning. What multi-sensory choices are offered?

I want to end with more statements from the adult with CVI who is writing the blog, the CVI perspective.

These are pretty powerful and make us think about things differently.

Vision alone never came into focus by itself. It had to be buttressed by something visual.

For this adult they mentioned semantic processing and language processing were their strength and kinesthetic processing.

The lesson in CVI isn't about seeing or not seeing. It's about a much deeper principle, autonomy and choice.

Of course we want to support visual access. Of course we want to do that. But even more than that, we want to think about autonomy and choice for our kids.

What CVI needs are options and the freedom to choose. What we need is respect as the experts of our own brains.

This is the only principle that works in every situation. Every narrative that promotes any one method or solution or answer breaks down when you introduce other factors to the equation.

I believe in presenting every CVI child with options and letting the child decide what works best for them. In fact, I believe in doing this for any disabled person.

All right, here we go. Last slide. Key take-aways. So there's a neurological and physiological reason for fatigue. We learn about serial processing, grinding it out and how exhausting that is and the inefficient visual system in the CVI brain.

It's not as flexible and it's highly sensitive.

Vision is often the first to go, right, given multiple sensory inputs when it's really hot out, really cold, when tired. It's unreliable when tired, stressed or anxious.

Know the signs of visual fatigue and how to build an accessible school day. Like really build an accessible school day and think creatively and flexibly about this.

Access multi-sensory approach, provide multiple entry points for learning. Freedom of choice and autonomy and build that toolbox.

So when individuals with CVI go out in the world they have all the tools they need to thrive and to fully access.

Individuals with CVI deserve accessibility all the times to reduce visual fatigue and help develop all the multi-sensory skills they need to be successful.

Lots of references.

Thank you very much.

>> Thank you very much, Rachel. Again, those references will be available in the presentation, which will be on our website soon.

I do have some questions that have come in and people continue to ask them.

I wonder, Mari, while we address these questions, if any new ones come in can you help me see that they're captured.

>> Mari: I will.

>> Thank you. So Rachel, talk a little bit more about fatigue and mobility. You talk a lot about motion. And one of the questions that came in was about a child who, you know, ordinarily can travel fairly well, with navigate space so perhaps when they're fatigued, how that might present itself and what you've heard from the families that you've

spoken with, the question specifically was does it seem like they suddenly lose those competencies and they can't navigate or they can't kind of move their body in space.

And what we know about that. So in the absence of a different ocular impairment, what kind of challenges come up when the student is using that part of their brain to try to travel or just move independently in space.

>> Yeah. It's talked about a lot. Henry, he will start walking and fall to the ground if he gets really tired.

You know, he will run into things more. And I think it's -- it's interesting, Henry broke his leg, I don't know when. Time is so weird right now. Almost a year ago. So he was in a wheelchair for about three months. And he was able to notice things visually more when he was in the wheelchair because he didn't have to -- the physical part of

walking. He has low muscle tone and walking can be really fatiguing. He was able to use his vision more.

So we now have a wheelchair stroller when we go on long walks so he doesn't become a noodle.

So I think it's really important to kind of watch for. If the kid has a really challenging morning, sometimes just being able to move where they want to move and to follow their lead might help, going on on a familiar route. Taking a route to a really motivating place where they can kind of let it out and be themselves.

I hope that answers the question. It can happen instantly, in the environment.

>> I think too if you think about someone who is working with these students and particularly let's say you're an O&M and OT and maybe you don't have all day every day. You don't always know when you're facing them at the height of their fatigue or they've been having a good day and it's the same thing that we talk about sometimes, pharmacology

and how if we had just done this lesson before his medication. There are all these pieces to think about.

A couple of questions about the really little ones.

So we have one parent with us who has a baby who is 21 months -- again, you may not have as much experience with this. You talked a lot about some of the behavioral feedback.

They report that their infant, their young toddler is having really irregular sleep. Sleeping-waking, which we also hear from those who are visually impaired and blind.

What do we know if anything about just that kind of irregular sleep or just physical tiredness that comes into play?

>> Rachel: Yeah, great question. Sleep has been difficult for Henry too. And there are a lot of families with kids with CVI where sleep has been a big challenge, really big challenge.

You know, he will take a nap at any point during the day -- I don't know how to answer this question, but what helps us get him to sleep regular is making sure that he doesn't nap erratically throughout the day because he would just fall asleep because he would be so tired.

So we actually started giving him, like it's hot now, more baths during the day. Something that's calming and helps to calm down his system that can kind of replace a nap time.

Because then -- he usually has a really easy time going to sleep. He will go to sleep at 5:30 if we let him, but that wouldn't work.

But it helped him sleep longer. He used to wake up at 4:00, 4:30, 5:00. Now he gets up about six.

21 months is a totally different situation than eight. But just thinking about what are some really credible calming activities for your kid. It may be some sensory input, it may be thinking about a sensory diet or thinking about -- water is really helpful for Henry to calm down and reset.

I don't know if that answers your question. I feel you as a parent. Sleep is hard.

>> And another individual says that so far their toddler doesn't seem to display this visual fatigue. Do you have ideas about what can kind of prevent it from coming into that position?

>> I think with increased visual demands so thinking about what's going on in school and what's expected of them in whatever situation they're in right now, thinking about -- I think the past year with COVID we weren't really able to go many places and it was actually quite nice for Henry. Things stayed very familiar.

So just be aware of the weekend days. I use Matt Teitjen's complexity framework on the weekends. Make sure we don't go to target and then the supermarket.

You know, making sure we don't take him to busy environment, busy environment. Even if he's really familiar with it. Each if he wants to go, it's going to show up.

So building in -- building your day around to make sure that it's accessible, that there's some really exciting times, but there's also built in quiet, calm times as well.

And again, fatigue is shown very differently. It may affect some kids more than others.

>> Thank you. Mari, have we gotten any new since we started talking?

>> We have, we have. So we have a question from Thea. My teen daughter is obsessed for being driven around for many hours. What do you think this provides her with visually? Rape Rach first thing that comes to mind --

>> Rachel: First thing that comes to mind is the feeling of being in a car that's driving. I wonder if the motion of the car is giving her some type of sensory input. Maybe the motion of things passing by is giving your daughter more access.

I've also heard from other parents that their kids hate the car because they can't process that fast motion.

Our kids are so fascinating!

So I wonder if it's the sensory experience. I feel like why Henry gravitated towards washers and dryers is it's full on, he can feel it running. It has beeps. He has an anchor to give him lots of information, that proprioceptive information as well.

So you just go with what works for our kid is what I'm learning. [Laughter].

>> Right. You can totally see it going both ways for some kids liking that and some kids hating it.

How do you choose the type of breaks to offer for students with complex needs and movement and communication issues.

>> Rachel: I think you have to start with families. Parents have the most observational data for their kids. And it could be anything. It could be -- I think parent really know what their kids like. It could be a type of snack. It could be listening to a certain song. It could be a type of pressure or a swing. I don't know.

We are forced to figure out how to make our day accessible for our kids. We're forced to figure out our kids for our survival and for our kids.

So talk to the families. They're going to really know what the kids love and what's going to keep them motivated and just build that naturally into the day. Don't make it like -- they will get this when they're tired, but start your day with it and make sure it happens three or four times a day. That should be a natural part if that helps you

answer your question.

>> I just want to share -- this is a comment, which is great, that my seven-year-old daughter is also doing well during the pandemic at home. I realize that some tantrums were because she was too tired when she finished school.

So now she takes more breaks and a nap and she has learned so many new academic things.

>> Rachel: That's amazing. It's amazing when our kids are shown the autonomy and choice to do what they want to do throughout the day they will show us all they can do, all they know. I love it.

>> Lots and lots of thank yous and great presentation. This is so informative. This parent says my son is now 21 and so much in what I expected about his behavior as a young person could be explained by visual fatigue.

Thank you. Yes, I agree. Having breaks is important.

How do you convince an IEP team to reduce the complexity of the environment and task and placing consideration for visual fatigue is absolutely essential?

>> I feel this question.

Your observational data as a parent, but also the research. Like bring the medical research to the table. Like this is what we know about kids with CVI. This is what I see with my kid.

This is what we've learned from our assessments with my child and the barriers to access. And when they don't have access this is what makes them shut down, this is what makes them not be able to progress on their IEP goals. And really frame it as without these supports in place they do not have access to FAPE. They do not have access to a free

and appropriate education.

Denying that understanding of what our kids need for access to their education is denying FAPE.

>> And that will get the attention of the IEP team.

>> We did have a couple of other questions about IEP and some other questions that I know we have had webinars about so jugs in the interest of time, I am pasting in the CVI for the TVI and other professionals link. You can see all of the past webinars there. Watch them on your own. Things like IEPs, things like literacy that I think you can

get much more in-depth than we will have time to hear because we are now at the top of the hour.

>> Rachel: Thank you all. This has been the best. Thank you so much. Thanks for being here.

>> Thank you.

>> Rachel: Feel free to reach out to me with any questions.

>> Great. Everyone go and make it a meaningful day.