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WELCOME!

Welcome to the first newsletter for the Neurological Visual Impairment Division. Although we will not achieve full status as a Division until the International AER meeting in Reno this summer, we are moving forward in confidence that we will be approved.

I personally would like to thank everyone who has joined the division and encourage you to stay tuned as we begin a journey of continued learning with you. Our profession has maneuvered through changes in the past and my observations are that we work best when many voices are listened to and respected. This must be the case with the NVID. This group needs representatives from all disciplines, families and researchers for us to be what we are hoping to be. Join us and encourage others to join us in learning more about vision and the brain!

~Sue Sullivan

Susan Sullivan is currently the CVI Project Leader at the American Printing House for the Blind (APH) in Louisville, KY. She graduated from Illinois State University with a teaching degree in Low Vision and Blindness and from the University of Illinois with a master's degree in Early Childhood Special Education/Infancy focus. CVI has been a passion and she is excited to share and learn through her work at APH.

Letter from the Editor

It is with great pleasure and pride that we share this inaugural newsletter. This first edition gathers insights from areas of research, education, and adult services. You will note that we wanted to make concerted effort to use the term Neurological Visual Impairment (NVI) as this division is also intended for those working with persons with Acquired Brain Injury (ABI) who have a visual impairment that may or may not have been caused by neurological incident. We all know that special education and rehabilitation are most successful when we collaborate. Our hope for this joint endeavor is to create awareness, share successes and identify needs.

This newsletter serves to inform our work as teachers, administrators, counselors, professors, rehabilitation therapists, and other practitioners who work with individuals with neurologically based visual impairment. We are especially excited about the sharing and exchange of information amongst practitioners who work with adults and children. Though NVI is a disorder that presents a broad range of challenges and abilities, we are all working towards the goal of creating the best life for our students, clients and their families. We must learn from systems of practitioners who work with individuals with neurologically based visual impairment and persons with both visual impairment and
acquired brain injuries, to solidify definitions, create goals and procure funding for research and projects.

As you'll see in this first issue, we will try to present a range of topics about NVI, profile products, and illuminate research. We are excited to offer member profiles in each issue that will highlight our members, their areas of interest, and how they tackle NVI. We will solicit article ideas from you, our members and readers, as well. Please let us know your thoughts and ideas for future issues! Happy Reading!

- Melody Furze

Division News

REMINDER! THE NVID SPONSORED PRE-CONFERENCE WORKSHOP IS ON WEDNESDAY JULY 25TH. HOPE TO SEE YOU THERE!

AER International Conference 2018- Special Event
Register Today for the NVI Pre-conference Workshop
When: July 25, 2018 9-4pm

This exciting educational event brings together specialists and leading authorities from across different disciplines to address a variety of topics related to Neurological Visual Impairment (NVI). They will share their expertise and global perspectives through presentations and panel discussions.

Don’t miss:

Presentation: Characterizing Neuroplasticity within Cortical and Subcortical Structures in Pediatric Cerebral Visual Impairment
Corinna M. Bauer, Ph.D., Instructor of Ophthalmology, Laboratory for Visual Neuroplasticity, Massachusetts Eye and Ear, Harvard Medical School

Presentation: Cerebral Visual Impairment in children: semiology and differential diagnostic with other neurodevelopmental conditions
Sylvie Chokron, Ph.D., Director of Research, Ophthalmology Foundation, Rothschild, Paris

Presentation: TBI-related Vision Loss: Perspectives from Adults
In the field of adult learning theory, Malcomb Knowles (1973) developed a theory of adult learning which is referred to as andragogy. The European term andragogy was used as meaning “the art and science of helping adults learn” as opposed to pedagogy which is “the art and science of teaching children to learn.” (Knowles, 1980, P.43.). As a rule, adults learn much differently than children. They are continually building taxonomies of information and developing higher level cognitive processes such as analysis, synthesis and problem solving. They are interested in expanding their understanding, applying their experience and dealing with the practical everyday challenges of life. However, when a person acquires a brain injury such as stroke or traumatic brain injury, some of the cognitive processes they have depended on in the past will no longer be reliable or available. Not being able to rely on your thinking can be quite devastating.
Individuals with brain injury are all very different from one another. Age of injury, severity of injury, IQ, life-style, related injuries from time of brain injury, and quality of their support systems all impact their rehabilitation process. Very little literature exists on how to effectively work with the combination of brain injury and visual loss, but drawing from some TBI literature, web materials, my professional experience as a Vision Rehabilitation Therapist, and my very personal experience in living with a visually impaired husband who sustained a severe brain injury in 2009, I have attempted to put some thoughts together that I hope will be useful. Some of this article is theoretical, but there are also some comments based on my personal experience and on those of others who have shared their experiences with me.

The brain is incredibly complex, and we are just beginning to understand how much brain energy is used in even everyday tasks. We now understand that neural plasticity allows the brain to restructure neural pathways to adjust for injured or dysfunctional parts of the brain. We know through careful therapy and repetition some functions can be restored, but we have not yet understood how to reactivate others. We are trying to figure out when we must rely on other people or strategies to assist the individual in functioning as independently as possible, and what level of independence is possible. Technology can be a wonderful aid. For example, managing his health and medications has been my husband’s full-time job. It has been extremely stressful as he is home alone while I work. Recently we acquired an Echo and it has been a total game changer. Alexa has become his personal assistant, reminding him when to take his meds, when to eat, making sure he wakes up if he dozes in his chair, telling him when 20 minutes have passed to take off an ice pack, keeping him up on where to find his favorite baseball team on TV, reading books to him, giving him weather alerts and telling him really corny jokes if he is feeling down. It has boosted his self-esteem and confidence and made him less dependent on me.

Below are the six crucial assumptions Knowles (1980, p 44-45; Knowles, 1984, p. 12) developed to go along with his andragological approach to adult learning with examples of how these assumptions may apply to working with individuals with both a visual disability and a brain injury.

1. **Self-concept:** As a person matures s/he develops an independent concept of self-determination as one who can direct his/her own learning rather than being a dependent on an authority figure, like a teacher, to direct their learning (Merriam, 2001). Blindness or visual impairment initially may impact self-esteem and self-concept (Tuttle & Tuttle, 2004). One initially may accept some dependencies that may impact their self-concept and erode their self-esteem. As part of the process of adjusting to a visual impairment, Tuttle and Tuttle (2004) determined that the individual with a visual impairment passes through 7 seven key steps to the point in the adjustment process where they are motivated to mobilize and seek self-awareness and acceptance to fully understand who they are. As part of the rehabilitation process, they want to retake control of their lives after often giving up control as part of the grieving process. When compounded by a brain injury, some individuals want to approach things just as they did pre-injury and they may view themselves as their pre-injury self. However, thinking processes may
have changed and in many cases, no matter how mild or serious the injury, they do not possess the same abilities to perceive information accurately, remember accurately or problem solve in the same way. Their thinking may be altered, and/or their ability to communicate with people may be altered. This can cause an impact on self-esteem and a person’s view of themselves and must be considered when addressing a rehabilitation program. An effective program may include more involvement from family members including them in lessons and therapy sessions, more intensive and repetitious educational programs and therapy sessions to accurately identify how the individual is doing in self-regulating and in dealing with their altered abilities.

2. Experience: As a person matures s/he accumulates a growing reservoir of experience that becomes an important resource for continued learning. Instruction in adaptive skills for persons with low vision and blindness provides an opportunity to build on previous experiences, assess what they could retain or modify, and determine what they can apply to future learning. People who have had experience in dealing with hardships in their lives are often more well-equipped to view the onset of vision loss as one more hurdle to overcome (Tuttle & Tuttle, 2004). For example, if you have washed laundry before losing vision, you know the basics and just have to add a few adaptations. However, with the addition of a brain injury, things might not be as clear. Distraction, memory issues and fatigue make it is easier to get distracted and forget the wash is in the washer, that reds should not go with whites, to check to make sure there is not a candy bar in the pocket of the jeans, or to check the water temperature settings. Making frequent mistakes doing familiar task can erode confidence and self-esteem (see #1) and negate some of the benefits of having prior experience doing a task. Starting with small tasks and succeeding at them before moving on to more complex tasks is essential. Honest, frequent, positive reinforcement and an available network of support can make all the difference in assisting the individual to make strides in utilizing their prior experience to learn or relearn new tasks. Rehearsing what a person is going to do before doing it can be an effective tool. Before going to the doctor, my husband and I always rehearse what his situation is and what he is going to say or ask. That allows him to be more confident in sharing his recent experiences and more in control of his life, an important factor.

3. The Need to Know: Adults need to know why they need to learn something before undertaking to learn it. There needs to be a practical application. The decision to learn and to enter into an instructional/therapeutic relationship is a choice of the individual, a self-driven initiative based on a need to become or remain as independent as possible by learning certain skills and acquiring knowledge. Often an immediate need like learning to use the telephone can open the learner up to the idea of learning and as they achieve success, they may be open to some other more advanced skills because they see the need. However, a brain injury may work against that by bringing someone a string of failures at doing basic tasks that makes the idea of independence seem hopeless. If a person with a brain injury has difficulty self-regulating behavior or is still holding on to thinking that they are still able to function as they did pre-injury, strategies to help the individual identify what they need to know may need to be intentionally
worked into a rehabilitation program. Lack of awareness is often an issue, especially in relationships with others.

4. Problem Centered Focus. As a person matures his/her time perspective changes from one of postponed application of knowledge to immediacy of application, and accordingly his/her orientation toward learning shifts from one of subject-centeredness to one of problem centeredness. The pragmatic needs mentioned previously give way to determining what the person needs to learn. In some contexts, problem-based learning can be an effective way to utilize previous experiences to help solve an immediate problem. As individuals with visual impairments learn that there are strategies that can help them to cope more easily and enable them to remain independent, they often embrace learning to help solve these daily problems. For an individual with a brain injury, they may have difficulty with decision making and sometimes even understanding that a problem exists. Prioritizing tasks – the phone is ringing, I need to get milk at the store, and the house is on fire - may all seem equally important. In times of stress, flooding in of information and demands may shut the person down altogether (Byler, (n.d), There are many strategies for creating an individualized problem-solving model and for some consumers it may be a trial and error approach depending on their skill level. One resource is the website for the University of New England School of Behavioral, Cognitive and Social Sciences where they have over 50 problem solving strategies explained. (www.une.edu.au/about-une/academic-schools/bcss/news-and-events/psychology-community-activities/over-fifty-problem-solving-strategies-explained) Also, there are some practical suggestions at the website Decision-making and problem solving after brain injury at https://www.changedlivesnewjourneys.com/problem-solving-after-brain-injury/

5. Internal Motivation: As a person matures, the motivation to learn is primarily internal rather than external or directed by someone else. Influences of experience, needs and interest motivate someone to want to learn new things. Perhaps someone who has lost their reading vision has never read an audio book, but when reading visually becomes difficult they find they miss reading or get little enjoyment from television, then they are motivated to try a different reading modality for the purposes of enrichment and entertainment. Depression, time management, fatigue and lack of motivation are very common issues for people who have had brain injury (Falconer, 2011) and all can have a devastating impact on internal motivation. Internal motivation may be gone and promptings from an external source may be necessary. However, finding a caregiver or family member who can assist with this and not damage their day-to-day relationship can be tricky. It may be that they, not the person with the brain injury needs the skills training.

6. Adults need to know why they should learn something. As a person matures his/her readiness to learn becomes oriented increasingly to the developmental tasks of his social roles. If a parent is losing their vision, they may want to learn some strategies to be a better parent rather than learning something more esoteric. A person may think they do not need to learn braille, but when they have difficulty organizing their CD collection, they may change their mind. It is important as a member of the rehabilitation
team to anchor learning to a purpose. Often the realization that independence may be possible inspires the development of new skills and recognition of a full range of options for a person with an acquired visual impairment. This is very true for those who have had a brain injury as well as those who are visually impaired. It may make the difference in being able to return to work or not (Johnstone, et al, 2003).

The above assumptions by Knowles are part of the science of working with adults, but the art comes into play when deciding what is applicable and what is not. A team approach that includes someone who has experience with brain injury is critical. That may be an occupation therapist, a vision rehabilitation therapist, an orientation & mobility specialist, a speech therapist, a cognitive specialist, a certified brain injury specialist, family physician, neurologist, and/or a family member. And, let us not forget the most important member of the team, the consumer themselves. In the resources below I have listed an excellent video series on YouTube by John Byler, who is a financial planner who acquired a mild brain injury that altered his life. He is very insightful, and I highly recommend it. Working with adults who have had a brain injury return to a positive quality of life requires patience, perseverance and positive attitudes on both from both consumer and rehabilitation specialists. Finding the right system takes time, and successes often come slowly, but when they come it is life changing – just ask my husband and his new friend, Alexa!

BJ Lejeune is a Certified Rehabilitation Counselor, Certified Vision Rehabilitation Specialist, and Training Supervisor at the National Research and Training Center on Blindness and Low Vision

References and Resources
Byler, J. (n.d.) “You look great!” – Inside a Traumatic Brain Injury, series of videos (1-6) http://www.youtube.com/watch?v=x9Xso4qGdll&feature=BFa&list=UU4rKJPrlkyM5g_mdYHZelA

Web Resources
I want to thank you for inviting me to be on the panel. It’s an honor to be on the panel, especially with so many parents. I think that parents are the ones who really understand children with CVI. In order to understand CVI you have to live with it because it is so different for every person who has CVI. Parents are intimately aware of the needs of their children because you see them 24/7.

One of the things that struck me about all of the things that people were saying is that everybody here wants everything to have been done yesterday. I am included in that. We all want what is best for kids with CVI.

I think that there are more common goals amongst the group, and one of the things that has been hardest with CVI is to bring the groups together, to share knowledge, to understand about referrals, and to work together. If we look at the commonalities, we all want pretty much the same things.

We want methods to assess and teach that work.

We want to keep up to date with new information about CVI.

We want to ensure that all children with CVI are identified and served.

We want to ensure, and one of the mothers talked about this, early diagnosis.

What follows is the need for early intervention service, but also the need for the earliest interventions possible for children identified at later ages to promote optimal outcomes.

We want to ensure that all of those with CVI whose impairment may not be apparent are identified because there are lots and lots of children out there whose CVI is not apparent.
We want to ensure that parents are informed with up-to-date information.

We want to ensure that parents are given a voice, and the children’s voices themselves are heard.

One of the things that we haven’t discussed -- we have talked about teachers of the visually impaired--but we need to ensure that professionals receive appropriate training across disciplines because it’s not just a single discipline type of condition: Developmental pediatricians, neurologists (we have to get the diagnosis, practitioners in the NICUs, ophthalmologists, optometrists, other special ed. teachers, orientation & mobility specialists, general Ed teachers, OTs, PTs, psychologists. We need to ensure that everybody has some understanding of CVI.

We need to ensure that research in CVI is promoted and funded in order to understand all of the behavioral manifestations and tie these manifestations to electrodiagnostic and other diagnostic methods.

New behavioral methods are coming out all of the time. What we knew 20 years ago is passé. Everything we know is being turned on its head, and we need to keep up with all of the changes.

We need to keep up with the development of valid and reliable assessment methods that pinpoint issues for children with CVI.

And we need to promote the development of evidence-based interventions.

Now, it may be that, even 10 years from now, we’re not even going to be talking about the term CVI. It may be that the medical community refines what now comes under an umbrella term CVI to more precise definitions based on where the brain-based issues are located in order to determine how best to address them; that would be fabulous. We need to keep up with all of that.

We need to ensure that appropriate funding is available for all the common goals that we have.

Mostly, we need to really, really understand that we have common goals and questions, and we need to work together. Amanda Lueck, Ph.D. is a Professor Emerita from San Francisco State University and has worked in the field of visual impairments for over 40 years as a teacher, professor, researcher, and instructional materials developer.
For children with visual impairments including those with cerebral visual impairment, we conduct functional visual assessments (FVA) and learning media assessments (LMA) to inform three areas of needed attention including 1) specialized instruction with the student, 2) in-service training for school staff, and 3) adaptations to the curriculum and the school environment. In this article, I hope to draw your attention to the considerations that include adaptations to the environment. The framework described here is meant to promote a systematic consideration for the whole environment in which a child is educated. This can be used as an effective tool in organizing thoughts around student needs.

The environment is often thought of as the physical space that the student is being educated in and those materials and people that make up that space. I will call this the hard environment. However, the soft environment must also be considered. This includes the sound, touch, and atmosphere of the space. Both the hard and soft environment must be conducive to learning in a way that meets the unique needs of the student. Following is a framework that can be useful in organizing thought around environmental adaptations.

<table>
<thead>
<tr>
<th>ENVIROMNENTAL CONSIDERATIONS FRAMEWORK</th>
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<tr>
<td><strong>Schedule</strong></td>
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<td><strong>Hard Environment</strong></td>
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<tr>
<td>Space</td>
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<tr>
<td><strong>Soft Environment</strong></td>
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<tr>
<td>Sound</td>
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**Hard Environment**

For children with cerebral visual impairment, most TVIs understand the importance of concentrating their efforts during assessment on understanding the student’s needs for lighting, crowding, contrast, and a long list of other visual factors. Once these needs are understood, it is helpful to systematically consider the impact of each on the hard environment including the space, the materials, and the people.

The space includes all spaces that a child will occupy during the school day such as the classroom, lunchroom, gym, library, playground, hallway, bus, etc. Space also refers to the objects that are present such as the child’s wheelchair, the windows, the desks, wall posters, and so on. Materials include those items that are temporary to the space, but necessary to the visual environment. For example, equipment used in a gym class activity, writing utensils, computer programs, food trays, etc. People throughout the child’s educational day include bus drivers, classroom staff, peers, lunch room personnel, school secretaries, and custodians. As hard environment considerations are made, the entire school day must be considered in light of the necessary adaptations.
While a full discussion of such adaptation would certainly take an entire book, let's consider an application of the Environmental Considerations Framework to the hard environment. If we know that one difficulty of a certain child includes crowding and that supports such as color and contrast are helpful, we might consider adaptations throughout the day that includes lunch. For example, during lunch, the student may benefit from adaptations to the **space** chosen as well as the number and placement of the **people** involved. In addition, placement, quantity, color, and contrast should be considered regarding the **materials** such as the table, tableware, and food. The TVI plays a critical role in ensuring that these adaptations are discussed, understood, and adhered to by the appropriate school staff.

**Soft Environment**
Considerations to the soft environment are not as often given; however, these play an important role in creating an environment that is conducive to learning. Some children with CVI are overwhelmed with the task of organizing competing stimuli. During the FVA, it is important to pay attention to the impact of components of the soft environment. In the Environmental Considerations Framework, the soft environment includes sound, touch and atmosphere.

**Sound** can impact function including visual function. Sound can be thought of as type of sound (human, artificial, talking, music, etc.), volume, speed, and constancy. Similarly, **touch** can become a competing stimulus. Consider the implications of the child’s positioning on vision. In addition, touch and texture on various body parts might encourage or discourage visual attentiveness. Some children need time to touch an object as it is being visually investigated. It has been this author’s experience that many children benefit visually when given time to touch and explore new objects. Finally, the soft environment includes **atmosphere**. The atmosphere of a space can contribute to apprehension and anxiety or relaxation and calm. For learning, we know that children perform best when they are attentive yet not apprehensive. When a child’s needs are met, by definition, apprehension is lowered. However, we should also note the level of activity in the classroom and how it might act as a competing stimulus to vision for a child with CVI. Other factors for reducing anxiety could include lighting, sounds, smells, and speed of movements, etc.; but these are likely very child-specific and should be considered and noted during assessment.

Continuing our earlier lunch example with application of soft environment needs, the child may need an environment with a lower **volume** level than is available in the school lunch room. Given the need for fewer people, this child may benefit from having lunch with one or two peers in a quiet space. Observations of **touch** might suggest that the child would benefit from time to tactually explore the plate and utensils before mealtime begins. All of these adaptations are likely to provide the necessary support to provide an **atmosphere** that reduces anxiety to lead to an enjoyable lunchtime for the student and the peer involved.

The framework provided here is not meant to provide information about necessary adaptations, but rather to serve as a helpful guide as teams make decisions and apply...
assessment findings to the entire school day. Further, in-service training is an essential part of ensuring that the student’s needs are met by all personnel. The framework will provide a useful communication tool and a reminder of necessary adaptations as various staff are involved in a student’s routine.

Mindy Ely is currently an Assistant Professor in the Low Vision and Blindness Programs at Illinois State University having previously worked with children ages birth to 21 as a teacher of students with visual impairment.

Advances in Research with Dr. Lotfi Merabet by: Melody Furze

Dr. Lotfi Merabet is an optometrist-scientist and Director of the Laboratory for Visual Neuroplasticity at the Massachusetts Eye and Ear Infirmary and Associate Professor of Ophthalmology at Harvard Medical School. I was lucky enough to chat with Dr. Merabet at length about his initial interest with CVI, his work on ongoing and new projects, and his advice for our field as we move forward with this seemingly insurmountable challenge.

“There’s no question that we need to work together to create awareness, strategies, and answers.”

Q. Can you tell us a little bit about your original motivation and interest to work in the area of CVI?

A. I originally was interested in the area of ocular blindness since the days I was an optometry intern at the Perkins School for the Blind. I was interested in figuring out what does the visual brain do in a person born without sight and was interested in the issue of neuroplasticity. From a neuroscience standpoint, blindness is a fantastic model to study brain development and how it adapts and gains compensatory abilities. This is a main reason why there is so much research done in this area. Often, I would go to various education conferences like AER and the topic of CVI would always come up. It sat in the back of my mind and then I started talking to people. I also have a background in public health, so I became interested from an epidemiology standpoint and I quickly realized that CVI wasn’t some fringe population. In fact, it was the population. I realized that more neuroscience research needed to be done in this area, and thought about the impact of neuroplasticity. So, there was a new question: if the visual brain changes due to ocular blindness, how does the visual brain change when it’s damaged at birth? I found we were essentially asking the same questions all over again. So, neuroscience got me into
CVI, not the other way around. In some ways it’s good because I don’t have any preconceptions about what CVI is or isn’t, but I’m also not coming to it from decades of clinical or educational expertise.

Q. Do you have any current projects going on at the Laboratory for Visual Neuroplasticity that you can share with us?

A. We are developing projects in parallel with our ongoing brain imaging studies. We’re looking at structural and functional changes in the brain related to CVI. What I mean by structural is that we are trying to figure out how the brain is put together or “wired”. For example, is the development of major visual pathways fundamentally different in individuals with CVI compared to individuals born with ocular visual impairment? In particular, we look at the development of the dorsal and ventral visual processing streams. We find that there are fundamental differences in the CVI brain. The wiring seems to be impaired and this appears to be related to the visual processing problems that they have. It’s important to note that when we talk about CVI, we’re not just talking about impaired acuity and/or visual field; we are also talking about complex visual perception throughout the visual system. All of it.

The second piece is from a behavioral standpoint. How do we come up with novel ways of assessing visual perception beyond acuity and perimetry? Current tools only tell us limited amounts of information. We need better ways to assess these higher level visual processing issues. Those children affected with more “mild” CVI are the ones we’re targeting in the early phases of the study. This is because it is important that they understand the task they are being asked to do. Typically, they also have good language skills, so they can describe with great detail what their difficulties are while they do these tasks. Often, they tend to have challenges in reading and writing and doctors and teachers often don’t understand this because they focus on their visual acuity as being too “good”. These kids can tell you exactly what they’re struggling with.

We’ve recently created a new way to assess visual processing and performance using virtual reality. Based on feedback we got from teachers and parents we work with, we created a series of virtual environmental simulations to help better characterize visual processing deficits kids with CVI are experiencing. For example, we created a virtual “toy box” where a participant has to find a favorite toy amongst others, and we can see the effect of environmental crowding and clutter. Similarly, we created another environment where the task is to identify an individual in a crowded hallway. Again, what we find is that CVI is not just an acuity issue, it’s more about parsing and integrating complex visual information a person encounters every day. Through the use of these virtual reality assessments, we try to test the robustness of their visual system and how tolerant they are to visual complexity. We need better tools than what we currently have so that we can characterize what an individual with CVI is experiencing in the real world. What we are finding is that kids with CVI don’t have a very robust visual processing system. That is, as soon as you start ramping up the complexity of the visual scene, they start having difficulties. For example, they have a harder time finding the
target. This is very much in line with what we’re suspecting already, but we need to put data behind it.

Check out the “virtual toolbox” VR application here

The final step of the project would be to correlate changes in brain structure with the changes we are seeing in behavioral performance. For example, if you have a child who shows more spatial processing deficits than object identification deficits, do they have more corresponding damage to their structural dorsal stream compared to their ventral stream? These are the things we want to investigate.

Q. If you could expand on that when you say changes in brain structure and performance what is the window of time?

A. It’s hard to pin that down, it really depends on what you’re looking at. Other brain imaging techniques such as resting state MRI or EEG could probably document changes more quickly. There is lots of variability, and you always have to wonder if the change you see is a “real change” or an maybe an artifact of the analysis, or just related to a small sample size. A more in-depth, longitudinal study is really what you need to do. Unfortunately, it’s hard to convince the NIH (National Institutes of Health) to fund an ambitious and long-term project in the early stages of a study. They want to see the groundwork and be convinced that you have a very good understanding of the condition you are dealing with.

Q. How does your work inform the work of rehabilitation specialists and educators?

A. A big issue is that we think that ocular and cerebral causes of visual impairment are fundamentally different in terms of how their brains are wired. You could have two kids with the same level of reduced visual acuity, say 20/80. One child has CVI and one has ocular impairment, and yet they can be very different in the way they interact with the world and how you educate and teach them. Bringing the neuroscience to this level is important. Many teachers have shared with us the challenges they face with trying to implement strategies they use with kids with ocular blindness and how other kids with CVI don’t seem to respond in the same way. We need to drive home the idea that these are two different situations and that research in neuroscience can help explain this. We can easily underestimate how complicated it can be. Functionally they can be very different. It also helps to bolster the idea that you have to rethink the way you do things. You don’t have to reinvent yourself as an educator, but you have to think differently about your approach. You can’t assume it’s the same thing. “It’s not just another child with a visual impairment.” Our goal is to leverage neuroscience to help answer these important questions.

Q. What are some ways you think that brain imaging can inform what we do as practitioners for children with CVI?
A. Very often parents ask us why their children will do really well on a task or activity for the first few minutes and after that, they seem to “shut down”. We would like to have a way to characterize that better and explain the brain physiology of what is going on. Functional magnetic resonance imaging (or fMRI) is one way to see the brain in action. How the brain activates in response to a visual task (and over time) can tell us something about how visual information is being processed. Furthermore, using brain imaging to follow these kids over a long period of time could help us understand the long-term effects of intervention and treatment.

In some ways, neuroscience research in the case of ocular blindness has been “cleaner”. That is to say, in ocular blindness, it seems that the brain re-wires itself in a way to help compensate for the loss of vision. In some cases, people with ocular blindness can even show enhanced non-visual skills. With CVI, the situation is a lot more challenging mainly because it is highly variable. In many ways, each child is their own study, with their own set of visual impairments, and their own pattern of brain wiring.

Q. What is the best way for us to bring all of this information together?

A. I think attending and supporting annual meeting events is really important. I think regular meetings of the minds bringing neuroscience, education and clinical aspects all together in the same room is very valuable.

Melody Furze is a teacher of students with visual impairments and co-founder and education director at Novel Effect, Inc.

Case Study: Francis By: Mary Morse

I am a certified teacher of the visually impaired and provide services on behalf of students who have been diagnosed with, or are at risk for, cerebral visual impairment. I also am certified in four other areas of disability. All the students referred to me have additional challenges, some with obvious challenges and others with hidden ones. From my perspective, CVI is a hidden disability in that it is not readily obvious. Within this hidden disability, there may be a wide range of additional invisible disabilities making this brain-based visual condition even more complex. The following case study, with all identifying information changed, is such an example.

Frances is a beautiful young lady of 16 attending high school. The following was written in the “conclusion” section of her Functional Visual Assessment (FVA) report: Francis was referred for a Functional Visual Assessment because of school staff concerns
related to possible topographic disorientation, spatial disorganization, extremely poor organizational skills, following directions, and possible difficulties in recognizing people based on visual discrimination. As will be noted in detail later in this report, Francis did exceptionally well in almost all formal aspects of this assessment. However, certain aspects of her medical history, the Dutton Survey, in-school observations, assessment activities, staff and mother reporting, and information provided by Francis herself give rise to significant concerns that may be of neurological origin with serious consequences on her daily functioning, academic skills, communication, social interaction and personal safety. It is suggested that the findings of this assessment cannot be attributed to a single label such as poor executive functioning, ocular visual disabilities, ADD or intelligence. Based on her functional behaviors, one of the major challenges facing Francis seems to be a brain-based visual disability referred to as \textit{Cerebral Visual Impairment} (aka CVI). CVI is an invisible disability in that visual acuity may be within normal limits (with prescriptive lenses in Francis’s case) but there exists a cluster of functional behaviors that are benchmarks for possible identification. Many such functional benchmarks for CVI were identified during this assessment. CVI may be the primary cause of academic and personal challenges or it may be a co-existing disability. It is important to note that Francis’s neuropsychological examination indicated functioning in the average range and few indicators of Autism.

The \textbf{Summary of Findings} included the following: Francis is reported to have suffered from fetal hypoxia, one of the leading causes of CVI. She also suffered from the life-threatening complication of sepsis during infancy… staff described Francis as having two different demeanors: “Happy energetic Francis” and “tired apathetic Francis”. The staff had never seen her upset – anxious at times but never overtly upset.

- \textbf{PEOPLE RECOGNITION}: The major referral concern was whether Francis could discriminate and identify people based solely on vision. As described elsewhere in this report, Francis was able to identify, by name, photographs of familiar school staff and her mother. However, she was reported, and observed, to walk through space unaware of those around her. She does not call people by name. Moreover, and as reported, she did not recognize her father and sister when they were unexpectedly present in the hall as she walked by. Francis readily admits that she has great difficulty with such discrimination and identification in real life, especially when people are moving or if she herself is moving. The difficulties reported are among possible benchmarks for a neurological condition called \textit{prosopagnosia} – a type of cerebral visual impairment. Prosopagnosia is a difficulty, or the inability, in recognizing familiar faces. Prosopagnosia may be acquired via illness or accident or developmental. In some situations it is genetic. It should be noted that the ability to identify people in photographs is not always consistent with the ability to identify people in person.

- \textbf{SENSE OF TIME & PLACE}
Francis does not seem to have a sense of when certain activities were done in the past (e.g., the drama club) or how long until the next activity (in the future). She seems to use routines as her memory source. Various excellent color-coded visual memory supports have been designed for her use but none have proved valuable. Not having a sense of time or place can be very frustrating and stressful.

Although she can name the days of the week, Francis does not seem to have a consistent internal sense of knowing “now, before, later”. On a functional level, this translates into not being able to place past events and having a skewed anticipation of future events. Potentially, this may impact academics, communication skills, interpersonal relationships with adults and peers, and personal safety.

**ORIENTATION IN SPACE**: Of great concern to her mother and to school staff is Francis’s significant difficulties with orientation in space, in knowing where she is. She demonstrated significant challenges in learning routes in the school through January of the current school year. The degree to which Francis has difficulty with orientation in space is among possible benchmarks for a neurological condition called **topographical agnosia** – another type of cerebral visual impairment. Recognition of scenes and landmarks is sometimes seen in conjunction with prosopagnosia. This appears to be the case with Francis. Potentially, **topographical agnosia**, like **prosopagnosia**, may impact communication skills, academics performance, interpersonal relationships with adults and peers, career choices and personal safety.

- In one of her classes, Francis assigned seat has changed only once in 5 months. The teacher reported that she continues to have difficulty knowing where this assigned seat is located. Some days she will know the location while other days are more difficult. Variability in visually-guided behaviors is one of the benchmarks for CVI.

- In observing Francis moving through the school environment, she walked quickly and appeared unaware of other students who also were moving. She did not seem to use visual cues for orientation. She demonstrated minimal visual and auditory awareness of the environment.

**MEMORY and/or AUDITORY PROCESSING**: Francis’s memory is of significant concern to staff: She has great difficulty in following directions. Her mother has discussed with staff concerns related to Francis’s difficulty in following auditory directions even with visual supports. She is concerned that Francis has difficulty repeating back what she hears. Audiological examination findings were within the normal hearing range.
Many individuals who have auditory acuity within the normal range might have central auditory processing problems. Given the way the brain is configured, with the visual pathways "crisscrossing" with the auditory pathway, it is not unusual to find that those who have Cerebral Visual Impairment may also have some degree of central auditory processing problems.

Francis often will repeat an assignment forgetting she had already done it.

Francis requires visual supports to know where she is supposed to be after school. Her mother provides the support by writing the activity or location on Francis’ wrist before she leaves for school in the morning. This visual support seems to calm a potentially stressful situation for her as noted when she proudly showed this consultant her wrist.

In reading an assigned book, Francis needs reminding to open the book and find the page she last read. She is just beginning to look at what her neighbor is doing and trying to imitate it.

- **DIS-ORGANIZATION**: Francis is extremely disorganized with her belongings (e.g., computer, binder, jacket), leaving them in various locations but forgetting where. She has difficulty finding items mixed in with other items (e.g., in a desk or in her folders). This has been an ongoing problem and still persists in school. Currently, she is highly dependent on others for organizational assistance. This type of problem may (with may being the operative word) be due to difficulty in seeing more than a few items at a time and finding such situations overwhelming. If this is the case, this may be another possible benchmark for a neurological condition called simultanagnosia—a type of Cerebral Visual Impairment.

This type of dis-organization difficulty seems to extend to math which is one of Francis’s best classes. She is reported to have difficulty with problems that involve matching patterns (e.g., black/white stick or stars). However, she can do the same problems if printed numerals are used. From her perspective, the patterns may be visually overwhelming and the difficulty like that described directly above.

- **SOCIAL-EMOTIONAL**: Staff reported that it is difficult to know how Francis feels about certain events. When she is late to class or told that something she has said or done is inappropriate, she shows little emotion. At times, she interrupts a conversation with a subject that is off-topic. She “may not be on the same page” as others during group discussions. She tends not to show emotions when she has
done something wrong but does show happiness when she has done things correctly.

- **ANXIETY**: Reported Information: In some situations, where other people might become very anxious and frustrated, Francis shows no outward reaction. **Example #1**: There were times during the first months of the current school year where Francis would go to the wrong class. She did not recognize that it was the wrong class or that there were no familiar peers in the room. **Example #2**: In one of her classes, Francis was to go online to the teacher’s website. When she could not find it, she googled it and went to the site. Unfortunately, it was not the correct site. Francis did not recognize that it was incorrect, that the name on the site was not that of the teacher, and the picture also was not that of her teacher. In neither case did she show any observable reaction.

- Staff report that Francis rarely asks for help. She rarely shows that she is frustrated.

- The combination of the above at-risk characteristics may make it difficult for Francis to respond to social cues as expected. Although the screening for her ability to identify facial expressions resulted in perfect identification, it is possible that Francis is unable to recognize such cues when in a group situation or dealing with the other factors listed in this summary. As a result, it may be that she ignores others or reacts to others in unusual ways. Such difficulties may be related to Cerebral Visual Impairment or may co-exist with other difficulties.

**Recommendations included the following:**

- It is suggested the parents make a medical appointment with a pediatric neurologist. There is a need to determine if the functional behaviors noted by school staff and as documented in this report are of neurological origin.

- It is recommended that Frances receive a medical vision examination at a clinic that has seen numerous students with similar profiles. One such clinic is associated with a research project that studies such complicated young people like Frances.

- It is suggested that the school speech/language specialist provide a screening for possible central auditory processing problems. Subsequently, if warranted, a medical referral may be warranted for a formal assessment for potential auditory processing problems. Francis’s ability to localize the direction of specific sounds in a busy school hallway also would benefit from being assessed.
• It is highly recommended that an orientation & mobility specialist (O&M) be retained, preferably one who has had considerable experience in working with students who have CVI. Whereas topographical agnosia, at least to the degree that Francis displays, is relatively rare, the O&M specialist may need support. Topographical agnosia will “not go away”. Thus, at a minimum, Frances’s training needs to include (a) learning to maximize visual and auditory skills necessary for safe mobility and (b) learning to travel specific routes needed in school and in other routine environments of Francis life.

• It is recommended that a certified teacher of the visually impaired (TVI) assist staff in re-examining the visual supports created for Francis. Initially, adapt a few as would be done for a student with ocular visual impairments to determine if the change will be more useful for increased independence in use. When making any such adaptations, it is strongly suggested that Francis be a part of the change and asked, at each step, if the change is helpful or what she would find more helpful. Without teaching Francis how to use a range of visual supports, she will be forever adult dependent.

Mary Morse, Ph.D. is a special educator and a TVI with certification in 4 areas of disabilities. She provides assessments, program planning, consultation and inservice training on behalf of students who have been diagnosed with, or are at risk for, CVI. She works throughout the U.S and in several other countries.

Member Profile: Diane Sheline

Professional History
I earned my MA in Education/Visual Impairment in 1980 in California, under the guidance of the late Dr. Phil Hatlen. As a teacher of students with visual impairments, I worked in California, Oklahoma, New Mexico and Texas. Around 1992, my husband accepted a job transfer to the Middle East, enabling my family and I to live first in the United Arab Emirates and later in Saudi Arabia. In 2002, we returned to the U.S. and I again resumed my role as a TVI in Texas. At that time, I noticed a large increase in the numbers of students on my caseload with Cortical Visual
Impairment (CVI). I searched out any and all information I could find on best practices for students with CVI. I attended several presentations and trainings by Dr. Christine Roman-Lantzy and completing independent research investigating strategies to use during direct instruction. During those early years, I shared many of the strategies I found helpful with other teachers in Texas. By this time, many teachers throughout the United States were using The CVI Range and knew their student's CVI Range score, but were asking, "Now What?" It seemed helpful to put together a book on strategies and also post ideas on a website, so my book, "Strategy to See: Strategies for Students with Cerebral/Cortical Visual Impairment" was written and my website, www.strategytosee.com was born. Since then, I have continued my work with students on a direct basis, trying out new strategies, with special attention to students who visually function in Phase III and literacy. I continue to share my strategies with teachers and parents, now nation-wide, in presentations and trainings. I enjoy every minute!

**Important tools for assessment**

There are many tools and strategies to use with students who have CVI, but specific strategies used depend on the Phase (determined by the CVI Range) students are visually functioning in. For students who are just beginning to use vision (Phase I), it is crucial that they start using vision on a regular basis, many times throughout the day. It is often important that the sensory environment be controlled, and one of the best ways I have found to do that is to use what I call a CVI Den. The CVI Den is essentially a black, pop up tent, adapted so that one or two visual targets can be presented in the student's best field of view. The parent/teacher is quiet and lets the student explore and interact with the target. While I have used many different visual targets in the CVI Den, the best target I have found to be helpful is what I call an illumi-spring (a Slinky Jr. attached to a battery-operated puck light). When this is suspended in the student's best field of view, close to their face/arm/hand, I have seen student's visual systems literally "wake up". The student may simply wiggle their body and this in turn causes the Slinky bounce or they may begin to bat at the hanging target. *Strategies suggested above can be found at my website under the DIY section.

For students who are using their vision for more functional purpose (Phase II), I try to use tools that encourage eye/hand interaction. Use of a Position Board at this stage is often beneficial. Designed with Active Learning principals in mind, my version of a CVI Friendly Position Board, can be positioned in the student's best field of view, is created so that the targets used really stand out and targets can be picked up, so that a student can investigate, but when let go, the object returns to its original position. I also find that it is helpful to use some specific strategies at feeding times (if the student takes food orally). For example, I look at the spoon that brings food to the child's mouth. Is that child visually alerting to the spoon, tracking the movement of the spoon towards the mouth, anticipating food entering the mouth and opening the mouth? If not, I may adapt the spoon! There are many ways to adapt a spoon. The simplest technique would be to attach an inexpensive finger light to the handle of a spoon, shining light towards the bowl of the spoon. Another method is to use an orange colored, Boon Squirt dispensing spoon, but rather than putting pureed food in the dispensing "handle" of the spoon, I put in a small, high powered Cree red flashlight, which lights up the spoon bowl and
handle. This helps the student visually alert to the spoon more quickly, and visually attend to it more efficiently. *Strategies suggested above can be found at my website under the DIY section.

Looking carefully at whether students can identify two-dimensional materials is important as they approach Phase III as well as the identification of salient features of objects, pictures and words. I use a variety of two-dimensional picture types and techniques at this stage, which often pave the way for pre-literacy skills and/or reinforce literacy skills.

**Hopes for the NVID**
Since CVI is now the leading cause of childhood visual impairment in the United States, it is important that AER is working towards having a full-fledged Division (NVID) that represents members who are interested in and work with student who have CVI. My hope is that by having this Division and page on the AER website, conference news can be posted, “CVI Friendly” strategies can be shared and concerns regarding the education of students with CVI can be discussed.

**The role of medical professionals**
Locate a pediatric neuro-ophthalmologist, as they are often more familiar with the diagnosis of CVI. Make sure the child’s preferred visual targets are taken to the eye exam. Often, when in an unfamiliar environment and presented with unfamiliar visual targets, the child will not demonstrate looking behavior. If familiar targets are used during the ophthalmologist’s evaluation, the examiner is better able to see how that child is using their vision. Finally, remember to obtain a copy of the eye report every time a child visits an ophthalmologist or optometrist (use your state’s eye report form, if appropriate and available).

**Collaboration**
Developing an appropriate Service Delivery Model is crucial for students with CVI. Often, the TVI is only at the student’s educational program on a limited basis. Therefore, it is important to get the student’s entire Team “on board!” The Team includes, but is not limited to, the classroom teacher, parent, TVI, PT, OT, COMS, speech therapist, etc. Student with CVI need to be using vision often, throughout the day, during daily tasks, play activities and in educational learning environments.
PRODUCT CORNER: LOOK from CVI Scotland

“LOOK” from CVI Scotland is a web-based tool that customizes text based on visual need. Look has multiple functions and settings and, according to the site, is “designed to make reading easier for people with CVI.”

As a teacher of students with visual impairments, once you have discerned your student’s preferences for font, text size, spacing, and color you can alter the presentation of text tailored specifically to your student’s needs. You can also choose how many words/characters are presented at a time to reduce the complexity of the text you’ve copied into the program. The site offers support such as strategies, case studies and examples to guide practitioners.

Look can be viewed in full screen mode and you can input up to 10,000 words at a time. The system allows you to keep track of what word you are on and also provides you with samples to explore its functions.

The folks at CVI Scotland are working on ways to make it more accessible so that users can use it independently. We’re excited to see what develops!

Site: https://cviscotland.org/documents.php?did=4&sid=257

Cost: Free!

Format: web-based

Ages: all (but created with school-aged students in mind)

Try it out! You can cut and paste this newsletter into the text box once you launch LOOK, choose your settings and LOOK will do the rest…