



# Horizons

A Family Newsletter of Project Reach Deaf-Blind Services

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Faith Rosenshein Young, Editor  
Spring, 2021

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## 2021 Texas Symposium on Deafblind Education Highlights Stress, Resiliency, and Partners

Stress, resiliency, and being partners in learning and communication were recurring themes in the 2021 Texas Symposium on Deafblind Education. In response to the global pandemic, this year's symposium consisted of 20 hours of live and pre-recorded sessions available from March 1 – April 15 and was attended by more than 1,000 teachers, professionals, paraprofessionals, and family members representing 19 countries. This virtual and expanded conference feat, a first for the Texas Symposium on Deafblind Education, required numerous and varied support personnel: ASL interpreters, captioners, language interpreters, marketing support, moderators, presenters, and technical support.

Dr. Judy Cameron, a neuroscientist and Professor of Psychiatry, University of Pittsburgh, in her presentation, *The Impact of Stress on Brain Development: How to Build Brain Resilience*, said the pandemic has created stress for all of us, some more than others. This includes our children. When it comes to brain development, resiliency can off-set stress. Dr. Cameron addressed ways to help children who are deafblind learn resiliency.

Building resiliency consists of three concepts: connection, reciprocity, and progression. **Connection** is evaluating your child's mood and emotions to meet them at their current level (e.g., if your child is glum or low energy, approach them in a similar low-key fashion). Starting activities at your child's activity level lets them know you will help them if you can. **Reciprocity**, or **Serve & Return**, is following a child's lead in an activity. For example, a baby coos and you coo back; the baby changes to making a face and you mimic the face. **Progression** is creating ownership of activities. At first, you help with everything, making no demands of the child. As the child develops, provide support, but allow them to do things on their own. As independence develops, provide encouragement and support, so they know help is available when needed.

Dr. Cameron shared *The First Pathways Game* as a tool for improving brain development by using specific brain circuits at age- appropriate times and by improving adult-child interactions. This game is free and available at <http://www.fptoolkit.com/>.

Dovetailing on the concepts of stress and resiliency, Maurice Belote, Project Coordinator of California Deaf-Blind Services, said in his presentation *The Need for Closure and Its Impact on Individuals who are Deafblind* that many children who are deafblind generally operate under high levels of stress, which can make children unavailable for learning or participating in activities. This point was echoed and illustrated by Sandra Felefli during a *Family Stories* session entitled *Educating the Child with Deaf-Blindness: A Parent's Perspective* in which she discussed a "stress bucket" as representative of the state under which our children who are deafblind operate.

The stress bucket fills with challenges our children face each day such as unfamiliar people/environments, unclear expectations, routine changes, communication barriers, sensory overload, distractions/interruptions,

fatigue/poor sleep, feeling unwell, boredom, hunger/thirst, and relationship breakdowns. We can lower our children's stress bucket level by siphoning off the building effects of these challenges. Offset techniques include routines and schedules, physical activity, sensory breaks, praise and rewards, physical supports, accommodations, clear expectations, patience and kindness, family support, and teacher support.

When the bucket is already full, Felefli said, a very small and insignificant event can cause it to overflow. This overflow can manifest as what many deem negative behavior. "Recognizing when the bucket is getting fuller and being able to reduce stress will have a profoundly positive impact on a student's ability to learn." She referenced a short video (<https://www.youtube.com/watch?v=Rp3fPKrwTNA>) as an example that illustrates this concept in a "slightly different but meaningful way."

Per Belote, lack of closure also contributes to stress. All people need closure, although the level of need differs based on the individual. Typical children find closure in activities such as finishing assignments, getting a grade, graduating, and participating in sports. Routine is the best way to give children the sense of closure. Create routines that have a clearly recognized beginning, middle, and end to provide closure. One at home example is to create a "finished box" and place items representing activities, events, and days into it. For example, place a symbol representing the current day into the finished box as part of a bedtime routine.

As parents, we need to be aware our children have a different perspective of events, as evidenced by their reactions. Belote gave the example of a birthday party where a cupcake (a favorite and special treat) is handed to a child who is deafblind. The cupcake drops to the floor. The child may become angry, extremely sad, or drop to the ground to eat the cupcake off the floor. Since deafblindness is a disability rooted in lack of access to information, the child is unaware of the table full of cupcakes from which theirs can be replaced. The child senses the uncertainty or lack of closure of eating the cupcake and reacts. While the child's reaction may seem extreme, it is not once we consider their perspective and lack of information.

This leads to Dr. Paul Hart of Sense Scotland and his presentation *Get in the Zone: Revealing the Exceptional in All of Us*. He points out that if we want children who are deafblind to become language and communication partners, we must start by seeing them as such. Dr. Hart's research clearly indicates individuals who are deafblind have a greater motivation to be understood and work hard to make it happen, as evidenced by their quickly adapting their communication partner's language, even using abstract signs for which they have no personal reference or connection. Dr. Hart theorized this is because communication partners are less motivated to develop meaningful communication with individuals who are deafblind as they have plentiful and meaningful communication opportunities. Going even further, Dr. Hart suggests that in a rush to bring children who are deafblind into "our world" we don't take "enough time to learn from the experience of the person who [is] deafblind."

To counter this situation, Dr. Hart discusses the Zone of Proximal Development (ZPD), defined as the space between what a learner can do with no assistance and what they can do with assistance or a learning partner. In a ZPD, others help close the learning or communication gap for the person who is deafblind; in a double-sided ZPD, the person who is deafblind does the same for the other person. This echoes Dr. Cameron's previous discussion of Reciprocity and Progression.

Dr. Hart explains, "The idea of a double-sided ZPD allows us to see both (or all) partners in an interaction are learning and contributing just as equally as the other. It is not about imposing language from outside, whichever partner attempts to impose it. Instead, it is about co-creating new languages in the tactile medium, languages that emerge from the contributions of both partners and are root in the cultural experiences of both partners."

This is a good framework for understanding the importance of Dr. Jude Nicholas' (Clinical Neuropsychologist & Researcher, Haukeland University Hospital, Bergen, Norway) discussion, *Understanding Working Memory*

***in the Bodily-Tactile Modality: The Tactile Working Memory Scale.*** The use of touch and motion to gather information is known as bodily-tactile perception. The ability to keep information you need in mind to complete a task is known as working memory. Why is this important? In a discussion after Dr. Nicholas's presentation, he emphasized "It seems that working memory has a huge influence on many of the functions of cognition. It's communication and language. . . It's a correlation between working memory and a lot of processes regarding language, cognitions, and communication." He went on to explain in understanding this and focusing on the way a learning partner interacts with and provides information to a person who is deafblind, we can improve our ability to provide information that builds cognitive, social, and emotional skills.

As learning partners (not imparters of knowledge) we must remember that bodily-tactile perception involves more than touch using fingers or hands; it uses the entire body to sense and make sense of information. Dr. Hart summarized ". . . it's not about, not having vision and not having hearing. It's a really positive thing about cognitive capacities in the brain that's wired for touch. And the world can be just as rich and just as detailed."



## Marvin's Storytime Adventure

By Angela Walters, Parent

I'm so happy we participated in Marvin's Adventure. Once we signed up, my son Brandon received two care packages in the mail. The first care package included Marvin himself.

The care packages were organized by week. They had toys, transcripts, and all the craft supplies to create characters in the story. Miss Gwyn was very cheerful, colorful, and engaging. She also acknowledged each child participating by name. I hope there are more story times to come. It was an enjoyable hour for my son and I to share together. Plus, Brandon still enjoys playing with Marvin and the characters we made.



## It's Another Marvin Adventure!

Did you miss Marvin's first adventure? Don't worry, Marvin and a special new friend are returning for a new adventure series, **Marvin's Seaside Adventure!** Marvin's Seaside Adventure will last seven weeks over the summer in 2021: July 14<sup>th</sup>, 21<sup>st</sup>, 28<sup>th</sup>, August 4<sup>th</sup>, 11<sup>th</sup>, 18<sup>th</sup>, and 25<sup>th</sup>.

There will also be short, holiday themed adventures! **Marvin's Halloween Adventure** will run over two weeks on October 27 and November 3, 2021. **Marvin's Holiday Adventure** will run over two weeks on December 14 and 15, 2021. Be on the lookout for the Constant Contact registration link later this Spring. If you have any questions, please email Patty Turner at [pturner@philiprocenter.org](mailto:pturner@philiprocenter.org).

## Low Interest College Loan Fund for Deaf/HH Illinois Students

The Therkelsen-Hansen College Loan Fund provides low interest loans to Illinois students who are deaf or hard of hearing and need financial assistance to pay college expenses. Loans may be used by full-time students to pay tuition, books, and fees to any vocational-technical, undergraduate, or graduate school. While loans are available for a maximum of four years, the student must reapply each year to receive the loan. For a brochure containing more information about this program, Contact Faith Rosenshein Young, Family Engagement Coordinator, at [FRYoung@philiprockcenter.org](mailto:FRYoung@philiprockcenter.org) or 630-568-8720.

## Project Reach Library



By Michelle Clyne, Project Reach Coordinator

Did you know Project Reach has a lending library? We have books, DVDs, and equipment that you and the professionals in your child's life may want to check out! Here is what's new (or perhaps new to you).

**CHARGE Syndrome: Second Edition:** The book's foreword says that it "provides a tremendous foundation upon which to begin building a working understanding of the breadth and scope of the challenges and opportunities presented by Charge Syndrome (CS)."

**Calendars for Students with Multiple Impairments including DeafBlindness:** This book explains both the why and the how of creating and using calendars with individuals with combined vision-hearing loss. It is a classic for a reason!

**DeafBlind 101 Do-It Yourself Simulation Kit:** Have you wished you could help family and friends, or you yourself, better know what your child's combined vision-hearing is like? This kit includes vision simulation goggles, the "Sensory Perspectives" 2-disk interactive DVD set, foam earplugs, and suggested activities to do while using the simulation materials. While no simulation is the same as being a person with deafblindness, using the materials may help somebody look at and do things differently.

**Switch Assessment Kit:** Might your child benefit from using a switch to activate toys, but are you and your child's teachers and therapists not quite sure what switch would be best? Are you not yet ready to attend an AT evaluation outside of your home? You can borrow our switch assessment kit and try a few types of switches. While this does not replace a full AT assessment, this kit may be a helpful tool to borrow if you cannot yet attend evaluations outside of the home.



## IADB: Calling all Families

Illinois Advocates for the Deaf-Blind (IADB) needs you! IADB is a non-profit organization of parents, families, friends, and professionals dedicated to protecting the rights and advocating for the needs of all individuals with Deaf-Blindness. The organization is looking for those interested in joining our group as well as joining our board. This is a great way to get to know other families that have been touched by Deaf-Blindness as well as learn about resources while serving your loved one. Get involved! We would love to have you join us! For more information contact Krista Bohl at [kbohl2000@yahoo.com](mailto:kbohl2000@yahoo.com).

## Illinois Families Together Parent Zoom



By Krista Bohl, IABD President

On February 12, Illinois Advocates for the Deaf-Blind and Project Reach hosted another *Illinois Families Together*. The topic for the February meeting focused on pre-employment transition services for Deaf-Blind family members. McKenna Liesman and Joann Rushing from Helen Keller National Center discussed services offered through their organization. These services can be layered with the school district and include such services as job exploration counseling, counseling on post-secondary education, work-based learning experiences, workplace readiness training, and instruction on self-advocacy. To tap into these wonderful services, one needs to first fill out a short application with the DRS-DHS. You can find that application at <https://www.dhs.state.il.us/page.aspx?item=48062>. After you fill out and submit the application a counselor in your area will contact you. This may take up to two weeks due to Covid. Once contacted, tell the counselor at the first meeting that you want HKNC to provide pre-employment services for your family member. They will then send the referral to HKNC for direct services.

Don't forget to watch for the next invitation for *Illinois Families Together* when we will discuss Deaf-Blind 101 topics from infancy to pre-kindergarten. We would love for you to join us on Friday, May 7 from 7-9 PM!

## David is a natural born star! Is your child?



On January 8, David (a Project Reach Student) was featured as the National Center on Deaf-Blindness #DBFamilyFunFact. David was shown riding Chief, a horse with whom he has learned to communicate using visual and tactile signals. Their shared language and communication enabled a strong bond that increases David's love of riding. Congratulations, David!



The National Center of Deaf-Blindness continues to look for Family Fun Facts to promote using Facebook and Twitter. Family Fun Fact is a story, photo, and/or video that celebrates families of children who are deaf-blind and provides tips and ideas that might be useful to other families. Submit your family star(s) or learn more at <https://www.nationaldb.org/fe/db-family-fun-facts/>.

## Reduced Guardianship Fees

Did you know you can ask the court to reduce the fee when you file for guardianship of your young adult? See [http://www.illinoiscourts.gov/forms/approved/procedures/fee\\_waiver.asp](http://www.illinoiscourts.gov/forms/approved/procedures/fee_waiver.asp) (in Spanish: [http://www.illinoiscourts.gov/CivilJustice/Multiple\\_Languages/Spanish/Forms/procedures/SP\\_Civil\\_FeeWaiver.asp](http://www.illinoiscourts.gov/CivilJustice/Multiple_Languages/Spanish/Forms/procedures/SP_Civil_FeeWaiver.asp)) for on-line help, instructions, and applications.

## Upcoming Events

- **May 7 – Illinois Families Together Parent Zoom** – Deafblind 101: Topics from Infancy to pre-K
- **July 14, 21 & 28, Aug 4, 11, 18 & 25 – Marvin’s Seaside Adventure** – See description above
- **July 29 - Aug 1 – Family Leaders Virtual Conference** – Resources & Inspiration for Adult Family Members/Caregivers of Children with Disabilities



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