



# Texas School for the Blind and Visually Impaired

## Outreach Programs

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## 2017 Texas Symposium on DeafBlindness

### Making Connections

The 2017 Texas Symposium on DeafBlindness was held in Austin, Texas on March 3<sup>rd</sup> and 4<sup>th</sup>. As part of this event on Friday afternoon a general session focused on current research from The Center on the Developing Child at Harvard University. Their research focuses on the impact of traumatic experiences in childhood and how it impacts brain development. A component of that research explores strategies that can reduce the impact of this type of trauma.

The Texas DeafBlind Outreach Project at Texas School for the Blind & Visually Impaired stumbled on to this research several years ago and has incorporated a great deal of their research and products in training we provide throughout Texas.

We first began to think about the impact of stress on individuals with DeafBlindness from Dr. Jan van Dijk, perhaps the most recognized authority on education of students with DeafBlindness, a number of years ago. As advances in technology have brought about ever expanding understanding of the human brain, like many others we have tried to assimilate this information into our educational practices.

Remarkably the educational strategies we have long advocated for in the field of DeafBlindness seem to work because they address a critical function in all human development. What Dr. Cameron and the researchers at the Center on the Developing Child at Harvard University call “serve and return” interactions between the child and adult.

In our field we have known for a long time that the key to learning for the child is feeling safe and having a trusted relationship with an adult. That adult has to be particularly attuned to the child’s often subtle ways of communicating and aware of just how much information may be missed by the child as a result of his or her vision and hearing loss.

We know that many if not most of the individuals with congenital DeafBlindness experienced trauma early on as a result of medical interventions needed to save their lives. They also may not received early intervention services from individuals knowledgeable about the impact of DeafBlindness since so few of the professionals have any training in this area. The world that they arrive into can be a harsh and scary environment simply because they do not know what is coming at them or what will happen next.

Of course, so many of these children are born into families where parents and extended family, guided by the force of love, instinctively provide the safety and emotional support these children need to develop into very resilient beings. Our goal as educators is to help these students feel equally safe in the school environments we create so we can help them grow in all areas of development.....physical, cognitive, social and emotional development.

The contents of the presentation and panel that are shared on the following pages offers some valuable ideas about how we move towards better educational practice for our students with DeafBlindness.

# Impact of Stress on Brain Architecture and Resilience

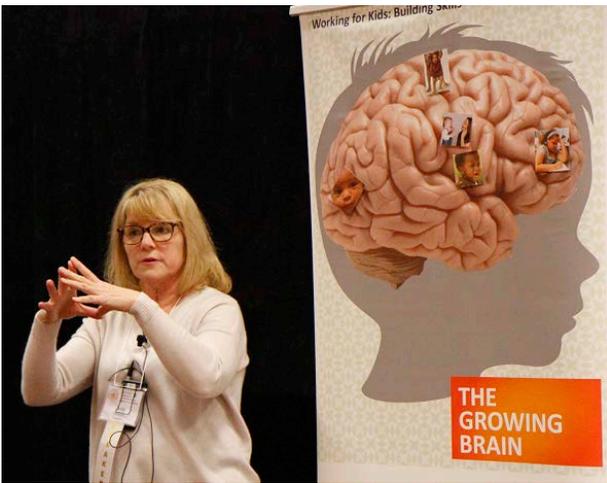
## Presentation and Panel Response

In February 2017 at the Texas Symposium on DeafBlindness, Dr. Judy Cameron, spoke on the developing brain and the impact of stress on that development. Dr. Cameron is Professor of Psychiatry and Obstetrics & Gynecology and Director of Outreach, School of Medicine, University of Pittsburgh, who is also affiliated with the Center on the Developing Child at Harvard University.

Here are some of the “take-aways” from these presentations. (You may want to take time to listen to these podcasts as well.)

### Dr. Judy Cameron’s Presentation

#### Four Principles



1. Brain architecture is established early in life and it underpins life-long learning, behavior and health.
2. The most important thing for adequate brain development is stable, caring relationships. If there's anything that matters, that matters.
3. Adverse experiences in the early years of life and can derail healthy development, because everybody can experience stress. Understanding how stress interacts with other things is important.
4. Resilience can be built through "Serve and return" relationships. Those close, personal relationships early in life help us to improve self-regulation, executive functions, and give children a sense of mastery.

#### Basics of Brain Development

Life experiences play a very important role in shaping brain development.

At the time you're born you have almost all the brain cells that you're ever going to have.

The cells reach out and connect to each other as each part of the brain develops and form neural networks.

During the earliest years (approximately birth thru three) billions of connections are made as a result of the experiences an individual has.

Then through a process known as “pruning” some of these connections begin to disappear because they are not used very much while others grow stronger.

These stronger connections work better, faster and more efficiently.

No two brains are alike because an individual’s experiences determine which circuits get used, and those are the circuits that you keep permanently.

Brain development starts before the baby's born, and it doesn't finish developing until a child is about 25 or 26 years of age.

The areas that control vision, hearing, taste, smell, the sensory pathways are making connections before the baby's born and during the first year pruning is happening in these area of the brain. So experiences that happen in the first year of life are really important for sensory functions.

Language areas of the brain start developing prenatally and a lot of connections are being made within the first year of life. Pruning occurs during childhood, between five eight years, so experiences have a big influence on those pathways in early childhood.

*To build strong brain pathways you have to use a circuit over and over and over again. So the challenge is how to make the action or activity fun so the child will want to repeat it over and over and over again to build a strong circuit.*

The prefrontal cortex is very late to develop. It's making connections for the first 10 to 12 years of life, and then the pruning process goes on until about age 25. So experiences, all through the teenaged years, into the 20s, are shaping the development of this part of the brain.

The prefrontal cortex controls planning, problem-solving, complex reasoning or trying to keep multiple things in mind at once and make a decision about what you should be doing.

The part of the brain that controls emotions, both producing emotions and recognizing emotions, is right in the middle of the brain. Pathways are being made for emotion recognition and expressing emotions throughout early childhood and up until adolescence.

The pathways for speaking and vocalizing start forming from birth, and for the first few years of life, and then pruning occurs. You talk all your life, but you're using the pathways you built early. You're not making new pathways.

Areas of the brain related to motor movement start making connections at birth and continue over the first year or two of life. Then pruning happens until about seven years of age.

To build strong brain pathways you have to use a circuit over and over and over again. So the challenge is how to make the action or activity fun so the child will want to repeat it over and over and over again to build a strong circuit.

People become experts on what they experience repeatedly.

*Ensuring that children have adult caregivers who consistently engage in serve and return interaction (beginning in infancy) builds the foundation in the brain for all the learning, behavior and health that follow.*

## Serve and Return Interactions

The key to forming strong brain architecture is a "serve and return" interaction with adults. It starts very early in life when a baby coos and the adult responds. The child is serving, showing what they are interested in or what they want to do.

Ensuring that children have adult caregivers who consistently engage in serve and return interaction (beginning in infancy) builds the foundation in the brain for all the learning, behavior and health that follow.

## Resilience

The brain's role is to keep us safe.

Individuals that experience adversity early, while brain pathways are forming, are more likely to have anxiety and depression. They are more likely to try to solve on-going adversity with addictions and more likely to have cardiac problems.



Figure 1 An adult and young girl share a moment of connecting through touch.



Figure 2 Chris Montgomery engages with a young DeafBlind girl in a cooking lesson.

In your teenaged years and early 20s, the prefrontal cortex of the brain is developing pathways and connecting to every other part of your brain.

This front part of your brain is about complex thinking--- problem solving, complex reasoning, inhibiting your actions. This type of complex thinking helps children develop resilience.

### Supporting Learning

Once children are interested in learning something, they need to engage in the activity. It's not good enough just to watch an adult do something. They have to use their own neural circuit.

As parents and educators we have to show lots of compassion, caring, motivation and eagerness about the child's activity, even if they're doing things not so well, to encourage the him to do something over and over and over again.

Once a learner has engaged, you want her to develop self-confidence so that she can do an activity on her own and not need adults all the time.

If children are in an environment where they have love, then they feel more confident to try new things. If they have support from people around them, they're more likely to engage in learning. This requires the adults to have patience.

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Stability really works very well for children. They need to know that they can trust the adults that are around them to provide a stable environment where they know what's going to happen, feel safe and can spend time learning things.

Children need to have their needs met and be taken care of. It's very hard to learn new things that are hard for you if you don't know whether you're going to get fed, have a place to sleep, etc. Care matters and it matters a lot.

When the child starts to be able to do things you need to step back. You need to be there and provide love, encouragement and support, but don't do it for him. Don't help too much. Let the child learn to progress on his own.

### Stress

Children can experience the exact same stress, but if they're at a different point in brain development, the stress will have different effects. Different parts of the brain are sensitive to the stress at different times.

Gene expression refers to which genes a cell is using. All the genes are present in every cell, but gene expression says which ones are directing the activity of that cell.

Stress can turn on genes and turn off genes and those can have permanent effects. So it isn't just that you have changed brain architecture, you've changed the recipes that are being used to govern your life.

Stress also leads to hormone secretion, so secretion of things like cortisol. Cortisol mobilizes fuel, glucose from the liver and fat cells, to produce some energy so we can “run away or fight” when we feel threatened. Cortisol expressed every day can suppress the immune function.

Changes in gene expression are the main ways that stress has an impact on your brain.

Learning to deal with stress is an important part of healthy development.

When experiencing stress, the stress response system is activated. The body and brain go on alert. There's an adrenaline rush, increased heart rate and an increase in stress hormone levels.

When the stress is relieved or a young child receives support from caring adults, the stress response winds down and the body quickly returns to normal.

*Toxic stress can be avoided if we ensure that the environments in which children grow and develop are nurturing, stable and engaging.*

The constant activation of the stress response overloads developing systems, with serious life-long consequences for the child. This is known as toxic stress.

Over time, this results in a stress response system set permanently on high alert.

In the areas of the brain dedicated to learning and reasoning, the neural connections that comprise brain architecture are weaker and fewer in number.

Prolonged activation of stress hormones in early childhood can actually reduce neural connections in these important areas of the brain.

Toxic stress can be avoided if we ensure that the environments in which children grow and develop are nurturing, stable and engaging.

Children are born at different places. Some children are very responsive to adversity; other children are very sensitive to positive things.

Another way of thinking about this is to think about a balance or scale. A child is born and some good things happen to them and kind of tip them towards the positive side, and some bad things happen and tip them back a little bit more. It's easy to think that maybe it's just a balancing issue. If they've had to deal with more adversity, let's just pile some more good things on here and tip them right back.

*But what we have to remember is that children are born at different places, so the fulcrum is different in different children. Some children are very responsive to adversity, so a little bit of adversity tips them way towards the negative or adverse experience.*

But what we have to remember is that children are born at different places, so the fulcrum is different in different children. Some children are very responsive to adversity, so a little bit of adversity tips them way towards the negative or adverse experience.

If we do a good job with the development of pre-frontal cortex circuits that develop in adolescence, we can overcome the negative repercussions of the adversities in early life.

Parents and educators must work to make sure children have stable, caring relationships.

Dr. Cameron is a Professor of Psychiatry and the Director of Pitt Science Outreach ([www.pittscienceoutreach.com](http://www.pittscienceoutreach.com)) at the University of Pittsburgh. For 10 years she was a member of the McArthur Foundation Research Network on Early Experience and Brain Development and she is currently a member of the National Scientific Council on the Developing Child and the Scientific Council for the Child Mind Institute. She has a well-established research program studying how life experiences shape brain development and lifelong brain plasticity, focusing on the impact of social stresses, exercise and nutrition. Dr. Cameron is also a member of the Dana Alliances for Brain Initiatives, a nonprofit organization of neuroscientists committed to advancing public awareness of brain research in an accessible fashion. She has given numerous public lectures translating science to the public and has spoken at national meetings for science educators and is now a member of the editorial board for 'BrainFacts.org,' a website targeted toward providing accessible information about the brain to the public. Dr. Cameron has overseen the development of all aspects of Working for Kids: Building Skills.



### **Working for Kids**

Educators need to provide educational tools that will strengthen families.

*Working for Kids* is a neuroscience based, hands on educational program designed to teach adults about how the brain develops and how experiences children have can actually shape the structure of the developing brain.

*Working for Kids* has been developed to meet the needs of a number of professionals who work directly with children, including doctors and law enforcement.

The *Working for Kids* staff are developing online training courses for professionals, text messaging and other resources to best support customers.

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Working for Kids: Building Skills is a program funded by The Bales Family Foundation (<http://www.balesfamilyfoundation.org>) and The Pittsburgh Innovator's Challenge (PINCH) ([www.pinch.pitt.edu](http://www.pinch.pitt.edu)). The program uses a “whole community approach” to facilitating healthy brain development for children in the early years of life and brings many community members together, working as facilitators to help young children learn important social-emotional skills and cognitive skills that will set them on a strong trajectory for life-long learning and success. Visit the Working for Kids website to learn more.

[The Center on the Developing Child at Harvard University](#) provides another exceptional resource on the developing brain and the impact of stress on this development.

## What Harvard's Research Means for Children who are Deafblind

### DeafBlindness Panel

In response to Dr. Cameron's presentation a group of experts in DeafBlindness shared their thoughts on what this means for educators and family members as they interact with children who have DeafBlindness. These experts included:

- Robbie Blaha, Consultant in DeafBlindness with Texas School for the Blind and Visually Impaired, Texas DeafBlind Project, Austin, TX
- David Brown, Consultant in DeafBlindness and acknowledge expert on individuals with CHARGE syndrome, San Francisco, CA
- Bernadette van den Tillaart, Consultant in DeafBlindness with Ohio State School for the Blind, Columbus, OH
- Dr. Suzanne Zeedyk, developmental psychologist at the University of Dundee, Dundee, Scotland



Figure 3 The panel of experts includes from left to right: Dr. Judy Cameron, Dr. Suzanne Zeedyk, Bernadette van den Tillaart, David Brown and Robbie Blaha. Chris Montgomery, served as one of the panel facilitators along with Matt Schultz. Chris is seen on the far left of the picture.

This panel was facilitated by Chris Montgomery and Matt Schultz, DeafBlind Project Consultants.

## Question

Can you talk more about serve and return in reference to young children with DeafBlindness, including the challenges our kids face and ways that we can overcome?

## Dr. Zeedyk's Response



Figure 4 Suzanne Zeedyk

The lovely description that we got from the film presented by Judy talked about serve and return. So it's a bit like a tennis game. The baby serves and any other adult, the parent a lot, but it could be a teacher (or other adult) returns it, if they notice it and if they think that it's significant enough to be returned.

They might do that unconsciously or consciously, but the point is that when it gets returned the baby's brain knows that somebody else noticed it. The baby responds to this turn from the adult, just like playing a tennis game.

Every time the call gets returned to the baby, the neural pathways get strengthened. So just knowing that helps us go, okay, I get it, that's how brains are built.

It turns out that you can respond to what the baby does positively or negatively. For example, you might perceive that the baby is misbehaving.

The baby didn't mean to misbehave, but you interpreted it as misbehavior. So when you respond in a negative fashion, the baby learns that that's a bad thing. If you respond positively the baby learns that's a positive thing.

So he is learning about himself, too. "Am I a good person or a bad person?"

Now let's put that in the context of a DeafBlind child who's just like any other baby, responding to the world as their brain lets them do that, but of course their world isn't like the world of a person who can see and hear.

Their behavior may not read the same to those of us who are unconsciously expecting it to look like the behavior of a person who can see and hear. Especially if we don't know that the baby is having trouble seeing or hearing.

In Selma Freiberg's work in the 1970s, studying babies who were blind, she talked to mothers who when the baby turned away, the mothers interpreted that as the baby didn't love them. The babies were probably orienting with their ear to hear what the mother was saying, and the mothers didn't know that the baby was blind.

*So those first lessons that you get about serve and return teach you about so much. They teach you about yourself. They teach you about the other person you're engaging with. And they teach you about what people are like.*

We unconsciously expect people to look at us because that feels like the return. We served you a look and when you looked back, you returned that look to me. I feel good about myself. If your baby looks away, you can easily unconsciously read that as my baby doesn't like me, then I feel bad about myself. That starts to filter into the serve and returns within a relationship.

That serve and return goes on and on and on and it becomes part of the rhythm of the relationship, as well as part of the baby's neural pathways and part of the baby's understanding about what people are like.

So those first lessons that you get about serve and return teach you about so much. They teach you about yourself. They teach you about the other person you're engaging with. And they teach you about what people are like.

This helps us think about what happens when modalities don't match up and they are hard for another person to read.

All of that developmental experience will be in all of us and in a person who is DeafBlind. So if you meet a person who is DeafBlind when they're 25 or 56 or 14, they have those early experiences of people built into their brains.

Some of those may have been really positive if you had a family who could tune in and was curious. Some of them may not have been quite so enriching because you had a family who was confused or overwhelmed.

This morning Joe (Gibson) said sometimes he wondered if those early experiences of being in long-term hospital had as much to do with the behavior of the people that he was working with as did the DeafBlindness. If we can think more, if we can get curious about what developmental histories might have been, then we start to have more avenues and insights as to how we can reach a person even now. Pathways continue to rewire. They rewire even after 25, just not as quickly or easily.

## Question

For so many of our kids, social interactions can be stressful situations. That problem can manifest itself in forming those good and positive relationships. Can you talk to us a little bit about how we can help our kids manage that stress and then go on to form those good, positive, strong relationships?

## Bernadette van den Tillaart



Figure 5 Bernadette van den Tillaart

I've been thinking about when Judy talked about the fulcrum. Where is the fulcrum? Where is the child? How can we move "the fulcrum" of a child so that positive experiences have greater impact and there's less stress and better brain architectural development.

If a child is born DeafBlind, then there are several issues. One is health. That gives bodily stress. Then maybe there are areas in the brain that are damaged which makes it vulnerable and gives stress. Then there is the vision and hearing loss. There is also a lot of medical care and possibly brain damage can be to a certain degree permanent.

Does DeafBlindness affect the brain architecture? Yes. Because we know from research when people are blind, their visual cortex is going to be used for touch and hearing. Then the same applies to hearing. The areas of the brain that should have been used for hearing will be used in some ways by touch or vision.

So there is a certain impact on it that is not necessarily bad at all. All right?

*...when these children are born, it is so difficult for parents and others to recognize their behavior as communication. The parents and others are not used to communicating with touch.*

But on the other hand, does DeafBlindness itself, vision and hearing impairment, really impact if a brain does not develop well? I think that the DeafBlindness is not actually the factor that impacts if a child can develop and if the brain architecture can develop or not. I think it can.

So what are the factors then that are so harmful for our kids when they're born?

Like Suzanne said, when these children are born, it is so difficult for parents and others to recognize their behavior as communication. The parents and others are not used to communicating with touch.

In the beginning when the child is a baby there's a lot of touch. But even that can be intrusive when the child does not pick up that mom looks at him before she picks him up. So touch can be intrusive.

The important "serve and return" is not going to happen in a way that it creates reciprocity. There's a mismatch between where the strength of the child is (touch) and what other people are used to

experiencing (hearing and vision). So what happens then is that there are misunderstandings which results in a tremendous amount of stress for the child, for the parents and other people who don't understand.

It's not only that this mismatch gives stress to the child, but the child also feels (tactilely) the stress of people around them, who may feel my child does not love me. With all of these misunderstandings and challenges to the relationship, the development of language and exploration of the world is difficult.

The intervention piece, which should move the fulcrum, is on tactile serve and return. There needs to be a single, strong and stable person available for that child who can do that. And that leads immediately to our efforts to get interveners for our children.

I think about one student with CHARGE syndrome with a history of stress. She moved between schools frequently and when she was seven she moved to her fourth school. She came in, hitting, biting, scratching and the only thing that we started working on was gentle touch. Gradually we began to use hand under hand and serve and return for interaction. And we did that for a year. Of course, there were activities, but that was the goal.

So this changed so much in this child. What happened is that her attention is there, and her processing time is decreasing.

I strongly believe that we should not do any cognitive testing when we have not established reciprocity with the child -- not that we shouldn't do it, but look at results and think about what it means. Because if a child does not have reciprocity in a relationship and no stress -- until that moment, the brain development cannot happen. We have opinions about all of the test results but we do not know anything about the potential of the child.

## Question

David, we've talked a lot today about the impact that stress has on our students, their development and their ability to connect. But I'm wondering if you could speak to us a little bit about how stress impacts our families and on their development as family units. What impact does that on their ability to connect with services and support?

## David Brown

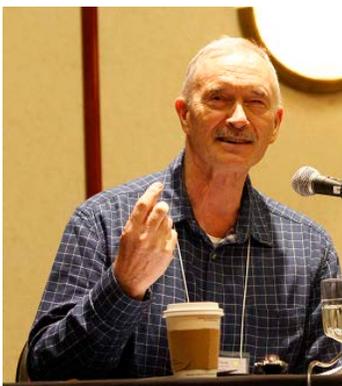


Figure 6 David Brown

First of all, we need to stop thinking about us and them. One of the beauties of all of the presentations today, all four of the presentations before this panel -- I think there were four -- the presenters never assumed we were talking about us and them. It was always children with DeafBlindness are people just like we're people. And I think that's a really important point.

We've all gone through adverse experiences in early childhood and we're still doing it now decades later. We've all had to struggle with various levels of sensory integration and sensory differentiation dysfunction. I know personally that those problems get more pressing with the passage of time and that's unavoidable to me these days, that realization.

I've always been an itinerant teacher and worked with parents and family members or professional teams. So much of my time is spent observing and analyzing and trying to understand the stresses and the capabilities and the motivators of those adults.... before I even begin to focus on the child and start trying to work out who they are.

Somebody had the brilliant idea of saying, “Working with students with DeafBlindness is about three main things: communication, communication, communication.” And I always disagreed. I thought that was far too limiting actually because it's about way more.

Then about two years ago I had a sudden “ah-ha moment” and I thought. “Yeah, the first “communication” for the child in terms of their experience (and the most urgent in terms of the way their brains are wired) is communication between the child's brain and the child's own body. This communication (between brain and body) is impaired in more children with DeafBlindness because increasingly we're seeing a population with complex multiple disabilities and multisensory impairment.

*I thought. “Yeah, the first “communication” for the child in terms of their experience (and the most urgent in terms of the way their brains are wired) is communication between the child's brain and the child's own body. This communication (between brain and body) is impaired in more children with DeafBlindness because increasingly we're seeing a population with complex multiple disabilities and multisensory*

We have to think of all the sensory systems not just think about vision and hearing and then bring in touch as the compensating sense.

The very first “serve and return” that that brain has to do is to ask its body to respond. Frequently the child develops movement patterns on what we dismissively called “self-stimming” behaviors as a way of getting that serve and return between the brain and body.

Once the serve and return between body and brain is in place, on some level that brain is then able to focus on the second “communication” which is the more traditional meaning of serve and return with another person, especially a significant other person.

Then the third “communication” would be communication between the child and the more extended social world and the more extensive inanimate world around it.

I think that's quite a useful way to think about this in every situation. Is that child's brain in contact with his body effectively so that it's available for the things I'm trying to do with the child?

I learned from Jan van Dijk decades ago that everything the child does has meaning, and our first job is to interpret and understand what that meaning is.

If we accept that everything the child does is a serve, everything they do (every movement, every sound, every change in breathing, every eye movement) is a potential serve that we can respond to. If we do this we're going to be in a much better position to build a relationship with the child because these kids are very hard to understand.

## Question



Our field has long had best practice methods, but very little DeafBlind specific research. In your opinion, has the Harvard Center on the Developing Child's work validated or strengthened our field's best practices?

### Robbie

You know, when our field got started in the '70s, educational approach was very compliance based. Most of the research came out of Peabody School, Vanderbilt and our curriculum had objectives like “follow a two-step command”. Lesson plans were based on task analysis where you brought down tying a shoe into 80 steps and then the student learned

*Dr. van Jijk made a huge point by saying that these children have attachment disorders due to the DeafBlindness, due to sensory deprivation.*

each step. You “trained” the student. Sometimes we also used adverseness or negative reinforcement to change behavior.

When I started working at the early deafblind pilots, we had these mimeographs from Jan van Dijk. He had a completely different spin on educating these students. Because of him the field did a sharp 90-degree field and left the usual practices of our time in the field of special education.

Dr. van Jijk made a huge point by saying that these children have attachment disorders due to the DeafBlindness, due to sensory deprivation. This is a baby undergoing sensory deprivation. This is a baby who can't tell what people are up to because all the people who contact him for months when he was first born hurt him. Their mother who cuddles them, hands them over to the people who hurt them. So they don't understand people. They think we're loose cannons.

So in order to teach them, we have to engage them. In order to engage them, we have to follow the child's lead. We have to watch what they do and do it back to them.

When you bring this up in an IEP meeting, it is a tough sell. The best practices we have are without research. We are very rich in best practices primarily because of the information that did come from the Netherlands and from Europe.

For a long time I didn't care about the research. I really didn't. But now we can say “serve and return” and point to the Harvard research. This research

shows that serve and return builds connections, fosters brain development. Without this engagement and interaction, these children with DeafBlindness do not have experiences that do anything but prune connections. They do not build connections unless our response is very carefully engineered to match what they're experiencing.

So I love fact that we have this research. I'm glomming on to serve and return. We needed this term.

In Outreach we get called in a lot on behavioral issues because we see children who have really been through significant adversity from their perspective because it's very easy to misinterpret the experiences of what's going on around you. Their experience of life is that it is very chaotic.

*Many children with DeafBlindness certainly don't experience a high degree of practice, which implies continuity. If you have eight people working with that child, continuity and consistency is difficult to achieve.*

As a consultant, you have tell people they need to limit the number of people who work with this child in order to provide the degree of consistency and the bonding that the child needs to start making connections. So when we're talking about related services and interveners, you need to make a case for how to limit the contact and funnel these things to the child in a way that's engaging and consistent enough for the connections to be built.

What we do is we go in and say you need to make this child a spot. What we mean is this child needs a place in the room that is so engineered for them that they feel secure and engaged. They need to have a place to recharge after braving the world.

This spot could be some type of den which is designed just for a particular student with particular objects under it, engineered according to his sensory needs. It might be a space where the child can play on his own with objects he likes to pull apart. The child could retreat there for a little bit. You



Figure 8 A mother and her child smile at the camera.

give this space a name. Give it a symbol. Put it on their choice board or schedule it in their calendar. But you give them this space. I see this working all the time for children with DeafBlindness. It's a haven and they can always find it. Now, thanks to Dr. Cameron, I'm going to call it a charging station, get this in the IEP accommodations or under supplemental aids and services -- designing a spot, a consistent spot with a name and engineered for that child is a very powerful strategy to consider.

I like the way this research validates some of our best practices and enables us to communicate more effectively to IEP teams as we develop programming.

## Question

Suzanne I saw you scribbling some notes a few minutes ago. Would you like to share them with us?

## Dr. Zeedyk

I want to throw in one more word that has not yet come up at all today. When we think of a charging station, we think of it giving us energy. It's got another half to it. A charging station is also a safety station. Okay?

Safety is the one concept that I would throw in that's really important that we "get" today because attachment is effectively about seeking a sense of safety. If you don't feel safe in the world, then you can't go exploring and take risks. And until you have a sense of safety, you keep seeking safety.

Safety comes from two sources. Primarily it comes from attachment, connection to one other human being and it also comes from lots of serve and return. "You pay attention to my needs."

You can have attachments to more than one person, but you need at least one. Romanian orphans died because they didn't have an attachment to one person. And those that didn't die were often very, very traumatized in a way that they couldn't recover from. Okay? I just use that example to give the picture in our heads. So you need a connection to at least one other person to have a sense of safety.

*Safety is the one concept that I would throw in that's really important that we "get" today because attachment is effectively about seeking a sense of safety. If you don't feel safe in the world, then you can't go exploring and take risks. And until you have a sense of safety, you keep seeking safety*



Figure 9 Two moms connect at the Symposium.

And then trust and safety comes through lots of serve and return.

So when you have calmed down because you feel safe, and you know that you can always get back to your safe base, you can go off exploring. You don't want to go off exploring if you don't know that your safe base is going to stay put.

All of us need a sense of safety, including children who are DeafBlind. Their sense of safety may be harder to achieve because of that mismatch that occurs in the interactions they experience.

In today's world, of course, there are more and more children who are born prematurely and that's the cause of some DeafBlindness. Their lives began in pain where people stuck things in them and life was uncomfortable. That's their first memories and lessons about life. That's

different than if DeafBlindness came from a different source.

*If we can put those two pieces together, that you arrive connected and everything is about connection with brain development, then we have all of the key tools that we need to make things different for lots of children and adults in this world.*

So if we think in terms of safety as well as charging, then we start to give our children the key things that they need.

I think the first thing they need is to reclaim a sense of safety so that their body can calm down --- especially if you have a child that's having behavior problems, challenging behavior.

I grieve the fact that psychology, developmental psychology, discovered many of these connection concepts a long time ago. Attachment research began in the 1940s. Connection, we knew a lot about that by the 1970s. But that information

has somehow not been of much use to people. Where it has now caught on is because of the neuroscience. When I go places everywhere people are excited about the neuroscience and about the sorts of things that Judy was talking about. But what I find that people don't yet put into that picture is an understanding that you come into the world biologically connected to other people.

If we can put those two pieces together, that you arrive connected and everything is about connection with brain development, then we have all of the key tools that we need to make things different for lots of children and adults in this world.

## Question

Dr. Cameron talked about experiences, right? Experiences are built in -- within the body especially early in life. It's not talking about something and thinking about something. It's really bodily experiences. Children with DeafBlindness hang on to their experiences more tactilely, unless and until language fully kicks in. I think that those bodily experiences can be part of a shared experience with someone else (serve and return). This helps the child feel at ease and really be able to make neural connections. What do you think?

## David Brown

I think one of the notes I made for myself was that all experiences are sensory. If a child can't see them or hear them or touch them, the child doesn't really experience them, so they aren't experiences. And I think of all the times I've gone into schools to see a child who is profoundly deaf and people are talking to the child. Not because that's their natural way of expressing themselves, but because they seem to think that the child can hear them. But the child won't respond, and they are under the impression that somebody like me has come in to make the child respond.

*I think one of the notes I made for myself was that all experiences are sensory. If a child can't see them or hear them or touch them, the child doesn't really experience them, so they aren't experiences.*

You've got to know or have an idea of what that child's sensory perception abilities are, what they depend on, how they vary from situation to situation, how they vary from time of day to another time of day. How they can vary from being with one person to another person or in one activity or another activity. And we all know children who are -- have much better vision and hearing and motor coordination in the swimming pool than they do when they're sitting at a table in the classroom. And that shouldn't be mysterious because we can explain that very clearly.

So getting to understand what the limits are from their sensory perception in every sensory system is really important. That way we can start to make sure that we're delivering experiences that really are experiences for them, meaningful experiences.

I'm a big believer in observing children. If I'm going in to meet the child or assess a child, I watch and listen and ask lots of questions and scribble lots of notes. People will often say to me, especially in the school setting, when would you like to start your assessment? For two hours I've written six pages



Figure 10 A young man with DeafBlindness raises his glasses to view his smart phone.

of notes, but they think somehow you have to do something to a child in order to find out who they are.

If we could just spend a bit more time finding out what children do, I think we would get at least 50% of our assessment data from what the children are doing --- because children don't do anything unless it's either meaningful or pleasurable or essential to them. It has to have a function for them or they wouldn't be doing it.

I know those behaviors can become habitual over time, but they all start with sensory need and sensory motivation. So we have to keep going back to that. Because even with older students and adults, we have to try to go back to the

beginning of their life to try and think that what we're seeing now came from those early experiences. And that's one of the beauties of what came out of Judy's presentation. It's all being laid out right from the very beginning.

Back to Jan van Dijk, I remember he said once, when you work with a baby you must make the effort to see them in 25 years' time in your mind's eye. And I thought, and when you're working with a 25-year-old you must make an effort to see them when they were three months old to try and fill out the picture.

And last point, Robbie's delighted that Harvard has kept us (in the field of DeafBlindness) okay to keep doing these crazy things we do. Good quality DeafBlind education has a focus upon sensory perception, self-regulation, executive function, emotional well-being, self-confidence, relationship building and communication and language development.

There's the link, however peculiar that things we do seem to the outside world, it all fits absolutely with everything you and Suzanne are talking about.

*If we could just spend a bit more time finding out what children do, I think we would get at least 50% of our assessment data from what the children are doing --- because children don't do anything unless it's either meaningful or pleasurable or essential to them.*

When you work with others around a child with DeafBlindness, you have to help people move into accepting that when we missed those vies for attention, sometimes our children got scared. Maybe we actually helped to establish some patterns that we never meant to, we were entirely unaware of it, and now we get how some of their behavior patterns may have gotten established.

So how do we help people do that while also holding them and not having them feel guilty? Because if we tip them over into guilt, we haven't helped, we've actually made things worse.

Holding them in this really tricky line becomes important and I think the solution is to try to move us to curiosity. We all have the capacity to hurt other people without ever having meant to. Be curious about another person's experience always. If we can be curious about our children, just wondering if that little tiny hand wave means something, then I think that keeps us on this side of not having to feel guilt.

I want to add one more thing. Dr. Allan Schore is another important researcher in all of this, and he talks a lot about the rupture-repair cycle. Repair is more important than rupture. I call that "making up is more important than messing up".

So if we remember that if we get it wrong, it doesn't matter. What matters is to come back and reconnect. Then we can be comforted. It doesn't matter what you didn't know. It doesn't matter what you get wrong. What matters is that you reconnect and that we don't have to feel bad. This stuff can stop scaring us and can excite us. And if you can get that, then can you it go tell all the other people

out there who don't yet know. Because this is as relevant to children and people without DeafBlindness as it is to those of us in this room.

## Robbie Blaha

*When we lose the engagement piece of the calendar and the importance in terms of creating safety and enthusiasm in children, we miss the point. All it is is a daily schedule that's kind of looks like a to-do list. It is not a daily schedule. That is not the point of calendars at all. It was always about engagement, it was always about safety for children.*

You know, this has been real helpful to me because I think it shows that you can use a good strategy or best practice for DeafBlindness, but if you don't have the theory behind it, it becomes really dry and useless. I see this happen with calendar systems.

Beginning with children with just emerging language, emerging attachment...The theory behind this is definitely about engagement because these kids do care about what's going to happen to them. They do have some things that they're interested in and they would like to know if it is ever going to happen again.

They also need to know who is coming -- what people are going to be approaching them. Who is scheduled to be here.

Those of you who are familiar with the calendar methodology know that it incorporates a high degree of repetition and practice. There's a structure to it. Every time you do it. You provide the student the scaffolding so they can start building connections. The student comes to know you are starting at this end and talking about something they are interested in, this is their future. And you see them start leaning in.

When we lose the engagement piece of the calendar and the importance in terms of creating safety and enthusiasm in children, we miss the point. All it is is a daily schedule that's kind of looks like a to-do list. It is not a daily schedule. That is not the point of calendars at all. It was always about engagement, it was always about safety for children.

It's amazing the degree of participation and attention you can get from a child when doing calendar because it's about what's going to happen to them. Also, that is the one place where you can start building the connections to new things by adding additional facts. Before that even happens to them, you can talk about the future. You are going to eat and you know what you're going to eat something in a package like this. You can give them information in a way that's so cleaned up and repetitive that they remember and understand it. You are giving them a highly engineered experience.

So I think that we need to remember when we sit down to do these things that we're building brains, we're building connections with human beings. These strategies are brilliant.

## Bernadette van den Tillaart

I've been thinking also about Dr. Cameron's model in regards to those students with Usher Syndrome. They have one way of connecting when they are little and another when they move into puberty and begin to lose their vision. When their vision is deteriorating, it changes their world and their brain has to adapt because all of the visual information that they were used to getting in is not coming in as it was. Their vision will not give them information.



Figure 11 A toddler takes a break from climbing steps.

The serve and return with peers is going to be affected. Their difficulties with homework and getting instruction, they blame that on themselves. In the time period that their body is changing in many ways because of puberty they don't feel secure anyway.

When we are talking about serve and return and connections we have to think also about these young adults. The impact of losing vision and the re-structuring of the brain. How serve and return interactions they have established are they going to be different. There are a lot of things that come up to mind that I would like to consider related to students who acquire DeafBlindness.

## David Brown



Figure 12 A young woman with DeafBlindness

The key phrase in our world, if you are doing DeafBlind education, comes from Jan van Dik and this is to "follow the child."

When Judy said it's the child who serves, your job is to respond, I just thought, yeah, Jan van Dijk followed the child. Students with DeafBlindness require a lot more work, a lot more observation, a lot more planning. Things have to be clarified, clutter has to be removed, consistency has to be built in, pacing has to be individualized for the student, not for you.

I always worried about going into a home or a classroom and saying, "All you need to do is be totally available all the time. You need to be completely observant all the time. And you need to be ready to respond at any time the child serves you anything."

And the fact is good, quality DeafBlind education is incredibly labor intensive. When we had the awards this morning, the thing that brought tears to a lot of people's eyes was when 14 professionals got up on the platform. To be honored for their work with one student.

It was just a reminder that you're not just looking for the one good teacher who gets it. Sometimes that's all you've got. Sometimes you don't even have the one good teacher. But really it takes an awful lot of people.

The child has to learn serve and return with their own bodies and with the environment, not just with other people. If you can't be there and be available, think about environments that are responsive to the child. I'm thinking about Lilli Neilsen's Active Learning approach. The Little Room and especially the resonance board. I used Resonance Boards in England for 17 years, with students from three months old to 19-year-olds.

*Students with DeafBlindness require a lot more work, a lot more observation, a lot more planning. Things have to be clarified, clutter has to be removed, consistency has to be built in, pacing has to be individualized for the student, not for you.*

Environments where they can go and do things that aren't just purely self stimulation. That aren't just poking the eyes or flapping the hands or blowing raspberries, but are actually interacting with something outside of their own bodies. So even if you can't be there for them, you have given them the option of doing something outside their own body space, which is sometimes the very best that you can do. But also I think should be seen as the least that you can do.

## Question from the Audience

One of the things we talk about in DeafBlindness is doing with, not for. When I was listening to Dr. Cameron this morning and she talked about the importance of stepping back and letting the child

do. And David just talked about Dr. Neilsen's notion that the child has to be able to do things on their own, of their own volition. Could you share a bit more about this?

## David Brown

Can I jump in? I want my hobby horse.

For two years I've been trying to write an article, which has never come to be. The title was why self-stimulation is great and why we should be encouraging much more of it.

I'm tired of that strange prejudice that sees us (non-disabled individuals) as not self-stimulating, and children with developmental difficulties as self-stimulating. It's very bad and we've got to stop it.

I learned more from children's self-stimulation behavior than I do from the IEP very often. Self-stimulation is the children serving all the time. Those behaviors are fulfilling a need and over time they acquire a social component. Maybe the individual is self-stimulating to avoid working or to aggravate, but that comes later. That's not where they started. It started with a sensory need.



Figure 13 A group of children with DeafBlindness and family members at the 2017 Texas Symposium on DeafBlindness.

*I'm tired of that strange prejudice that sees us (non-disabled individuals) as not self-stimulating, and children with developmental difficulties as self-stimulating. It's very bad and we've got to stop it.*

I think it speaks to the way these children are desperately undervalued by all our societies (and I've worked in Latin America and in India and in Australia). These kids are undervalued in the same ways everywhere I go.

We have to keep fighting that perception with the kind of evidence that we've heard about today. But for me it's always been the work Jan van Dijk and Lilli Neilsen and Jean Ayers, the occupational therapist who came up with sensory therapy. They're my three gurus. They all pushed very strongly the

notion that children do things that have meaning for them and we need to work out what that meaning is before we decide to step in and try to change things or stop things, unless it's dangerous or illegal. It should not be a primary goal of education to **STOP** the child from doing things. That turns everything completely the wrong way around.

So think of self-stimulation as children giving you insights into who they are, what's working, what's not working, what's providing for a need. Then you are in a much better position to know how to respond and how to behave with them.

## Bernadette van den Tillaart

That I often see exactly the behavior that you describe as related to what Dr. Cameron said about self-regulation. If you understand that behavior, you get to the source of the stress, be it from boredom or be it from something that was intrusive. Then you can help the child by acknowledging their self-stimulation and maybe doing it together. The child learns that by doing it together and you are with him in the stress and can

*So if we can understand that kind of behavior as an effort for them to regulate their stress, then we can come together with them and not leave them alone with their behavior. We can use the behavior as a serve and then return. We can help regulate the stress and they can find ways to ask you for resolve.*

work to solve the stress together.

An example...a 12 years old student, when she experienced a stress, was biting and such. But her behavior has changed with intervention; it's now really rocking, really heavy rocking. Now she walks up to the teacher or the aide and she turns around (asking them to rock). They rock with her, you know, in the right way. And now she is not biting.

So if we can understand that kind of behavior as an effort for them to regulate their stress, then we can come together with them and not leave them alone with their behavior. We can use the behavior as a serve and then return. We can help regulate the stress and they can find ways to ask you for resolve.

### Robbie Blaha

This gives enormous power to the child when you let them know that you're aware they've served. Even if your answer is "no, we're in the wrong place" or "no, it's the wrong time" or "there's no way we can go swimming when it's 10:00 at night at home, and there's no pool at home". Letting them know they're being listened to, they're being noticed, even if the answer is "no, I can't provide what I think you're asking for, but I am here for you." Maybe you want to use the diversionary tactics ultimately, but first it's good to let them know because this is all about -- as Bernadette was just saying, it's about relationship building, it's about making those connections and then maintaining those connections.

I think it's too often that children will do something and people will say, "Oh, she's asking for that, but it's the middle of the morning. She's not going to have a bath." But nobody actually let's her know that that's been seen and understood, but it's just not an appropriate time.

With some kind of calendar system you can let them know perhaps when the bath will be coming or when swimming will be coming.

*I always think one of the important strategies to use with a child is teaching the sign for "wait" and helping them to understand that "wait" means "yes", just not right now.*



Figure 14 A dad shares an affectionate interaction with his baby during a break at the Symposium.

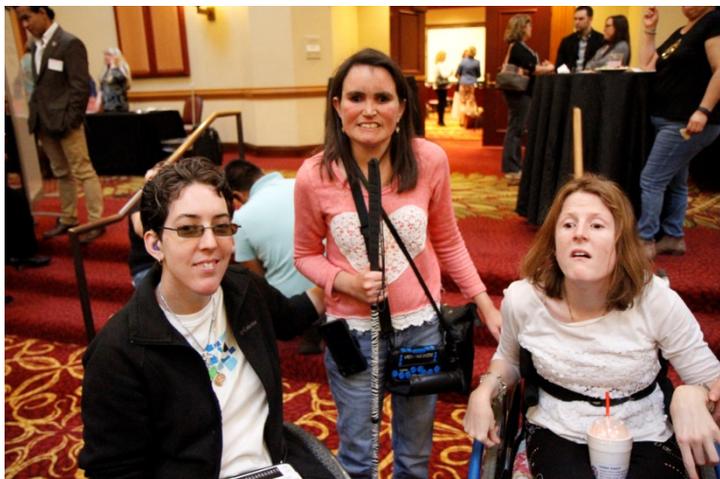
I always think one of the important strategies to use with a child is teaching the sign for "wait" and helping them to understand that "wait" means "yes", just not right now. They need to understand "Wait" means "Yes, I know you absolutely think swimming is wonderful, and we're going to get wet and we're going to get our towel and flip-flops, yes. We're waiting for swimming and we're scheduling it up here like a contract in the future box."

I think that that teaching "wait" means "yes" is a validation --- I got you, I understood you. That's always such a relief when people understand you. It's such a relief when people understand you.

Now about stress...

All the things that we're saying here are because these children are human children. They're not children from Mars. Therefore everything that we're saying here applies to all the children who don't have DeafBlindness, as well. Every single thing we have said here is good for children, whatever sensory capacities, mental health capacities, socio-economic level, whatever situation they live in and body they live in, all of this is good for them.

So take temper tantrums. We live in a society that sees temper tantrums as children behaving badly when in fact it is children coping with disappointment when their brain is not yet fully developed.



Here is an example. Mom, who claims to love them, left them in day care all day long after they already coped with parting from her in the morning and waiting all day long for her to come get them ....oh, and she got there late. So when mom arrives to pick him up, the child serves up his best smile to let her know how well he has cope. But mom doesn't return his serve because she is on her mobile phone trying to tell daddy that they're going to be late. But the child has waited all day long to see her and the child codes that as a response. It's not a non-response, but it's a response of non-acknowledgment.

I'm not trying to make you feel guilty. I'm trying to make you laugh. But it is important to try to understand that children's brains work like that so

Figure 15 Three young women with DeafBlindness visit with each other during a break.

we can get curious and think at a deeper level.

Now after all of that, mom puts the child in the car seat in the back away from her and drives to the supermarket. The child has coped all day with all these very difficult things, and just wants this chocolate candy that was put at his level by the supermarket manager.

Mom tells him "no".

Now the child feels betrayed, bereaved, and disappointed. Annd guess what? He doesn't have physiological system and a prefrontal cortex that allows him to cope with one more thing. Here comes the melt down.

That's kids who aren't necessarily DeafBlind. So if the DeafBlind community can understand this, you can help a whole lot of other communities get it, too. It turns out that these children with DeafBlindness are human children and not Martian children, and we all need these very basic things that we are talking about. Because, to go back to what Joe said first thing this morning, it really is all about connection. And if we get that, a whole lot of problems begin to be more easily solved.

*It turns out that these children with DeafBlindness are human children and not Martian children, and we all need these very basic things that we are talking about. Because, to go back to what Joe said first thing this morning, it really is all about connection. And if we get that, a whole lot of problems begin to be more easily solved.*

## Question

I'm wondering, Robbie, if there are tools or procedures, or advice that you can share with our teachers about how to implement these type of ideas and follow up on their curiosities on these topics?

This is a really cool question and if you will pop up a picture.... A while back, David Brown recommended a curriculum that came from Sense Scotland (where Joe worked). This curriculum is free and downloadable. What I found was this curriculum is based in the theories of Lilli Neilsen and Jan van Dijk It has interaction training for the staff. It also addresses Suzanne's safety issues and her concern for educators who can feel very overwhelmed without a reliable curriculum. It shows these are the steps, these are the strategies, and combinations that you can do for four levels of children with DeafBlindness. It starts with children who are really withdrawn, not interactive and not coming

out of their bodies even to interact with objects, much less people, and moves through four levels of children to those using formal language.

Just google Sense Scotland. Type in DeafBlind. It will come up on the website.

### **Dr. Suzanne Zeedyk**

If we're talking resources I have one.... a book published in 2008 by Jessica Kingsley called *Promoting Social Interaction for Individuals with Communicative Impairments: Making Contact*, It's based entirely on the theory about connection and inter-subjectivity and each of the chapter authors came from a different sector. That's not the right word. So there's one on autism, there's one on dementia, there's one on multiple disabilities, and there's one on DeafBlindness. It puts DeafBlindness in the context of a whole lot of other challenges.

### **Question**

Dr. Cameron, would you like to put a bow on this session?

### **Dr. Judy Cameron**

Well, I certainly would. This has been an incredible panel. I want to thank all of you. This has been a very enlightening afternoon for me.

I want to come back to something that actually each person said in their own way, but I think David started by saying that there were many general principles that I covered today that resonated. It made you realize the children with DeafBlindness are children and not Martians.

The take-home message to me is that you are doing an incredible job and I really am impressed by you. I would like to be able to use some of the examples I heard today.

So some of these wonderful stories and things that you are doing to put into action the principles I talked about, I will be sharing with other audiences. So thank you.

## Resources

Below are some of the resources mentioned during the panel you may want to explore further.

Active Learning Space, [www.activelearningspace.org](http://www.activelearningspace.org)

Nielsen, Lilli, 1993. Early Learning Step-by-Step: Children with vision impairment and multiple disabilities, SIKON 1993.

Nielsen, Lilli, 2003. Are You Blind? Promotion of the development in children who are especially developmentally threatened, SIKON 2003.

Nielsen, Lilli, 2003. Space and Self: Active Learning by means of the Little Room, SIKON, 2003.

Schore, Allan, <http://www.allanschore.com/index.php>

van Dijk, Jan,

Malloy, Peggy, 2007. Harmonious Interactions. Practice Perspectives - Highlighting Information in Deaf-Blindness Number 1 June 2007, National Center on Deafblindness.

Murdock, Heather et al, 2007. A curriculum for multi-sensory impaired children from MSI Unit, Victoria School, Birmingham, UK. <http://www.victoria.bham.sch.uk/pdfs/msi-curriculum.pdf>



# Texas School for the Blind and Visually Impaired Texas DeafBlind Outreach Project



Figure 16 TSBVI Logo



"This project is supported by the U.S. Department of Education, Special Education Programs (OSEP). Opinions expressed here the authors and do not necessarily represent the position of the Department of Education."

Figure 17 IDEAs that Work logo and U.S. Department of Education, Special Education Programs disclaimer.