Intervention Strategies For Children Who are Deaf-Blind and/or have Significant Disabilities

By Sherri Nelson, ND Project Coordinator

North and South Dakota professionals were excited to have Linda Alsop from the University of Utah, spend three days in Fargo (September 28-30, 2011) talking about Deafblindness and the role of the Interventioner in providing effective intervention. One parent and thirty-three professionals from throughout ND, Aberdeen and Sioux Falls, SD, took advantage of the opportunity to learn more about the unique disability of combined vision and hearing loss. Deafblindness creates a disability of access to visual and auditory information about people, things, and events necessary for learning, communication, and overall development. This results in isolation and disconnection from the world, and can prevent equitable access to learning and participation in educational environments.

Children with Deafblindness pose unique challenges to the educational system because they have a wide range of diverse needs that require highly individualized programming. The educational and functional impact of combined losses on each child will vary depending upon the degree and type of vision and hearing losses, the stability of the losses, the age of onset of each loss, and the presence or absence of additional disabilities. The effects of both vision and hearing loss together are not additive, but rather multiplicative. Often children with mild vision and hearing losses can be greatly impacted. Deafblindness can result in significant difficulties in developing educational, vocational, communication, and social skills.

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We discussed the need for effective intervention for children who are Deaf-Blind and how to connect them to the world and provide clear, consistent information needed for learning and development. This connection to the world can be made through an Intervener. By definition, an Intervener is a person who works one-on-one with children who are Deaf-Blind and who has specialized training and skills in Deafblindness. In our state, we often use the term “Paraeducator” in the classroom. The Intervener helps the child gather information, learn concepts and skills, develop communication and language, and establish positive relationships. Thus, the Intervener provides a bridge to the world for the child who is Deaf-Blind and encourages independence rather than dependence.

We focused on the role of the Intervener, which includes: 1) facilitate access to environmental information that is usually gained through vision and/or hearing, but which is unavailable or incomplete to the child who is Deaf-Blind; 2) facilitate the development and/or use of the child’s receptive and expressive communication skills; and 3) maintain a trusting, interactive relationship with the child that promotes social and emotional development and well-being.

“Access” is a key term in the requirements of IDEA, and under IDEA, a Free and Appropriate Public Education (FAPE) is mandated for all children with disabilities. FAPE provides for access to general education, the general curriculum and activities, and specialized educational services in the Least Restrictive Environment (LRE). Access is a critical issue for children who are Deaf-Blind. Many educational environments are restrictive for these children because of the inability to benefit from the flow of visual and auditory information that other children receive automatically and that is necessary for learning and interaction. The Intervener is an individualized support that provides this needed access and facilitates participation and progress in general and special education environments.

The final day of the conference was spent brainstorming, coaching, and mentoring the educational team from Aberdeen, SD. A special THANK YOU goes out to the SD Project Coordinator, Rose Moehring, and Jon Harding, our regional specialist from the National Consortium for Deaf-Blindness, for their assistance and financial support in sponsoring this informative event.
From the workshop
South Dakota Update on Interveners

By Rose Moehring, SD Project Coordinator

South Dakota currently has 2 interveners working directly with 2 Deaf-Blind children, one in a residential school and the other in a public school. Intervener training was obtained through the completion of two courses offered on-line through the Intervener Training Program in Deaf-Blindness available through Utah State University. South Dakota encourages at least one other staff person from the child’s team to take the same coursework to help facilitate understanding of the coursework and the role of the intervener. Thus far, there have been a total of six people who have taken this training in South Dakota. Recently, one of the South Dakota interveners received her intervener credential, which was provided through a newly established process offered through the National Resource Center for Paraprofessionals and Related Service Providers (NRCP). This process involves the intervener completing a portfolio and demonstrating an understanding of what was learned through the coursework and hours spent with the student(s). The required coaching aspect was provided through the South Dakota, Center for Disabilities, Deaf-Blind Project.

Although the need for Intervener training programs has long been recognized in the field of Deaf-blindness, there seemed to be a general lack of common standards, competencies, and practices among these training programs. The National Intervener Credentialing Program, administered through the National Resource Center for Paraprofessionals and Related Service Providers (NRCP), establishes common standards, competencies, and practices in a way that is both rigorous and affordable. Administrators of local and state education agencies can be assured that students who have completed the NRCP-approved training, practicum, and credential process, have met standards that are rigorous and recognized beyond their local school, district, and state. For additional information check out this website: http://intervener.org/
As October dawns, the most popular movie in America is “Dolphins Tale” based on a true story about Winter, a 3-month old bottleneck dolphin who was successfully treated for a life-threatening infection at the Clearwater Florida Marine Aquarium in 2005.

The infection, however, claimed the mammal’s tail. To ensure the dolphin could continue to swim and negotiate its way through the water, the staff at Clearwater created a silicone prosthetic tale for the dolphin. Now it turns out that Winter, who plays herself in the movie, is becoming an inspiration for people – especially children - with disabilities. California news outlets reported Winter’s affect on 11-year-old Megan McKeon of Fresno, who said the dolphin’s success with an artificial tail motivated her to wear her own prosthetic leg, which she had avoided because it was bulky and uncomfortable.

The staff at Clearwater sees this kind of transformation among children with special needs on an almost daily basis. "Children have a unique and strong attraction to Winter," says David Yates, director of the Clearwater Aquarium. The dolphin's strongest devotees include children coping with autism or limb loss caused by disease and accidents. Wounded veterans injured in Iraq and Afghanistan have also found inspiration from Winter. "Thousands of people come through here and see Winter, but many of the kids and adults with disabilities stay in touch with us on a regular basis," says Yates. A lucky few get treated to close encounters with Winter inside her pool, though those visits are restricted and generally brief. But children with disabilities take precedence, says Abby Stone, 31, a senior marine mammal trainer at the aquarium.

"There's a real connection," says Stone. "The kids are appreciative and happy and the time with Winter charges them up to face whatever challenges lie ahead. It's remarkable."

“Do not go where the path may lead, go instead where there is no path and leave a trail.”

Ralph Waldo Emerson
Dear Readers,

I was asked to write an article about a trip my family took last summer. With the assistance of the North Dakota DualSensory Project we attended the 10th International Charge Syndrome conference in Orlando, Florida. I have to confess that the vacation was more about spending time with my family than attending the conference. If you will allow I will share my prospective on Charge Syndrome and how it affects our family.

Our vacation lasted seven days and seven nights. This was the best seven days of my life that I can remember in a long time. Not because I was so moved by the families at the conference but because I was able to engage my family’s attention somewhere other than a sporting event. My children are 18, 15, and almost 13 years old. The time I spent with them meant more to me than any conference. With today’s busy schedules I rarely get to see these kids, not to mention, spend any quality time with them. They are active in 2-3 sports throughout the entire year with very little break in between. Add in school, homework, church, work, and other activities and, oh yah, a social life there is just not any time for family anymore.

I attended the Charge Syndrome conference in Costa Rica, California back in 2007 without my family. I brought my daughter, with Charge, to Chicago, Illinois in 2009. This year I wanted my whole family to experience and learn what other families, with Charge, live with every day. We arrived in Orlando the day of the conference. The older kids kept asking when we were going to see other children with Charge. I said, “You will know when you see them.” These beautiful children all have a special look about them, some more dramatic than others but there are definite similarities. You see, until this year our daughter, Eden, was the only diagnosed case in North Dakota that we knew about. There are no parent groups, family get-togethers, or sharing network, that come to be so helpful for families when affected by a significant disability. Eden doesn’t ask questions about other children with “Charge” because she doesn’t feel different. Charge Syndrome is a combination of characteristics that a group of people share. The letters in “Charge” each stand for a characteristic or a group of characteristics.

It was first observed by doctors in the UK when diagnosing children who were afflicted by a complex set of mental and physical disabilities that were unexplainable by professionals. The “C” stands for Colobomas. This causes a decrease in vision or blindness depending on the severity and location of the Coloboma. The “H” stands for Heart. Some of the children born with Charge can be born with heart defects requiring surgical procedures throughout their life. The “A” stands for Atresia. Many of the children have G tubes or tracheotomies for the majority of their lives or until they can eat and breathe on their own. The “R” stands for Retardation, whether cognitive or growth, it can also be both.
According to the National Deafblind Consortium there are a high percentage of children that have altered curriculum or classroom placement. Also, the children of Charge are typically very short in stature. The “G” stands for Genitals which affects puberty. The “E” stands for hearing. Some of the individuals involved have some kind of hearing loss or balance issue because of the complexity of the inner ear. This is my account and not one of a medical professional. I simplified each characteristic for your benefit. This Syndrome is extremely complex and no 2 children are alike now having said that, the most important characteristic is that these children have an unfailing will to live productive lives.

The Charge Syndrome conference was well received by my husband and two older children, not to mention the 850 people in attendance… the largest conference on record. According to the website, there were 160 individuals with Charge in attendance. There were 40 states and 13 countries represented in Orlando. The conference is a place where everyone shares a commonality and loves to tell their stories with people who are understanding and compassionate. It is where you can go to learn but you never truly leave with the answers. If you can come away with a little more information than you came with, it is worthwhile. After all, you may live a lifetime and never fully understand how, why, or when this happened to your child.

In many ways our family has been blessed by Charge. We have a greater understanding of suffering, acceptance, and faith. Without suffering, we would not learn compassion. Without acceptance, we would dwell on “WHY ME” and not be able to move on. Without faith, we would not be able to accept the path we were given. Eden has Charge Syndrome but it does not define who she is. Her vision and hearing are her major disabilities. Eden has learned to overcome many obstacles to reach her full potential in school and in the world around her. She is turning 13 years old soon. She is an A student, a competitive swimmer, a gifted Cellist but most importantly a good person. Our family is not complete without her. We feel blessed that God would allow us the joy of loving her and teaching her the things she will need to live an independent life. That has been our goal from the beginning. Although Eden is unsure of her desire to leave our home someday, hopefully she will realize her significance in this world and want to spread her wings.

Charge Syndrome is very rare, often going undiagnosed. The parents of children and adults living with Charge Syndrome are even rarer. Where else can a specialized group of people be so many things to so few; a teacher, doctor, coach, friend, therapist, but most importantly, a parent.

Sincerely,

Jody Neva, mom to Eden, Madison, and Ryder
I’m a Charge Mom

To many this means nothing, but to us, it means the world.

In this world, being a charge mom means you hear that first heart beat on a sonogram, you’re told something is not right from the beginning, but that doesn't stop our love from growing, it only makes it stronger.

When you’re a charge mom time is critical at all ends, it doesn't matter if its 2 in the morning, we always have to be on our toes.

We are the moms that have to come to accept more than the usual, and most don't realize what we really do.

Like most moms, there are always sleepless nights, but most of us aren't listening for a babies cry. We’re listening for the silent cry that we have to train ourselves to hear in the middle of the night in the middle of a dream.

As a charge mom, the abnormal is always the normal, most see a trach as scary, we see it as the blessing. To let our child breath another day, many see a syringe or bag filled with milk being given to a two year old through a tube in his stomach. As weird, but to us, this means we’re given the chance to help build, to help build a stronger body to grow and thrive.

Hearing aides tend to send a message as hearing better, to us, hearing aides are the gift of sound and balance

A slanted face from a palsied smile is an odd look to those who cant read behind it. In the eyes of a charge mom that slanted face and crooked smile is full of love and happiness, and it’s the best feeling in the world. Because you know, because of this smile your doing something right. Most moms would look at the amount of our child's medications and think, how does that child even function? Charge moms see it as what keeps our child from seizures that cause brain damage, or what keeps fluid off the heart and kidneys, or what keeps his lungs working, or what keeps his food down and even what helps his little bones to keep growing.

To many when you use a walker your considered with a handicap. To a charge mom, using a walker is a ray of hope to know that one day, Even if it takes years. Our child will work hard everyday to learn to walk. To many when you use a walker your considered with a handicap. To a charge mom, using a walker is a ray of hope to know that one day, Even if it takes years. Our child will work hard everyday to learn to walk.

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Surgeries are a life long process, and most of the time a hospital room is our second home with these accommodations: many needles, incisions, fluids, and pain can be involved, some see this as cruel, charge moms see this as a chance to see there child live another year. Or the chance to live a more normal life. Public isn't always the easiest task to deal with, children point, people stare, voices whisper all because. Maybe they hear the rumbling of the suction machine in a quiet place or the child makes strange noises at certain times, or maybe because we still have a 2 year old in a stroller. Sometimes it can be because he has uncontrollable behavior or maybe he just looks a little different when he smiles, it could be because of the oxygen he’s hooked up to or an apnea monitor so we know he’s still breathing correctly. For reasons unknown this is a routine we are often faced with. But in a charge moms heart, this does not bother us, we only know facts. To us, we are proud of what God has blessed us with.

And are proud of what we've worked so hard to accomplish. So when we see those children pointing, eyes starting, and whispering voices, we just smile and keep walking. As a charge mom I know its not something we wished to struggle with, but its something we were blessed to be chosen though no one said it would be easy. But someone once told me God only chooses those who he knows can take care of something so special, and life as precious as this. So for this reason I’m proud everyday to wake up to unusual banging, I'm proud to be able to hear the only sounds he knows how to make, I'm proud to know that no matter what I do, I will always be loved by someone who knows only love. I'm proud that out of unknown circumstance, I was chosen to have a miracle brought into my life that would not only change me but everyone around me. We were given the strength, courage and motivation. We were given the patience, dedication and heart to do what we do everyday and that’s to love and love unconditionally, to love our miracle and to love who we are.

I'm a charge mom and I wouldn't have it any other way.

By Joy K. Patterson

Dedicated to my beautiful miracle, Bentley Bryson Gerstman

(Permission was granted by Joy to print this poem)
It is time for the annual census to ensure children in North Dakota who have combined hearing and vision losses are identified and registered with the ND Dual Sensory Project. This will guarantee that the families and teams can access our training and services. If you know a child who has a combined vision and hearing loss, including those with processing disorders, please let us know.

Be aware that:

- You can register a child any time during the year on the census. On December 1 of each year, we count how many children are accessing services. This is done in all states. The numbers are then submitted to the National Consortium on DeafBlindness (NCDB), who then submits those numbers to the Federal Government. Since we are funded by the Federal government, we do this to ensure continued funding and services to the children and youth in North Dakota.
- Many of the children with hearing and vision losses have additional disabilities (approximately 90%). These children have complex needs and challenges.
- Sometimes the term “Deaf-Blind” can be misleading. Many of the children who are considered “Deaf-Blind” have low vision and a mild hearing loss. Very few are legally blind and profoundly deaf.

“Life is like riding a bicycle. To keep your balance, you must keep moving”
Albert Einstein
“Preparing Leaders for Today and Tomorrow:
Leadership in the 21st Century”

Everyone will learn new skills, receive invaluable resources, meet families from around the country and return home with new ideas to help them, their child and their community.

Location: Austin, Texas

Parent Leaders are encouraged to apply!

For more details about funding opportunities, please check our web page after Jan. 2012.

For additional information contact Janette Peracchio at (860) 742 8612
Or via email: jbperacchio@gmail.com

“The Flower that blooms in adversity is the rarest and most beautiful of all”

Walt Disney Company
It was Paul Olson who came up with the game called Trek. The game that helps teach directions to the sightless who need to know north, east, south and west. The game has been accepted by the American Printing House for the Blind. It is advertised in its catalog for the current year. It can be viewed online at http://shop.aph.org. He says Treks is designed to be challenging, educational and enjoyable. “Like a good walk outdoors, it is full of variety.” You can change the game to make the play simpler or add rules to make it more complex.” The goal of the game is to be first to move all five of your pieces, called “treksters,” from your home row into the opponent’s home row. After each move, players must announce the direction and number of spaces moved. The game is suitable for ages 8 and older. Olson hopes to see it played in families. It is a game that calls for options and strategic moves. It also calls for good manners. Players are encouraged to say “excuse me” when they penalize another. And they might say they are sorry. The Treks game seems established with its inclusion in the national catalog of the American Printing House for the Blind. Now that it is widely available, Olson said about 350 have been distributed. More games will be made to meet demand. In the process of developing the game, Olson has seen how it helps with basic knowledge of compass directions. The need for making a mental map of the community is basic for the blind, as well as those who have limited sight. The game makes them think and announce the directions they are moving or miss their next turn. For him, it is a way of adding fun to the challenge of helping sight impaired students across the state of North Dakota. He is reaping no financial rewards, but because of the educational value of Treks, it is provided at no cost to eligible students through what are called “Quota Funds.” Olson is feeling the glow of having the game catch on.
Dear Friends,

I am writing you to tell you all about my trip to Florida for the International CHARGE Syndrome Conference. We had a lot of fun, and we are very grateful you helped make our trip a possibility. We left from Minneapolis early in the morning a couple days before the conference so we could enjoy a family vacation. It was me and my Daddy’s very first plane ride, and my Grandma and Grandpa said I did great! The conference was at Rosen Shingle Creek resort in Orlando, Florida. It was beautiful and they had a lot of pools. I loved spending time in the sun at the pool. I splashed around and swam with my Grandpa, Daddy, and my Aunt. First we went to Disney World. There were a lot of people there, and for me, it was a little overwhelming. We saw Cinderella’s castle, a parade, and rode some fun rides. Grandma and my Aunt added some pictures so you can see the fun we had! The next day we went to Sea World. We saw so many sea animals. I got to pet a stingray, feed the dolphins, and at the end we saw the SHAMU ROCKS! Show. They played great music and Shamu did some really neat tricks! After all that fun, we were ready for the conference to begin.

Prior to attending the conference, my family and I had never met anybody else with CHARGE Syndrome. We were excited to meet other kids like me and learn all that we could from them and their families. There we met many families with children with CHARGE, varying in ages and severity. There were adults, teens, kids, and some babies with CHARGE. We even got to meet Eden, another girl from ND with CHARGE. She’s almost a teenager and our families got along very well. My Grandma says it will be great to be able to talk with them as I grow, so they can tell us what worked for Eden. While my family went to the workshops to learn about CHARGE, I went to camp. My camp counselors were very fun. It was at camp that I took my very FIRST STEPS all on my own!! When my Grandma came to pick me up from camp, she saw me walking up and down the hallway all by myself!! She was very impressed. My family says this is particularly special because when I was born the doctors told them they weren’t sure I would ever walk.

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As you can see, this trip to Florida was important to us for many reasons. We had fun adventures, learned a lot, and met some great people! All of this could not have been possible without the help of the ND Dual Sensory Project and the ND Vision Services/ School for the Blind Foundation. Thank you so very much for giving me and my family the opportunity to make these important personal connections and memories to last a lifetime!

Sincerely,

Ryder Schlafman-Hieb and Family
Hands & Voices Will See a Transition in Leadership

The nation’s largest parent-led organization supporting families with children who are deaf or hard of hearing is saying goodbye to its co-founder, Leeanne Seaver. Seaver has resigned as executive director of Hands & Voices so she can “pursue the next adventure” in her life. In a letter to the board of directors, Leeanne wrote “…and now it’s time for me to move on to new things. It’s time for Hands & Voices to have a new executive director, so I resign from this role with the feeling not unlike the one I had when I dropped Dane off at college. It’s undeniably time, but what a bittersweet inevitability and difficult separation it is for me.”

Leeanne and her husband Tom have three children; their oldest, Dane, is profoundly deaf. She has been involved in family support from the time of his identification at 18 months of age. Along with Cheryl Johnson and Janet DesGeorges, Leeanne co-founded Hands & Voices based on the philosophy that whatever makes the communication choice work for the child and his/her family is what makes the choice right. Hands & Voices mission continues to be one of unbiased support to families regardless of how they are communicating with their child with hearing loss.

Seaver will continue to serve on the Hands & Voices board of directors, and will continue as a featured speaker, and will work on special projects for H&V. Her column, “In a Perfect World” will remain a regular feature of The Hands & Voices Communicator. For more information on her, see: http://www.handsandvoices.org/services/sp_bureau/bios.htm

Cheryl Johnson, President of the Board of Directors, and Janet DesGeorges, newly appointed Executive Director, will oversee the transition process of this non-profit organization that has over 40 chapters (including new “start-up” groups and fully approved H&V chapters). For more information on Hands & Voices, please visit www.handsandvoices.org
PATHFINDERS SPONSORS SPEAKERS FROM HANDS & VOICES

BY LINDA EHLERS, NDSD Outreach

Executive Director, Janet DesGeorges, and Leeanne Seaver, former Executive Director of Hands & Voices, will be presenting at the 2012 Parent Involvement and Technical Assistance Conference to be held in Fargo, April 26, 27, and 28th at the Doublewood Inn in Fargo.

Each will be giving two presentations. The Director will be speaking on, “Keeping It Real: Parents and Professionals as Allies.” This will focus on the positive partnerships that can exist between parents and educators in school based settings. Getting “Beyond the IEP” to a meaningful, equality based relationship to enhance student outcomes will be explored. Successful teaming concepts and strategies will be discussed, including IDEA requirements for parent participation and how to engage “challenging and/or under involved” families.

Ms. DesGeorges will also be doing a breakout session entitled, “Educational Excellence: What Do We Need to Ensure Success.” There is a huge diversity of educational needs among students who are deaf/hard of hearing. She will discuss what is the ‘thing’ that leads to success. Unique considerations for students will be addressed, including educational placement, modality/language needs and proficiency of staff. This session will explore the unique characteristics of supporting children who are deaf/hard of hearing, while examining the core components that lead to success for ALL children.

DesGeorges is co-founder and part of the national/international staff at Hands & Voices, serving as the Executive Director. She is from Boulder, Colorado and has three children, including one daughter who is hard of hearing. Ms. DesGeorges has presented to groups nationwide and internationally about the experiences of families as they journey through life with a child with a hearing loss.

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Leeanne Seaver will present at one of the breakout sessions called, “Education Law and Advocacy for Students Who are Deaf or Hard of Hearing.” This session is designed to help families understand the law, and what their role in the educational process is. It will start with a broad overview of the legal mandates on education and related services for students with qualified hearing loss or deafness including eligibility, IEPs, and procedural safeguards. This sets the stage to look at effective advocacy strategies to ensure that all our efforts to deliver a free and appropriate education to the student actually succeed in helping this student reach his/her highest potential.

Ms. Seaver will also be doing a closing keynote, discussing, “Beginning with the End in Mind: Parent Reflections on What They Wish They Knew from the Very Start.” Parents are the “expert” when it comes to their own children, but becoming fully qualified for that job title is very much a process. Parents learn a lot along the way and when they share from their experiences with one another, there is a lot said about “been there...tried that.” either for good or bad or in-between. From a survey of families with children who have a disability, the most common answers to the question, “What do you know now that you wish you knew from the very start” comprise the material covered in this keynote. Come prepared to be inspired about the journey, and consider sharing your thoughts on beginning with the end in mind.

Ms. Seaver is from Carthage, Illinois and is a mother of three children including her oldest son who is deaf. She is on the board of directors for Hands & Voices, and is a founding member and the former Executive Director of this organization. Ms. Seaver recently completed a sabbatical in New Zealand where she developed a public relations and communications campaign for the Kelston Deaf Education Centre.

For more information about the workshop go to info@pathfinder-nd.org or call 1.800.245.5840
There’s An App For That!!

“The Technology is brilliant, but the magic is in the teaching.” Phyllis Brodsky

Just like any other learning medium, before using an iPad with your child or student, you must first know the child’s vision and hearing, their level of foundational information, what additional supports are needed. Apps should be chosen based on the desired outcome. Think about what skills you are trying to teach, think about accessibility – can the child see it, hear it? What additional learning supports need to be in place to make this understandable. As with all aspects of teaching a child (either at school or in the home) you must first ask why. What is the purpose of this activity? Is this to assist in communication, for helping the child in concept development, to use in social interactions, to increase independence, or to promote more positive behaviors. There are many apps that can be used in each of these areas. Let’s separate them out!

**Communication:** Answers Yes No, First Then Visual Schedule, Proloquo2go, Tap To Talk

**Concept Development:** Uzu, Cosmic Top, Pocket Pond, Vocal Zoo, Peekaboo Barn

**Social Interactions:** Fruit Ninja, 10 Pin Shuffle, 2 Player Xylophone, 1 on 1 Hockey, Align Four, Tic-tac-toe
  - **Literacy:** Pop Out! The Tale of Peter Rabbit, Bob Books #1, Alphabet World, Letter Tracer Preschool Letters, Flying Word
  - **Math:** Math Ninja, Math Bingo, Baseball 1 – 6 Facts
  - **Independence:** LookTel Money Reader
  - **Behavior:** That’s How I Feel, iReward,
  - **Other Uses:** Fluidity turns your iPad into a Light box!

A simple but powerful app, That’s How I Feel, uses brightly colored and easy to understand illustrations to help children express their feelings. The app is easy to use. Designed with a traffic light in mind, the app uses three primary colors to express different emotions. The app contains children’s most powerful feelings. Simple voice recordings convey appropriate intonation for each feeling on That’s How I Feel.

For more on iPads go to:
  - http://a4cwsn.com/
  - http://sites.google.com/site/digitalstorytellingwiththeipad/apps-for-digital-storytelling
  - http://www.babieswithipads.blogspot.com/
  - http://ipadacademy.com/
  - http://ipodsibilities.com/iPodsibilities/Home.html

* Taken from the West Virginia SenseAbilities newsletter, Winter 2012, pg. 8
We wanted to update you on the plans for the National Consortium for Deaf-Blindness (NCDB) for 2012. As most of you know, NCDB was awarded two additional years of funding that, while building on work done over the past five years, includes **OSEP directed priorities** that refocus some of what we will do.

All of our work in this next funding cycle will target activities designed to **increase collaboration** among state projects and with key partners at local, state and national levels. We will work to develop new infrastructures for the delivery of technical assistance that serve as models for future applications and strengthen our capacities to work together, thus building the capacity of the national Deaf-Blind Project network.

**NCDB 2.0**
What’s in a name? As we begin our new work, it’s important for all of our partners to understand what NCDB is funded to accomplish. Parts of our work will look familiar while other parts will be “new.” We are going to use the acronym **NCDB 2.0** to better illustrate the point that while we are still NCDB and honored to continue as the national center on deaf-blindness, we will also be engaging in new work that will have us operate a little differently.

**Initiatives**
Some of our work over the coming two years will look familiar (including the Deaf-Blind Child Count, and the NCDB website and other information services), while other parts will be “new.” The new work will initially target our technical assistance and dissemination efforts through four initiatives. Each initiative is designed to address a specific area of content and, while work in each initiative looks different, we believe that the overall effort will create great opportunities for coordinating technical assistance.

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**Early Identification**
The Early Identification Initiative will work to strengthen the network’s efforts to identify infants and toddlers with combined vision and hearing loss. We will be working with state projects to collect, organize and make available tools and resources. We are completing a model framework that can be used in identification efforts, and plan to connect those states that share an interest in this area through collaboration and web-based dialogue.

**Family Engagement**
The Family Engagement initiative will use a systemic approach to build relationships and collaborative partnerships with and among family members of individuals who are deaf-blind at national, state and local levels. We will also work with states to cultivate and increase the number of parent advocates and youth leaders. Partners include the Parent Training and Information Centers (PTI’s), NFADB, CHARGE and NAPVI.

**Interveners**
NCDB has been directed by OSEP to provide them with recommendations for continuing and future services related to the provision of interveners for children with deaf-blindness. The deadline for NCDB to submit the recommendations to OSEP is May 30, 2012. We have identified a two step process to get the work off the ground. The first step is to identify and report detailed information about the current status of intervener services and practices in the U.S. Step two will be to craft recommendations for future services based on analysis of this information.

**Technology Solutions**
NCDB 2.0 is committed to integrating new and emerging technologies across all project activities. Within TA technology can be used to build relationships, promote effective teaching strategies, improve team communication, and measure changes in both child and service provider behaviors. We will use one model that has shown promise (the Distance Mentorship Project) as a springboard for further replication and innovation. At the same time, we will examine and promote the following technology categories as vehicles to provide TA remotely: video capture, wikis, and web conferencing.
Support for *Language is the Key* -- Free, reproducible language and early literacy activities.

The "On the Go" materials include 14 activities designed to be used outside the home: in the car, while walking, during bus rides, etc. The activities encourage early language and literacy development from birth through preschool. They are appropriate for children with disabilities as well as children who are developing typically.

The materials are designed to encourage parents to interact with their children while they are "On the Go" to facilitate language, early literacy, and positive parent-child interactions. The 14 activities are accompanied by hints for each of the activities about how to modify them to meet the specific developmental needs of the child. Each activity fits on a half-sheet of paper, so it can be easily provided to parents as a take-home.

Developed by Angela Notari-Syverson, Ph.D. and Judith Challoner.
The authors allow the materials to be reproduced and distributed as long as they are not sold.

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Training Opportunities
Knowledge is Most Powerful When it is Shared

CEC’s 2012 Convention & Expo is scheduled for

April 11-14, 2012 in Denver Co.

CEC Convention is a unique opportunity to learn about proven instructional strategies, converse with internationally recognized speakers, and renew your professional enthusiasm. Hundreds of sessions, posters, and roundtables are included.

CEC’s Constituent Services Center
(888)CEC-SPED
TTY:(866)915-5000
Fax:(703)264-9464

Please join us at the 2012 Parent Involvement Conference. This year’s conference will take place at the Doublewood Inn, in Fargo, ND on April 26th, 27th, & 28th (until noon). The conference is jointly hosted by the Pathfinder Parent Center, the Department of Public Instruction, the Department of Human Services - Part C and the Anne Carlsen Center. Parents, educators, social workers, & therapists are all invited. The Anne Carlsen Center is hosting several technology speakers and keynotes. Email dpage@srt.com and we will send you a link when the registration is ready. Stipends will be available for parents living outside of the Fargo area through a grant from the ND State Council on DD. Details will be available when registration opens. If you would like to be considered as a presenter for the conference, contact cath-yh@pathfinder-nd.org or call 1.800.245.5840

July 13-15, 2012 NFADB 2012 Symposium in Austin Texas

“Preparing Leaders for Today and Tomorrow: Leadership in the 21st Century

Everyone will learn new skills, receive invaluable resources, meet families from around the country, and return home with new ideas to help them, their child, and their community. For more information contact Janette Peracchio at (860) 742-8612 or email: jperacchio@gmail.com

Hands and Voices of North Dakota:

Hands & Voices is a non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them. We are a parent-driven, parent/professional collaborative group that is unbiased towards communication modes and methods. Our diverse membership includes those who are deaf, hard of hearing, and hearing impaired and their families who communicate orally, with signs, cue, and/or combined methods. We exist to help our children reach their highest potential. PO BOX 5734, Fargo, ND 58105 or call 701-484-1605 or email at handsandvoicesnd@midco.net
FYI: We’re going GREEN!

North Dakota Dual Sensory Project is in the process of sending a majority of our newsletters electronically. This will save the project time and money and thousands of trees! If you would like to receive the Informer by e-mail, please fill out the form on the last page and mail/e-mail it to Shelly Laverdure @ ND School for the Deaf/Resource Center for Deaf and Hard of Hearing 1401 College Drive N Devils Lake, ND 58301 or shelly.laverdure@sendit.nodak.edu

Thanks for your help!

A Special Note to Families: PROJECT CARSON

Dealing with the diagnosis of your child can be very stressful and heartbreaking. In dealing with our own personal experience, we decided to help make a change. Our goal with Project Carson is to offer families, the one-to-one help, resources and support you need during this challenging time in your lives.

WE ARE HERE TO HELP!

Carson’s Mommy & Daddy--Cassie and Matt

Project Carson is a new project which offers support to new parents who receive a prenatal or at birth diagnosis. Project Carson is sponsored by Designer Genes of Bismarck, Pathfinder Parent Center, and Family Voices of North Dakota. Project Carson offers support through a partnership of professionals, organizations, and parents who have personal experience in receiving a prenatal or at birth diagnosis. Project Carson's goal is to assure that families receiving a diagnosis, whether it be before or after birth, have access to a support network of parents and organizations that understand the emotions, joys, and challenges that come with the word "diagnosis." As a parent-to-parent support program, Project Carson provides emotional and informational support to families of children who have unique needs at birth.

How do I contact Project Carson?? Once a referral is made to the Project Carson team by calling 1-888-522-9654 or emailing Family Voices of ND (fvnd@drtel.net), you will receive a call from a representative of Project Carson. The person contacting you can answer questions and provide information to help you better navigate this sometimes confusing time, making sure your family has the support it needs to walk down this unexpected path.
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