

North Dakota
Dual Sensory Project

D - B I N F O R M E R
F A L L 2 0 1 3

WWW.ND.GOV/DEAFBLIND/ 1-701-239-7376



Dear North Dakota Deaf-Blind project,

My name is Ryder Schlafman-Hieb, and I am writing to tell you about the CHARGE syndrome conference my family and I attended this summer.

The International CHARGE Syndrome conference was held in Scottsdale, Arizona in July 2013. For those of you who aren't sure what CHARGE Syndrome is, I'll give you a crash course. CHARGE syndrome is a pattern of birth defects including extensive medical and physical difficulties that differ in each child. I was born 6 weeks early and I was diagnosed with CHARGE. I had a number of issues upon my birth, including breathing and feeding difficulties. I had emergency surgery right away and had to use a feeding tube for the first couple years of my life. This is common in kids with CHARGE. I am also legally deaf and blind. I wear hearing aids and glasses that help me greatly. CHARGE kids are often both deaf and blind. While I may have all those issues, I consider myself lucky because I have no heart problems (another common CHARGE symptom), and I am able to see and hear with my aids and glasses. Now that you know a little about CHARGE, onto the fun part!



A division of the North Dakota
Department of Public Instruction
Kirsten Baesler
State Superintendent



It was my first time to Arizona and boy, was it hot out!! To get to Arizona we had to ride an airplane up in the sky. I wasn't nervous because I rode in an airplane to Orlando for the last conference. We arrived in Scottsdale pretty late, but I was so excited because the next day we were going to the zoo! We went to the Phoenix Zoo and saw lots of animals. We even saw my favorite animals, an elephant and some giraffes!



After the zoo we went to the Butterfly Wonderland. That was so neat! We went into a huge room with butterflies flying all around! Some even landed on me! Next, it was time for the opening of the conference. They had dinner for us and a social for people to meet and catch up. I am a social butterfly, so I made some new friends! Seth, a boy from Ohio with CHARGE and I became fast friends. We played with my giraffe I got at the zoo. I was also very excited to see my old friends Henry and Stephanie! I met them at the conference in Orlando, and we picked up right where we left off! I gave them big hugs!

The next few days were conference days, so while my grandparents and aunt were down to business in the workshops, I got to go to camp! In camp we did arts and crafts, played with toys, and we even saw some traditional Native American dancers perform! I thought that was so neat! My friends Seth and Stephanie came to camp too!

My Grandma and Papa wanted me to tell you how great they thought the conference was too. They really learned a lot from listening to the other family members. It's really important to hear about the experiences of others because CHARGE is quite rare, so often my family isn't sure how to navigate the doctor's office or the school system to be sure that I get the best care. My grandma said she talked to other families about some challenges they've faced with school and education plans; and now she feels more prepared for my upcoming school years.

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My aunt said she listened to a number of behavior workshops. That's really important too, because sometimes in an effort to communicate how CHARGE kids are feeling, like pain and over-stimulation, they can do a number of odd behaviors. The workshops taught her how we can work together to figure out what I'm trying to communicate through my behavior.

In addition to the workshops, we spent a lot of time with other families with kids like me. I got to hang out with my friends and meet people from all over the world! We also made sure to spend as much time as we could in the pool! I love to swim! Unfortunately, our time in Arizona was limited and the conference was over before we knew it.

After the closing ceremonies we had one more afternoon before our flight to North Dakota the next morning. We decided to go with some friends to the Phoenix Children's Museum. There was so much to do! I got to play in their grocery store, pretend I was a pizza chef and make a pizza for my Papa; and I got to run through the noodle forest!

We sure had a lot of fun in Arizona!



All these fun memories and experiences wouldn't have been possible without your support. We are so grateful to the ND Deaf-Blind Project for your help with our registration and hotel fees. Thank you, Thank you, Thank you!!!!

Enclosed are some pictures of our fun times in Arizona. Thank you so much for helping us to be a part of the conference.

Sincerely,
Ryder Schlafman-Hieb



“EXPERIENCE THE WONDER”

11th International CHARGE Syndrome Conference

By Sherri Nelson, Project Coordinator

The 2013 Conference held in Scottsdale, AZ, July 25-28, was a huge success! There were over 925 attendees from 10 countries and 42 states, including 180 individuals with CHARGE. It was the best-attended conference and simply the BEST!

The Foundation is already looking forward to the 12th International Conference to be held July 30-August 2, 2015 at the Renaissance Schaumburg Convention Center just outside of Chicago, IL.

Sheri Stanger, Director of Outreach for the CHARGE Foundation, has been busy assisting new families and long-term members with questions, membership information, etc. She is also active with the Deaf-Blind projects across the nation. If you need to contact her, send her an email at sherri@chargesyndrome.org.

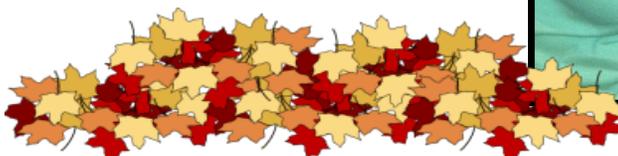
For the first time in the 21-year history, the CHARGE Foundation has been able to fund significant research this past year. While they were pleased to provide pilot grants, they know there is more to do in all areas of research, education, and outreach for CHARGE Syndrome.

The Professional Day started Thursday, July 25, 2013. Topics included: “Functions for CHD7, Phenotypes in a Drosophila model of CHARGE, Epigenetic Regulation of Neural Crest Cell Development, CHD7 in Neural Crest-mediated Cardiac Development, Role of CHD7 in Development of Midbrain and Hindbrain, and Identification of Molecular Markers to Predict Auditory Neuron Function for CHARGE Syndrome, the Cerebral Cortex in CHARGE, Gene Therapy , How to Identify Pain, the Clinical Overlap Between 22q11.2 Deletion Syndrome and CHARGE Syndrome. Poster sessions were provided on numerous topics throughout the conference including: CHD7, Behavior as Self-Regulatory adaptation, Self-regulatory strategies, Getting ready to talk to a psychiatrist, Fathers in CHARGE, Self-regulation of Emotion, Understanding Behaviors, and Headaches in CHARGE.

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Sheri Stanger & Mo McGowan (HKNC)



Opening remarks were made by David Wolfe, President and Fundraising Chair for the CHARGE Foundation. General and Breakout sessions were held Friday, Saturday, and till noon on Sunday. I attended some great one hour sessions on diagnosis of CHARGE, Sensory deficits with CHARGE, Language and Communication, Breathing and Anesthesia, CHARGE and Genetics, Neurology and CHARGE, Behavior and Psychiatry, and Making Sense of Behavior.

Kathy Buckley a five-time American Comedy Award Nominee as Best Stand-up Female Comedienne and winner of countless awards for her work as an actress, writer, producer, humanitarian, and motivational speaker inspired the families and professionals at the conference. She spoke about her experiences of being Deaf and her work with children charities such as NO LIMITS, a non-profit organization for children who are Deaf and Hard of Hearing.

Numerous sponsors and exhibitors such as Oticon Medical, Seedlings, American Printing House for the Blind, Canadian Deaf-Blind Association, Center for AAC and Autism, Cochlear Americas, Discovery Toys, DynaVox Mayer-Johnson, Enhanced Vision, Freedom Concepts, GeneDx, Helen Keller National Center, iCanConnect, NAPVI/Jewish Guild Healthcare, Perkins, National Family Association for Deaf-Blind, Pro-Ed, Sorenson Communication, Sweet Spirit Productions, Lily Voelkel Foundation, The Joys of Jennifer, Catherine Lacey Photography, and other AZ agencies were available for families and professionals. Special events included the Thursday night reception, Friday night dinner and Conference Idol performance, and Saturday's CHARGE-A-Palooza festivities!

Two families from North Dakota were sponsored by funds from the ND Dual Sensory Project and the ND School for the Blind Foundation to attend this wonderful conference. Camp Discovery and Camp Explorer are arranged for children who have CHARGE and their siblings during the conference so parents can attend sessions. This is a huge endeavor due to all the complicating medical conditions that many of the children who have CHARGE are faced with such as feeding tubes, ventilators, suctioning machines, medicinal needs, etc. Just seeing this in action left me in AWE!!! I wanted to mention the Conference Planning Team—Lisa Weir, Brownie Shott, David Wolfe, Jody Wolfe, Susan Wolfe, Neal and Sheri Stanger. Without these parents, this would not be possible!!



The Hieb Family



Alex & Mom



Friends from Charge Family



Kids at Camp



Student Panel

2013 OSEP Project Directors' Conference

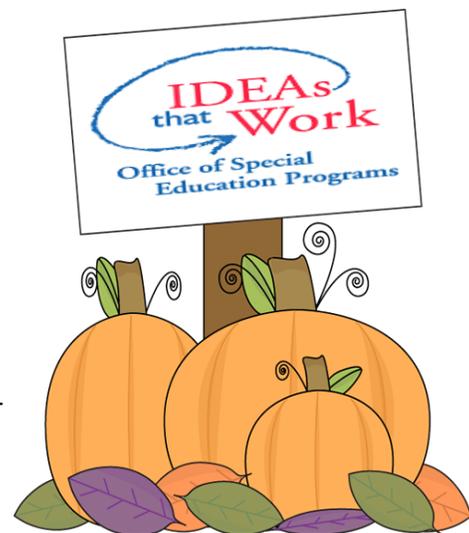
Washington DC, July 15-17, 2013

By Sherri Nelson, Project Coordinator

The Office of Special Education Programs (OSEP) held their annual conference in Washington DC , July 15-17, 2013. Larry Wexler, Director of Research to Practice at OSEP, talked about the fact that the US ranks 12th in the number of college graduates. In 2020, we want to lead the nation in college attainment. We need to improve outcomes for all students. The keynote speaker, Vanessa Siddle Walker from Emory University presented findings from a one-year pilot collaboration, Teaching in the Urban South (TITUS) to argue that the professional educators of a bygone era have left a useful legacy for a new generation of scholars seeking more successful engagement with schools and communities. Other topics of interest at the conference included: Preparing Students with Disabilities for College, and Careers in the 21st Century, Investing in High-Quality Early Learning Opportunities for All Children, Our Choices, Our Voices: Student Perspectives on Transition, College and Disability, Ensuring Access to Common Core State Standards (CCSS) for All Students with Disabilities, Online Learning and Students with Disabilities, An Overview of OSEP's Results Driven Accountability, Designing Validity into the Dynamic Learning Maps, Using PowerUP, Using Evidence-Based Strategies and TA to Improve Identification of Infants and Toddlers with Combined Vision and Hearing Loss, and Models of Research Collaboration with Part C Providers and Parent to Implement Naturalistic Communication Intervention with Fidelity.

I particularly enjoyed presenter, Ann Turnbull from the University of Kansas. She spoke on the family and community partnerships that led to an "enviable life" for her son, Jay (1967 - 2009) who experienced multiple disabilities. She shared ways educators can foster family and community partnerships during school years than will enable individuals with disabilities and their families to experience no double standard in living their lives inclusively over their entire lifespan. The importance of meaningful partnerships must include respect, commitment, trust, and high expectations! She emphasized the importance of Person Centered Planning and the need to create connections with home, neighbors, jobs, community, school, and friends, share expectations, and solve problems. She reminded us to never squelch the individual's SPIRIT!

In addition, there were Program Officer meetings for all Deaf-Blind Projects to meet with their OSEP Project Officer, the Technical Assistance & Dissemination (TA & D) Program meeting, and poster sessions on over 50 topics relating to Special Education.



“A mistake is a crash-course in learning.”

Building for Tomorrow, Family Weekend 2013

Linda Kraft, Outreach Teacher NDVS/SB

The 2013 Family Weekend, entitled “Building for Tomorrow”, took place in Fargo, ND on April 5-6, 2013. It was a spectacular event highlighted by an awards banquet attended by over one hundred friends and family, to honor the art winners of the biennial greeting card contest. Family Weekend was sponsored by the North Dakota School for the Blind Foundation, North Dakota Dual Sensory Project and ND Vision Services/School for the Blind. The primary goal of this yearly project is to provide families of children who are visually impaired or blind an opportunity to share experiences of parenting a child with a visual impairment and to provide learning opportunities on issues related to blindness.

A favorite speaker at this year’s event was Keith Bundy from Madison, South Dakota. Keith, who was born blind, is a pastor and assistant dean of student development at Dakota State University in Madison. He is a very dynamic speaker, using humor and personal stories to help parents understand the importance of having expectations for their children, in order to encourage them to set and achieve goals. Keith told of how he learned to tie his shoes on his first date with the woman who would later become his wife, sharing that although his parents had high educational expectations for him, those expectations did not always carry over into expectations at home.

The North Dakota Dual Sensory Project supported bringing Tanya Frazier, a Fargo native and nationally known presenter on the Nurtured Heart Approach. The philosophy of the Nurtured Heart Approach is to “ignite greatness” in all children by neutralizing negative behavior while energizing positive behavior. Not only did Tanya give parents tips for home use, she also spent time with our students and children “igniting their greatness”!

One activity that was a highlight for young conference attendees was a visit from some of the animals from the Red River Zoo. Everyone had the opportunity to get “up close and personal” with a variety of small animals, including a snake and a rabbit. Our young conference attendees also enjoyed constructing sock puppets and then using them to present a puppet show to their friends.

An event of this magnitude could not take place without a host of volunteers. Thank you to the ND School for the Blind Foundation, The ND Dual Sensory Project, and ND Vision Services/School for the Blind for supporting this project financially. Thanks to the staff from NDVS/School for the Blind, The Delta Gamma Sorority from the University of North Dakota and to Nick and Jake Anderson for supervising activities for our young learners. A very special thank you goes out to First Lutheran Church of Fargo for allowing this event to be held in their beautiful facility and to Julie Anderson for her help in coordinating the weekend.

Family Weekend 2014 will be held at the Comfort Inn in Bismarck, ND on April 4-5. Watch for more details to come!



West Regional Early Intervention

Cindy Williams, Outreach Vision Teacher NDVS/SB

This past summer, I had the wonderful opportunity to attend the Western Regional Early Intervention Conference on Sensory Disabilities through funding provided by the ND Dual Sensory Project. The conference took place June 19 – 21st in beautiful Jackson Hole, WY and the theme was “Assessment and Strategies for Infants, Toddlers, Students and Adults with Sensory Loss.”

I began the conference by attending a session presented by the legendary Dr. Jan Van Dijk and colleague Dr. Cathy Nelson of the University of Utah on “New Research on Brain Development and Child Guided Strategies: The Van Dijk Approach to Assessment.” As I sat in the audience listening to his stories and watching video clips of Van Dijk working with children, I was in awe by being able to learn from him!

One of the keynote speakers was Millie Smith, who has worked at the Texas School for the Blind and Visually Impaired, co-authored a book on visual and multiple impairments, and after retiring is working as a consultant for the American Printing House for the Blind developing products.

The conference provided the opportunity to attend various breakout sessions. The variety of sessions I attended included instructional strategies for dual sensory loss/multiple impairments; instruction on Millie Smith’s APH product, SAM: Symbols and Meaning; O & M for birth to 3; yoga for students with visual impairments; and the expanded core curriculum for students with multiple impairments.

Besides the formal learning opportunities that were available, attending the conference also provided the opportunity to network with other professionals in the field. Working in a low incidence disability field, I feel this is especially important, as we are able to discuss our work and intervention strategies with one another and learn from each other.

Attending the Western Regional Early Intervention Conference was a wonderful educational experience for me and I was thankful for being able to attend a conference specific to sensory loss and intervention. I am grateful to the ND Dual Sensory Project for providing me this opportunity, which has and will continue to have a positive impact on myself, and the individuals and families I serve.

PEPNET 2

“Building State Capacity to Address Critical Issues in Deaf Education: Transition from Secondary Education to Postsecondary Options” Chicago, IL November 6-8, 2013

PEPNET 2 is supported by the Research to Practice Division, Office of Special Education Programs. Their mission is to improve postsecondary outcomes for individuals who are deaf and hard of hearing, including those with co-occurring disabilities. Pn2 provides resources to individuals who are deaf and hard of hearing (D/HH) and the educators, schools, and agencies who work with them. The goal is to increase the educational, career, and lifetime choices available to individuals who are D/HH. They also offer trainings, presentations, topical summits and conferences that connect individuals, agencies and institutions enhancing their capacity-building efforts.

During this Summit, critical issues in deaf education that addressed positive student outcomes, graduation, and transition to postsecondary education and training were discussed with staff from 28 states. The goal of this Summit was to begin the process of identifying needs within each state and determining ways to affect change in preparation for future Summit activities. Our focus was three-fold: 1) Reduce Barriers, 2) Build Capacity, and 3) Effect Change.

A multidisciplinary team including a parent, outreach specialists, teachers of the deaf, and a postsecondary disability services coordinator attended the Summit in Chicago on behalf of our state of North Dakota. The following activities took place at the Summit: the teams obtained new and current information regarding transition issues and options for D/HH, each state identified strengths and areas to change or improve regarding transition, an action plan was developed by the teams to work on when they returned home, and identify additional stakeholders that would be needed in this statewide effort.

Marcia Kolvitz from Pepnet worked with all the teams to organize and coordinate efforts to bring all individuals together in Chicago. There were topical presentations, small and large group discussions, and state team planning activities for the 2 ½ days. It was clear for North Dakota that we needed more data regarding transition of our D/HH youth. It was determined that the team’s first action step would be to send out a survey to determine a baseline of statewide support services. Information obtained will be used for improving educational programming, employment opportunities, services, and outcomes for North Dakotans who are D/HH, including those with co-occurring disabilities. Our goal with this step is to develop collaborative relationships state-wide to better serve North Dakotans with hearing loss.

The next Summit meeting will be held in Denver, Colorado January 27-29, 2013, to gather all teams from the 50 states to share information. For further information on PEPNET go to www.pepnet.org



PEPNET Team for North Dakota---*Pam Smith* - Adult Outreach Services for ND School for the Deaf/Resource Center for Deaf and Hard of Hearing (NDSR/CDHH), *Kristen Vetter* – NDSR/CDHH, *Bambi Lambert* – Teacher of the Deaf, Fargo Public Schools, *Kathleen Peterson*, UND Disability Services Coordinator, and *Sherri Nelson*- parent and Director of ND Dual Sensory Project.



A day spent without learning something is a day wasted.

Genetic disorder doesn't slow Eden Neva

By: SARAH GEARHART, USA TODAY HIGH SCHOOL SPORTS

West Fargo (N.D.) freshman Eden Neva is adamant that nothing will interfere with her pursuit to qualify for an event at the state swimming meet — not even her lack of sight and hearing.

Neva was born with CHARGE syndrome, a genetic disorder occurring in approximately one in 8,500 people that often results in life-threatening defects, including sight and hearing impairments, along with heart and breathing complications.

She is legally blind, but can see faces up to six feet away. She is able to read words with her left eye from six to 12 inches away.

Neva, who is expected to lose all of her hearing, currently wears a hearing aid in her right ear, unless she's in the pool, where she depends on reading lips during practices and competitions.

She doesn't know where the pool wall is until she arrives at it, and sometimes she doesn't realize when her body is flipped in the water because the semi-circular canals in her ears affect her balance. While the disorder has affected Neva's physical development, it has yet to be a barrier in her swimming endeavors.

"She's completely fearless," West Fargo swim coach Sally Sautner said. "She always asks for feedback and wants to know how she can get better. She's definitely a role model for her attitude and for what she's willing and able to do."

Last year Neva accomplished her goal of swimming the 50-freestyle in less than a minute. Her next challenge is to surpass last season's efforts by qualifying for an event in the state meet.

Not one to back down, Neva finds ways to adapt to whatever challenge presents itself. While standing on the diving block at the start of each race, she watches her neighboring opponent so she knows when to jump into the water.

"In her mind, she wants to do more," Neva's mother, Jody, said. "She takes on everything."

Neva hails from a family of athletes. Her older brother swam for West Fargo, and her older sister is a junior on the team. Neva has been swimming since she was 6 years old.

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“It didn’t look a lot like swimming,” Neva’s mom said of her introduction to the pool. “There was a lot of flopping.”

But after lessons with the West Fargo Flyers swim club, she soon improved. While in middle school, Neva swam with West Fargo High’s varsity swim team, which includes swimmers as young as seventh grade. Neva’s mom admitted she was hesitant to let her get involved at that level.

I didn’t think she was emotionally, physically or mentally prepared,” she said. “But if Eden has high expectations for herself, I have to allow that.”

Neva hopes to one day swim in college, but that’s not her only driving force.

“I know Olympic swimmers get up early and work really hard and swim a lot of hours,” Neva said. “That inspires me.”

Her unrelenting approach carries over to her academics. Most nights after practice Neva, who maintains a 4.0 GPA, spends up to four hours completing homework for German, algebra and geography classes.

In school, Neva also participates in a physical education class, but certain activities are off-limits. She’ll sometimes run on a treadmill during class instead of participating in activities that would leave her vulnerable to a sudden blow to the head, which would cause her to lose all of her vision and hearing.

“She has taught herself how to adapt to every situation,” Neva’s mom said.

Neva will continue to do so as she prepares for her first indoor triathlon on Nov. 10 at Family Wellness in Fargo. She intends to ride a stationary bike along with participating in the swim and run. In the future, Neva would like to complete a triathlon outdoors, so long as her parents can figure out how to haul around Neva’s three-wheeler.

“A lot of kids like Eden are in wheelchairs,” Neva’s mom said. “She wants to be competitive. It’s pretty incredible. She’s definitely a **miracle**.”



Annie's House Welcomes Students from ND Vision Services/School for the Blind

By Paul Olson, NDVS/SB Superintendent

Every Fall ND Vision Services/School for the Blind (NDVS/SB) hosts an event called JAM. This weekend event has been in several locations in the past and this year it was held at the Bottineau Winter Park. The goal of this event is to gather junior and senior high age students with visual impairments and blindness for social, recreational and educational activities. All students in North Dakota attend their local schools and many of these students receive services and support from NDVS/SB. Students receive a variety of outreach services and may attend numerous one-week instructional sessions at NDVS/SB in Grand Forks.

JAM is an example of a program that allows students with visual impairment to socialize and learn together. Outdoor recreational activities are so important and many activities are not available in every student's community. The Turtle Mountains and Lake Metigoshe provided the best possible location for this two day expedition. The students were so fortunate this year to have JAM hosted by Gary Nelson and a number of other local volunteers. Gary made all of the necessary arrangements for hiking, horseback riding, boating and fishing. The weather was perfect and this setting was simply beautiful.

The students stayed at Lake Metigoshe State Park on Friday September 20th where they sat around a campfire, ate smores and got reacquainted with each other. Gary came to visit with the group later in the evening and shared the story of his daughter—Annie. He also shared his hopes for Annie's House. The students all listened carefully and asked Gary questions about his daughter. He explained that building a house in North Dakota was on her bucket list. After she died in the September 11th attack on the World Trade Center, a friend made her wishes known and an organization called New York says Thanks You Foundation, made this dream come true. Now Annie's House is a special place and an invaluable resource in North Dakota.

What made this trip special for our students was the personal touch of the caring volunteers. Gary took great care to understand what our students needed and wanted. The volunteers that brought horses were phenomenal. The students not only rode these gentle animals, they learned about the care required to take care of horses properly. Three pontoons, a fishing boat and several fabulous volunteers were also at our disposal on Saturday afternoon. Every student caught fish and had a great time.

Several instructors from NDVS/SB also attended this event and were available to assist. What was ironic was that all of the volunteers were natural guides when it came to working with our students—we really stood back and let them work with our kids.. As one volunteer coached a student when fishing, he emphasized how the feel of the line was much more important than seeing the rod or line. What was being taught this day was independence! Although someone with a visual impairment may need to do things differently, the goals are the same.

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There are numerous individuals who deserve thanks for making this event happen and we cannot name every one. We would like to thank Special Education Director Mary Stammen for her assistance in making this connection and also Gary Nelson for putting so much time and effort into making this a great experience and a wonderful memory. NDVS/SB will hope to return again in the future and we urge other groups to take advantage of this gem in the hills of Bottineau County.



Annie's House is a state-of-the-art facility that replaced the lodge at Bottineau Winter Park with a new facility designed to accommodate the needs of skiers with both physical and cognitive disabilities from across North Dakota and neighboring Manitoba. Approximately 50% of the public space will support the adaptive skill program and needs of disabled skiers and their families. This will be the first facility in North Dakota focused on empowering disabled skiers and their families to enjoy outdoor sports during the winter while also providing a year-round facility to accommodate other adaptive sports like fishing, canoeing, waterskiing, and horseback riding. Other year round activities planned at the facility include folk festivals, theater productions, hiking, biking, running events, bird watching, and hosting community events and receptions.

A proud resident of Stanley, ND, Ann Nicole Nelson's life was tragically cut short when she perished on September 11, 2001 while working for Cantor Fitzgerald on the 104th floor of the World Trade Center. Annie's spirit of kindness and sense of adventure continues to make impact in the world and is making lasting impact on the citizens of ND and Canada. Annie left behind a "Bucket List" expressing her desire to someday return to ND and build a home. Her dream has come true and will provide hope and enjoyment for special needs children and wounded warriors from across ND and Canada for years to come.

This project is the result of a two-year collaboration between the Bottineau Winter Park, Annie's parents Gary and Jenette Nelson of Stanley, ND, the Bottineau Area Community Foundation and the New York Says Thank You Foundation, the country's leading volunteer service organization focused on the 9/11 Anniversary.

For further information contact Bottineau Area Community Foundation, 519 Main Street, Bottineau, ND 58318 or Bottineau Winter Park, PO Box 168, Bottineau, ND 58318 or visit www.skibwp.com or www.NewYorkSaysThankYou.org



2013 TEXAS SYMPOSIUM ON DEAF/BLINDNESS

FEBRUARY 22-23, 2013 – AUSTIN, TEXAS

By: Lanna Slaby & Linda Kraft, Outreach Teachers NDVS/SB

As I reflect back on my experiences at the Texas Symposium on Deaf/Blindness held in Austin, Texas this past February, I am reminded of so many thoughts and experiences, which were well represented by the conference title, “Hands Matter!” The first thought that comes to mind is a reflection of time spent not at the conference itself, but at the Texas School for the Blind, observing Deanna, their teacher for students who are deaf/blind. If I were to sum up that experience in one word, the word would be “PACE”. Deanna is a master teacher whose calm personality motivates and encourages her students to participate fully in activities designed specifically for them, while allowing the student to set the pace of the activities. “Jill’s” activity for this particular day was to make and sell smores. In my opinion, this seemed like a monumental task for this particular student, but Deanna patiently prodded and encouraged Jill as she proceeded to move through the process, never losing her patience (even though it took three tries to get the chocolate on the graham cracker instead of in Jill’s mouth). Though I do not know sign language, I was excited to have the opportunity to be able to have a conversation with Jill. As Deanna first introduced me, using a name sign we quickly created (the letter “L” for Linda with hands moving down my cheek). Jill immediately began exploring my face (I must admit, this was briefly unnerving). The conversation point for Jill was that like her, I wear hearing aids! After our conversation was over, I purchased my smore and went on my way. What I concluded as I walked away from Jill and her very gifted teacher is while we all have goals for each student we work with for any particular day, just as important as these goals are the incidental learning opportunities that are just as meaningful and relevant in the life of that young learner. Maybe the best way to put it is that old adage “life is a journey, not a destination”.

One session that I found particularly influencing was a panel discussion led by Barbara Miles, author of the book, “Remarkable Conversations”. Barbara is another master of the profession and at the art of tactual conversation. She shared an experience she had with her friend Julia and Julia’s first introduction to pea plants. Julia was 47 years old before she learned about peas coming from a plant and growing in a pod. Two thoughts came to mind during this discussion. The first was a reminder that the learner who is deaf/blind has huge gaps in his or her knowledge base because of the lack of incidental learning opportunities that take place in their lives. We need to be diligent about providing an education that “fills in the gaps” for our young learners. The second point is how respectful Barbara is of her conversation partners; this is demonstrated by the way she touches their hands, never forcing, instead gently guiding. Barbara reminds us that when an individual is blind, their hands become their eyes. We should treat their hands as we would a sighted individual’s eyes. Barbara shared that communicating and exploring through touch is a very deep and reciprocal way to explore, one that needs to be done with mutual respect. **Continued on Page 17**

Another session introduced me to something new called Pro Tactile. Pro Tactile is an approach for providing conversational information to individuals that are deaf/blind. This is done by having an interpreter stand behind the speaker or conversation partner who is deaf/blind and act as their eyes on their audience. For example, if the individual that is deaf/blind tells a joke, the interpreter lets the speaker know the audience's reaction by drawing on the speaker's back. For instance, if there is lots of laughter after hearing the joke, the interpreter might draw a smiley face on the speaker's back. (After all, if you told a joke to a room full of people, wouldn't you want to know how it was received?) Another category of information that might be communicated through Pro-Tactile is called body mapping. The body map provides information on who is in the room, who is speaking, the lay-out of the room and people coming and going, all communicated through diagrams and symbols drawn on the back of the speaker. This helps to improve social interactions for individuals who are deaf/blind, helps them to build emotional connections with their audience and fills in gaps of information.

It is always very inspiring to have the opportunity to observe others who are doing similar work. It helps us to become better at what we do by having the opportunity to pick up new techniques and it serves as verification that many of the things we are doing are correct!



Linda Kraft & Lanna Slaby, Outreach Vision Teachers



Making the Curriculum “Fit” with the IEP

By: Lanna Slaby & Linda Kraft, Outreach Teachers NDVS/SB

It is always a challenge to make the curriculum “fit” for students who have multiple learning challenges. Martha Majors from the Perkins School for the Blind presented on this topic in Sioux Falls, SD last November. Martha is an Assistant Education Director at Perkins and has a number of educational specialties including deafblindness. So how does an IEP team make curriculum “fit?” First the team must ask themselves two very important questions, how does this child learn and how does this child think? These two answers will help a team determine appropriate curriculum. After addressing these two questions, to further improve the learning outcomes for students, teachers need to take a look at the three components of a good curriculum; language and communication, teacher strategies and types of curriculum.

At Perkins, their philosophy is a total communication approach. What is total communication? It can be simple sign language, tactile sign language, speech, gestures, facial expression, body language, objects, pictures, line drawings, print, and Braille. Teams can ask themselves, what can we do to get this student to say more or express themselves. Other components of total communication include the use of calendar systems, choice making, needs boards, and taking the time to teach social communication. One can have a conversation even without language! There are a number of teaching strategies that are effective for students who are young thinkers. These include having a beginning-middle-and end to the activity, choice making, partial or full participation, motivation, following student’s interests, clear expectations, needs board, pause time for response, structure and routine, active vs. passive learning, prompt levels, organizational skills, task analysis, signals: verbal;/auditory/visual and people preferences.

In addition to using the above teaching strategies, other factors present in a good curriculum include fun and age appropriate content. One can modify the curriculum to their developmental level but change up the material to be age appropriate. You might still be teaching the same concepts that were taught at preschool but using age appropriate materials to do so.

Martha has identified five curriculum types of where a student might be placed at in their educational career. These types include: Early Childhood/Preschool (ages 3-6), Early Academics (K-3, ages 6-12), Academics (K-12, all ages), Functional Academics (not reflecting an academic need) and Vocational. Once you have identified the student’s curriculum level, you can make Unit Based Curriculum “fit” the student’s curriculum type using Martha’s template.

Martha has developed a template to assist teachers in planning curriculum to ensure that all concepts are taught within a particular unit. Martha believes that certain concepts need to present in all instruction for that particular unit. These concepts include components of matching and sorting, sequencing, organizing, fine motor activities, classifying, literacy and social or group activities. She also encourages documentation of the expected vocabulary that will be reinforced for each activity. This format enables teachers to tailor their instruction of various concepts to appropriately fit any developmental level.

And finally, how does one align the curriculum to the state standards? It’s important to ask yourself, what is the most important thing for your student. You are writing the goal on the needs of your student, not for the state. For students with visual impairments or deafblindness, it is essential to include the Expanded Core Curriculum into the student’s daily curriculum and goals on the IEP. Martha has created another template to follow to help teachers align the goals on the IEP to the Expanded Core Curriculum. These templates and Martha’s Matrix follow on page 19.



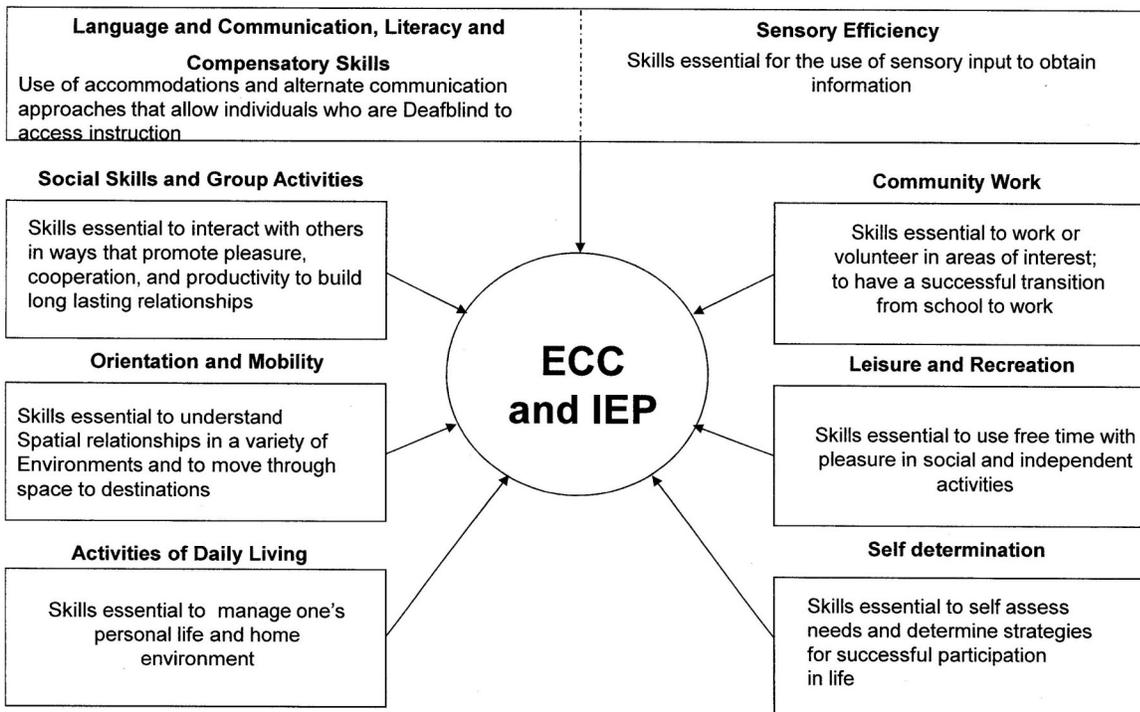
Martha Majors & Lanna Slaby

Martha's Matrix and Concepts
Children with Deafblindness and/or Multiple Disabilities

Content Concepts	Preschool Early Academics 3-10/12 years	Functional Academics 12-16 years	Vocational Functional Academics 16-22 years	Notes Based on age not Developmental level
Calendar Systems	Used across all areas: objects, pictures, symbols	Used across all areas: objects, pictures, symbols	Used across all areas: objects, pictures, symbols	All Students Must have a System
Concepts: Matching, sorting, classifying	Early childhood concepts: Matching, sorting, classifying	Functional Skills of Matching, sorting, classifying	Vocational Skills of Matching, sorting, classifying	Students content can overlap areas
Organizational and Sequencing Skills	Sequencing, work from left to right	Sequencing, work from left to right	Sequencing, work from left to right	Helps for reading/work
Fine Motor Skills	Early childhood skills	Use of two hands together, use of utensils, grasp/release	Use of two hands together, use of utensils, grasp/release	Important for all skills and Use of sign language
Social	1:1 with adult Parallel play with other students	Small group/turn taking Community outings	Small group/turn taking Community outings	Social in all settings: crafts, cooking, play
Helping out	Early childhood helping out	Errands, simple shopping	Daily errands, shopping	Rotate on 4-6 week schedule; small groups; jobs
Group activities	Early childhood play with turn taking	Group games, share toys/materials	Group activities, turn taking sharing	Recreation, cooking, jobs, community
Math	Early concepts	Functional numbers, time, money	Functional numbers, time, money	Use in jobs, cooking, (vocational)
Reading	Early concepts Recognition of objects/pictures	Functional reading, shopping lists, schedule	Functional reading, shopping lists, schedule	Adjust based on cognitive level

Martha M. Majors Deafblind Program Perkins School for the Blind

Functional Academics and Expanded Core Curriculum



Martha M. Majors - Deafblind Program Perkins School for the Blind/Tom Miller

HAPPENINGS

DEAF-BLIND PROJECT DIRECTORS' Meeting, Sunday, July 14, 2013

The day prior to the OSEP Project Directors' Meeting in Washington DC, all Deaf-Blind Project staff gathered to focus on the areas of Intervener Services, Family Engagement, Common Core/Literacy, Transition/Employment, and Early Identification for all students who are Deaf-Blind. Jay Gense, the Director of the National Consortium for Deaf-Blindness gave the introduction and welcome. The keynote presentation "*Moments of Joy: The Past, Present, and FUTURE of Working with Children and Youth with Deaf-Blindness*" by Kathee Scoggin from Washington Sensory Disabilities Services and Robbie Blaha with the Texas Deaf-Blind Project followed. The remainder of the day was spent in Round Table Discussions and Action Planning sessions to look at state needs, contributions to the network, value of the network, and immediate action steps for each state.

Law Enforcement & the Deaf Community

The North Dakota School for the Deaf/Resource Center for the Deaf and Hard of Hearing Communications Department is launching a presentation for law enforcement agencies about effectively communicating with victims, witnesses, and citizens that are deaf or hard of hearing. "Law Enforcement & the Deaf Community: The 4-1-1 for the 9-1-1 about the 7-1-1" will be presented by a Deaf adult and a nationally certified sign language interpreter and includes valuable resources and tips for law enforcement officials. To book this free 45-minute presentation, please contact Renae Bitner, NDSD – Bismarck office, by telephone: 701-328-3988 or by email: renae.bitner@sendit.nodak.edu.



Keep away from people who try to belittle your ambitions. Small people always do that, but the really great make you feel that you, too, can become great.

Mark Twin

Upcoming Events

2014 Pepnet Summit Series, Building State Capacity to Address Critical Issues in Deaf Education: Transition from Secondary Education to Postsecondary Options, Denver, CO, January 27-29, 2014.

ND Council for Exceptional Children (CEC) Conference, "Celebrate Sweet Success", Feb. 5-7, 2014, Seven Seas Best Western, Mandan, ND.

ND Speech-Language Hearing Association Spring Convention, April 3-4, 2014. Grand International Hotel in Minot, ND.

Alexander Graham Bell 2014 Conference, Walt Disney World, Orlando, Florida, June 16-30, 2014.

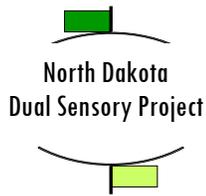
2014 OSEP Project Directors Meetings, Washington DC, July 21-23, 2014.

PEDALING for POSSIBILITIES P4P 2014

IPAT Pedaling for Possibilities is an annual stationary bike race fundraiser. It helps people with disabilities and those experiencing the effects of aging, residing in ND and Moorhead, MN. It helps by purchasing assistive technology such as electronic magnifiers, communication devices, personal amplifiers, and computer access tools. P4P will be held Saturday, February 8, 2014 from 1:00 – 6:00 p.m. at the NDSU Wellness Center in Fargo, ND. For more information or to become a team participant, call *SHERRI NELSON* at #701 239-7376 or email to shnelson@nd.gov

Together we can make a difference! We need bike riders, sponsors, and volunteers!

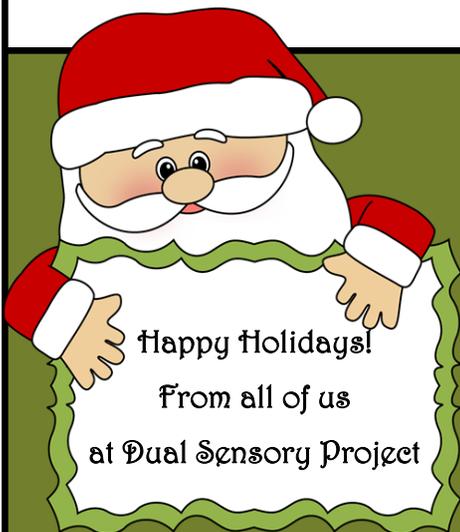
Family Weekend Retreat, NDVS/SB
April 4 & 5, 2014
Bismarck Comfort Inn, Bismarck, ND



GRANT APPROVED

The ND Department of Public Instruction was contacted the end of September regarding the application for the 2013 Technical Assistance and Dissemination to Improve Services and Results for Children with Disabilities Program – State Technical Assistance Projects to Improve Services and Results for Children who are Deaf-Blind (CFDA 84.326T). The ND Dual Sensory proposal was reviewed and approved for funding for the years 2013 – 2018.

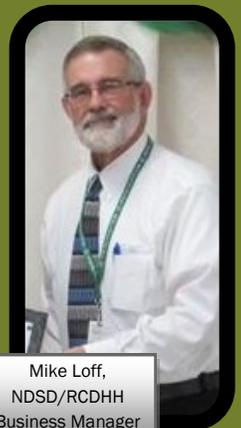
The goals for the ND Dual Sensory Project are to: 1) Promote early and appropriate identification of all students who are Deaf-Blind, 2) Develop a systematic model of technical assistance statewide for families and professionals, 3) Provide onsite and long distance technical assistance training and professional development utilizing evidence-based practices, 4) Ensure that family members of children who are Deaf-Blind have the training and information needed to maintain and improve partnerships with teachers and service providers, and 5) Disseminate information and resources statewide.



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ND Dual Sensory
Project Director



Nancy Skorheim, DPI Coordinator



Mike Loff,
NDSD/RCDHH
Business Manager



Shelly Laverdure
NDSD/RCDHH
Admin. Assistant
Informer Publisher



Diane Frelich
NDSD/RCDHH
Admin. Assistant
Dual Sensory Census/Data



Paul Olson NDVS/SB



RESOURCES

GAMES for People with Sensory Impairments: Strategies for Including Individuals of all Ages, Lauren Lieberman and Jim Cowart, American Printing House for the Blind, 2011.

Physical education teachers and activity leaders in the trenches are always on the lookout for appropriate, appealing games and activities for their students. This resource draws upon the authors' experiences in teaching and reaching students of all ages who have visual impairments, blindness, deafblindness or multiple disabilities. The authors have assembled fitness, recreation, and aquatic activities for elementary – high school youth. The principles they present for adapting games, activities, and procedures as instructional strategies can be applied to situations that involve nondisabled youngsters as well as those with disabilities.

Visual Impairment in Children due to Damage to the Brain, Gordon N Dutton & Martin Bax, MacKeith Press, 2010.

The increased awareness of cerebral visual impairment in children, combined with improved recognition of its wide ranging manifestations, has led to its recognition as the most common cause of visual impairment in children in the developed world. Yet the subject is in its infancy, with very little published to date. Information on this complex topic has been needed by all disciplines working with disabled children for many years.

This ambitious book links the work of authors from many of the major research teams in this field, who have made significant contributions to the literature on the subject of cerebral visual impairment and provide a structured amalgam of the viewpoints of different specialists. The book contains some very novel concepts, which will be of great practical value to those who care for children with visual impairment due to brain injury. Summaries of the more specialist chapters as well as clear diagrams and a glossary have been provided to increase the book's accessibility to a broader readership.

D-S Advisory

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Project Director

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Superintendent, NDVS/SB

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Special Education Teacher

Jody Neva

Parent

Eden Neva

Student

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NDSD Deaf Outreach

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!

ND Department of Public Instruction
Kirsten Baesler, State Superintendent
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North Dakota
Dual Sensory Project

