



SANFORD SCHOOL OF MEDICINE

The University of South Dakota
CENTER FOR DISABILITIES

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In Touch

A PUBLICATION OF THE CENTER FOR DISABILITIES
A University Center for Excellence in Developmental Disabilities Education, Research and Service



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Office of Special
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Center for Disabilities Deaf-Blind Program Update

Grant Activity:

The South Dakota Deaf-Blind Program is funded through the US Department of Education. The Deaf-Blind Program provides services in five key areas:

1. Provide technical assistance and dissemination activities for educators, service providers, advocates, policy makers, families of children who are Deaf-Blind, and individuals who are Deaf-Blind. These activities are in an effort for early identification, enhancement of services, and improving outcomes for children who are Deaf-Blind.
2. Conduct leadership and coordination activities with local, state, and national agencies and organizations in order to enhance services and improve outcomes for children who are Deaf-Blind.
3. Provide transition activities for children who are Deaf-Blind. These activities are provided in order to improve services and outcomes as they move into the adult system and to promote self-advocacy. The program's transition guide can be viewed on-line at: www.usd.edu/cd/upload/transitionguide.pdf
4. Build capacity of statewide services and supports through collaboration and partnerships in order to enhance services and improve outcomes for children who are Deaf-Blind.
5. Deliver family service activities as an effort to increase the ability of families to bond with, support and meet the needs of their children who are Deaf-Blind.

Deaf-Blind consultative services are available free of charge. Services include on site consultations, information dissemination, and training.

Employment Opportunity:

The Deaf-Blind Program is currently taking applications for the program's Family Specialist. If interested in this position, please view the posting for more information: yourfuture.sdbor.edu

Dedicated to *Life* Without Limits

Annual Census Required by the Federal Government:

In January 2011, the Deaf-Blind Program will be sending out our annual census mailings to school districts across the state, in an effort to identify new children who have combined hearing and vision loss. Please note that children may be coded under other disability categories (such as multiple disabilities, hearing impaired, or visually impaired), but would still qualify for services if they have a combined hearing and vision loss. Even a child with a mild vision and a mild

hearing loss can qualify for services. Since the Deaf-Blind Program is a statewide program, it is important to extend services to underserved areas. This year, outreach activities will occur in Tribal areas in an attempt to identify children who may qualify for program services.

Currently, the program serves 27 children throughout the state of South Dakota. Most of the 27 children reside in the eastern areas of the state.

CHARGE Syndrome Seminar

Keys to Successful Education and Development

featuring David Brown

In September of 2010, The South Dakota Deaf-Blind Program, in cooperation with the National Consortium on Deaf-Blindness, sponsored a seminar titled, "CHARGE Syndrome: Keys to Successful Education and Development," presented by David Brown from the California Deaf-Blind Project. Approximately 30 people attended the day-long seminar. Participants included teams and families of three children diagnosed with CHARGE Syndrome. One family/team joined the seminar from the North Dakota Deaf-Blind Project.

David has worked in the field of Deaf-Blindness for over 30 years. He has a special focus in CHARGE syndrome and is particularly skilled at explaining the multi-sensory issues that children with CHARGE syndrome often experience. According to David, children with CHARGE syndrome are truly 'multi-sensory impaired', having difficulties not only with vision and hearing, but also with the senses that perceive balance, touch, temperature, pain, pressure and smell, as well as problems with breathing and swallowing, eating and drinking, digestion, and temperature control."

As a result of these immense difficulties, children with CHARGE syndrome experience a high level of stress and often develop their own personal skills of coping and accommodating. David Brown encourages professionals and families to always take this into consideration and to provide the necessary support, especially when there are expectations placed upon a child.

David spoke extensively about proprioception and vestibular senses: what he calls "The Forgotten Senses." One training participant exclaimed, "David provided the best, most simple and understandable explanation of what proprioception is that I have ever heard before."

David explained that the sense of proprioception informs us about the position of our body in space, as well as all of our limbs, and if anything is moving. Proprioceptive receptors are in the muscles and joints throughout our bodies.

Children lacking in this area may compensate by stamping or slapping their feet repeatedly on the floor when walking and/or walk on their tip toes. They may also use too little or too much force when touching, patting, grasping, pushing or pulling things. They may drop objects when lifting or placing them somewhere, seek strong pressure or stretching inputs (this may include squeezing into tight spaces, crossing/twisting limbs around each other or around an object, binding body parts with tight clothes, pulling down on teeth or grinding/tapping teeth, hand clapping or flapping, leg swinging or kicking, hanging from bars, jumping up and down, banging their head, and/or hammering objects).

Their lack of body awareness results in the appearance of being clumsy and having poorly coordinated movements. David suggests that we attempt to understand the reason for these compensation mechanisms and allow the child

to engage in them whenever possible. He also recommends that appropriate activities also be developed to help children receive the type of proprioceptive input they are seeking. An example is a weighted blanket on the legs of the child to provide sensory input in this area.

David explained the vestibular sense as the sense which tells us about our head position and the pull of gravity, and serves to detect motion. This sense has close links with the eyes (including how our vision works), and the sense of proprioception. The receptors for this sense are located in the inner ears. (Note: According to information found on the CHARGE Syndrome Foundation website, 90% of children who are born with CHARGE syndrome experience inner ear problems and therefore will have vestibular problems as well). Problems in the vestibular system can have a significant impact on mobility, awareness of body parts, muscle tone and posture, crossing midline, motor control, coordination and sequencing, auditory and vision perception, and the child's arousal states and ability to modulate, which are needed for maximum attention and calming.

David presented on the equilibrium triad, this includes the sense of touch/proprioception, the vestibular sense, and vision. He explained how all of these need to be working well for maximum functioning. David provided many examples of how to assist children with vestibular/proprioceptive problems, these include making sure their complex needs are understood, that their self-developed accommodation mechanisms are respected (including allowing them to be in a body position that allows for maximum security and optimal use of their vision), providing a space that is comfortable for them, providing support, and providing cues so they can anticipate events. He encouraged others to be aware of the various arousal levels and how to address them.

David cautioned against assuming that once a child has learned to compensate for their vestibular and proprioceptive difficulties, the child's difficulties are now



David Brown presenting at the conference.

solved. We need to keep in mind that children with CHARGE syndrome have to work much harder than typical children. They may have increased difficulty when in unfamiliar situations or part of the equilibrium triad is not working well. He cited the example of a young lady who was walking to her destination without any problems, until her vision was obstructed and she fell down. Her vision served as a major compensatory mechanism and once restricted, her other senses were unable to function properly. David stated, "People need to realize

that children with CHARGE syndrome may have learned to compensate, but they did not grow new vestibular systems."

David spent time addressing the communication needs of children with CHARGE Syndrome. He relayed that possible obstacles to good oral communication include hearing impairment, vision impairment, facial palsy, low muscle tone, poor tactile sense, oro-facial clefting, enlarged tongue, poor tongue movement, small lower jaw, larynx/pharynx anomalies, breathing difficulties, swallowing difficulties, dental anomalies, and delayed/immature eating skills. Possible obstacles to good use of manual signs include low/poor modulated muscle tone, poor tactile sense, poor proprioceptive sense, poor spatial awareness, dyspraxia and poor body awareness, poor bilateral coordination, poor sense of balance, various postural difficulties, low vision or blindness/visual field losses, and skeletal anomalies.

David indicated that the challenges are sometimes compounded because of a tendency for children with CHARGE syndrome to have difficulty with vocabulary recall and initiating communicative exchanges (possibly related to executive function). David suggested the services of a speech language therapist be employed, and that a communication system with a concrete component (objects, symbols, pictures, written words) which can be used as an aide for recall encourage initiations, clarify meaning and foster confidence, animation and fluent

communication. He did stress that this concrete system should be used as a supplement and not replace the child's oral or signed communication.

Some children with CHARGE Syndrome display inappropriate behaviors, which David feels strongly is generally related to their sensory and communication difficulties. Therefore, rather than perceiving these as

behaviors and addressed in this manner, they should be addressed by taking into consideration the child's sensory and communication needs and providing the necessary supportive services/accommodations.

For additional information from David Brown regarding the "Forgotten Senses" see the following website: www.cadbs.org/publications/

Interveners:

The South Dakota Deaf-Blind Program continues to address the need of staff training, including the needs of Para-educators (interveners). An "intervener" is described as a one-on-one Para-educator who has received specialized training in the area of Deaf-Blindness. These individuals provide a bridge to the world for the student who is Deaf-Blind by helping in several cognitive areas.

Each student's team decides whether or not the child requires the services of an intervener. For additional information in this area, please contact the South Dakota Deaf-Blind Program.

The role of the intervener:

- Facilitates access to environmental information that is usually gained through vision and hearing, but which is unavailable or incomplete to the student who is Deaf-Blind
- Facilitates the development and/or use of the student's receptive and expressive skills
- Develops and maintains a trusting, interactive relationship with the student that promotes social and emotional development and well-being.

There are few intervener training programs in the United States. Some states have developed their own in-service training program as part of their Deaf-Blind Project, and other states have included an intervener credentialing program within their university setting. Ski-Hi Institute, located at Utah State University in Logan, UT, has such a program. The program at Ski-Hi Institute is the program South Dakota has used to meet the training needs of Para-educators working with

children who are Deaf-Blind.

Training occurs over two semesters and may include a course practicum. As a result of the National Intervener Task Force efforts, more stringent guidelines are being placed on the type of training and level of certification required for interveners. South Dakota has made great strides in aiding Para-educators becoming interveners by taking advantage of the long distance intervener training program offered through SKI-HI. South Dakota currently has four Para-educators who completed the initial two courses and two who are currently in the first semester of training.

For more information on the Ski Hi Intervener Training program check out this website: distance.usu.edu/html/online&d=95



Jada and her intervener, Ms. Schmidt, providing "access to information" by exploring the environment (window/sunshine).

Matt and his intervener/teacher, Ms. Kurtz, learning time concepts and sign language during calendar time.



Technical Assistance:

Onsite Consultations:

The Deaf-Blind Program staff continue to provide on-site consultations to school districts and have been visiting more schools than ever this year. Services vary from annual consultation to intense services including on-site consultations and trainings. This past year, the program was able to support the long distance consultation services of Ellen Mazel (consultant from Perkins School for the Blind) to work with one student's team and provide helpful recommendations and follow up services. Activities accomplished included completion of the Communication Matrix (a communication assessment tool) and implementation of calendar systems for activities provided by various disciplines. Currently, completion on the "Insite Model" is being completed, to help determine appropriate activities for this student. Much of what has been learned can be duplicated for other students to whom the program provides services.

Trainings:

The South Dakota Deaf-Blind Program presented at the following training events:

- 2010 Statewide Special Education Conference: "The Communication Matrix-a communication skill assessment tool for individuals with multiple disabilities, at the earliest stages of communication development." In March of 2011, Rose is scheduled to present again on the topic "Deaf Blindness: Effective Intervention Strategies and the Role of the Intervener."
- Aberdeen School District: The interpreters/intervener, Deaf Educator, and teacher from SD School for the Blind and Visually Impaired attended a training titled "Communication Strategies for Deaf-Blind Children." Information regarding the use of Signals and Cues, Co-active Sign, and Tactile Sign was provided, as well as hands on practice experience. RID credit was made available for interpreter recertification.
- Baltic School District: A simulated vision loss experience was provided for staff to give a better idea of what a student experiences/sees. This was beneficial in developing appropriate modifications in the classrooms.
- DakotAbilities: Rose provided information on accommodations for hearing and vision impairment. A simulated vision loss and simulated hearing loss experience was provided to staff who work with adults with developmental disabilities. Rose's continued connection to the adult service delivery services is helpful when developing transition activities for young adults who are Deaf-Blind.

Information Dissemination:

- Center for Disabilities Deaf-Blind Program website: www.usd.edu/cd. New to our site is Deaf-Blind Topic Pages!
- To receive program updates via email, please sign up for our project's list serv at: www.usd.edu/cd/db-resources.cfm

Upcoming Trainings:

- March 20-22nd, 2011: SD Council for Exceptional Children Annual Conference, Rapid City, and SD. Check out this website for details: www.usd.edu/cd/sd-cec-conference.cfm
- April 4-5, 2011: Focus on Success 2011 Conference, Pierre, SD. Sponsored by Services to the Blind and Visually Impaired, Pierre, SD. There will be two sessions related to Deaf-Blindness. Check out this website for details: www.dhs.sd.gov/sbvi/
- April 28-29, 2011: Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER), Fargo, ND. Sponsored by the Dakota AER Chapter. Check out this website for upcoming details: www.ndvisionservices.com/newsletter/

Resources:

iPad: With the growth in technology, Apple technology offers many new avenues of learning and communication



for children who are Deaf-Blind. The Apple iPad can be used as a large screen, mobile web device which utilizes thousands of downloadable iPad applications. Child friendly applications include art, interactive books, communication, early academics, music and interactive musical instruments, and a variety of games. Communication in particular includes language

comprehension, learning facial expressions, utilizing storyboards, communicating basic needs, text to speech, learning to speak, and learning sign language. For a more expansive list of how the iPad could be useful to you and your child, and for an extensive list of applications, please visit www.connsensebulletin.com/2010/05/apps-for-education/.



Other Notable News:

Rehabilitation Center for the Blind and Visually Impaired staff person Laurie Megard (communication instructor/Braillist) participated in the certification training in Deaf-Blindness Program offered through Northern Illinois University. This program is designed to provide quality continuing education to rehabilitation professionals who wish to enhance their skills in providing quality services to persons who are Deaf-Blind. This program is funded by the U.S. Department of Education, Rehabilitation Services Administration. This 15 credit hour coursework program consist of on-line classes and 8 days of on-campus training at the Helen Keller National Center. Additional requirements included 200 direct service

hours and the completion of a project which directly benefits individuals who are Deaf-Blind in South Dakota. Laurie completed the program in August and received a certification in Deaf-Blindness. Training at the Helen Keller National Center included hands-on classroom activities, a luncheon where participants experience eating without the use of vision or hearing, and participating in various activities with Deaf-Blind consumers in order to better understand their needs. The Rehabilitation Center for the Blind has previously worked with transition age students from the South Dakota Deaf-Blind Program. For additional information regarding this certification training program, contact the South Dakota Deaf-Blind Program.



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This newsletter is available in alternate format upon request by contacting the Center for Disabilities.