



D - B I N F O R M E R

SEPTEMBER 2010 WWW.ND.GOV/DEAFBLIND/ 1-800-421-1181



“Explore Winter Wonders” at NDVS/SB

By Cindy Williams



North Dakota Vision Services/School for the Blind held a new short-term programming session titled “Explore Winter Wonders” which focused on early childhood and early primary grade students. The program took place the end of February with students from North Dakota and Northwest Minnesota in attendance. The students were exposed to many educational and fun activities that promoted independence, literacy, socialization and sensory experiences.



Decorating and sewing mittens during literacy center

A few highlights of the programming session involved activities related to books the students enjoyed. One literacy center was



Enjoying group music and learning to play “boomwhackers”

based on the book The Mitten by Jann Brett. The students had fun creating and decorating their own mittens. They also practiced their Braille skills by writing about animals that would enter their mitten. During a daily living skills session titled “Growing Vegetable Soup,” they learned about and examined different kinds of vegetables. It was an extra special treat to serve their homemade soup to the parents and teachers! While the students were having fun socializing and learning, the parents were able to partake in educational sessions to aid in their child’s learning and development including topics on

American Printing House products, orientation and mobility, daily living skills, and library resources.



A division of the North Dakota
Department of Public Instruction
Dr. Wayne G. Sanstead
State Superintendent



Cortical Visual Impairment (CVI)

By Lanna Slaby

Cortical Visual Impairment, better known as CVI has become the fastest growing visual impairment diagnosis today according to the American Printing House for the Blind. Traditionally, TVI's or teachers of the visually impaired, served children with ocular impairments resulting in reduced acuity or blindness. Today, TVI's are also serving children with this brain-based condition or disorder which presents itself with unique visual/behavioral characteristics. Based upon these facts, the Family Team decided to include a session on CVI at its annual Family Weekend. Parents were given the following handout describing these 10 characteristics:

1. **Color Preference-unusual preference (usually red or yellow).** Color is the anchor characteristic where you start your intervention. Use visual cues that match the child's preference.
2. **Visual Novelty-** start with what the child knows; they don't seem to respond to novelty well
3. **Visual Complexity**
 - ★ Prefer objects with a plain surface-single color
 - ★ Prefer simple visual array-consider background –avoid clutter and crowding
 - ★ Other senses overwhelm vision –allow lots of time for visual processing
4. **Visual Field Preference-almost always present;** usually kids with CVI have difficulty with their lower fields (steps might be an issue)
5. **Light Gazing or non-purposeful gaze**
6. **Visual Latency-a delayed response to visual stimuli**
7. **Attraction to Movement-Children in the early stages of CVI need movement.** If the object is not moving, the object is not there. Any reflective material is good. Reflections are actually supercharged movement. Reflective pom-poms are good. You can take apart a pom-pom and wrap strings around future objects such as toothbrushes etc.
8. **Visual Reflex Difficulties-**
 - ★ Touch/blink response-if the bridge of the nose is touched, the child blinks
 - ★ Visual threat-typically present in all children around 6 months of age
9. **Distance Vision Difficulties-CVI children act nearsighted because they are visually overwhelmed**
10. **Visual Motor Difficulties-It is common for a child with CVI to look at an object, look away, and then reach for it.** This is one of the last areas to resolve for a child with CVI.

In addition to receiving the handout, participants watched [part of the *CVI Perspectives*](#) DVD produced by the American Printing House for the Blind. This DVD explores cortical visual impairment (CVI) from three perspectives: medical, educational, and personal. In the educational section, APH CVI Project Leader Dr. Christine Roman presents an educational perspective focusing on characteristics and recommended approaches. The medical perspective is led by neonatologist Dr. Alan Lantzy explaining the causes of CVI. In the final segment, seven families talk about their personal experiences from the difficulty of the diagnosis to finding help and hope. Families also viewed videoclips of two students with diagnosed CVI. Families were able to see how differently CVI can affect visual functioning in different individuals.

CVI is a complex visual disorder that requires intervention strategies dependent upon the level of CVI. Since CVI is a relatively new visual diagnosis first recognized by the American Printing House for the Blind in 2004, our knowledge of CVI continues to evolve and grow as we continue to work with students who have the disorder. Dr. Christine Roman-Lantzy, the narrator on the CVI Perspective DVD and the author of the historic first book on CVI, *Cortical Visual Impairment: An Approach to Assessment and Intervention* often challenges her workshop attendees with the following quote by Will Rogers, "Why not go out on a limb? That's where the fruit is." She explains that the best fruit is out on the limb and we need to get away from "canned fruit." With canned fruit, you always know what you are going to open up, and those of us who work with students with CVI, need to be the pioneers and be willing to move away from the tree trunk. Happy climbing!

Family Centered Services in Natural Environments

By Jacky Mergner

SE Kids Infant Development Program

ND Early Intervention programs are starting to work with families using a different approach called Family Centered Services in Natural Environments (FCNE). What is FCNE?

- Supports and services meet the unique needs of the child and family
- Based on the child and family's everyday life
 - * Young children learn throughout the course of the day, at home and in the community
- Learning is encouraged during activities that the family and children enjoy and are motivating
- Team based and coordinated
 - * Provider and family work together to support the child's learning
 - * Learning occurs between home visits!

I have been working with Julianne Woods and Emily Martuana from Florida State University for the past year on the FCNE approach. It has been an amazing experience and I hope that the families that I work with are as excited as I am. So if you notice home visits are going a little bit different in the next few months this may be why.



Family Learning Vacation

By Kari Sandberg, Parent



Hello my name is Kari and my family and I attended the Family Learning Vacation in Minot. This was our first year attending the event. I was very impressed and can't wait for next year. My family lives in Minot and it is because of our youngest that we became involved with infant outreach services through the School for the Blind. Jack is 18 months old and spent his Saturday in the hotel room with the staff and volunteers from the school for the blind. I was worried he may get upset so during the morning break I went to check on him and when I arrived I found the room full of guitar music and the little children holding various musical instruments. Jack had a maraca in his hand shaking it and smiling. It brought tears to my eyes.

My husband and I enjoyed the morning speaker. He gave wonderful advice and he knew how to get participants to interact. It was nice to meet the staff from the School for the Blind. My favorite part of the day was getting to know the other parents and hearing about their children. The day went too fast. Our 6 year old daughter spent her day at St. Leo's Activity Center and when we picked her up she could not stop talking about all the wonderful things she did. She loved making cotton candy, the crafts, and decorating cupcakes. I interrupted her to ask her if she met any children that were blind and she replied, "No" and went on with how amazing her day was and a couple of minutes later she made the comment that some of the children used sticks when they played.

I can't imagine all the hard work that went into planning the event but I want to thank the school staff and parents. I never knew such services were available but am thankful for them everyday.



ANNUAL NORTH DAKOTA DEAF-BLIND STUDENT CENSUS

The ND Dual Sensory Project is federally required to identify children and young adults (age birth – 21) throughout the state of ND who have a combined vision AND hearing impairment and report this information to the National Consortium for Deaf-Blindness (NCDB). Our 2009 Deaf-Blind Census count was 39 children in North Dakota. Identifying all the students who qualify as Deaf-Blind ensures that adequate funding is made available to provide support services to these students, their families, and the professionals that work with them.



Fiscal Agent Change for KIDS Infant Development Programs

The KIDS Infant Development Programs along with the Northern Plains Special Education Unit, are pleased to announce a formal interagency agreement with the Anne Carlsen Center in Jamestown. Effective July 1, 2010, the Anne Carlsen Center will serve as the fiscal agent for the Grand Forks, Devils Lake, Fargo and Jamestown KIDS programs. The changes that will occur will be administrative only. The programs will continue to be managed and operated by the same personnel employed through the NPSE KIDS Program. Services being provided to children and families will remain the same.

This affiliation will not only enhance the Anne Carlsen Centers' mission to provide outreach services to young infants and toddlers, it will help expand the KIDS Program mission of utilizing existing community and state resources to assist the parents and children we serve. KIDS Staff is excited about the affiliation and intends to maintain and improve the quality of our services that we provide to parents and children.

Collaborating with ND State School for the Deaf and ND Vision Services

NE KIDS staff has had the opportunity of collaborating with different people and programs through the ND State School for the Deaf and ND Vision Services to support caregivers and promote children's additional development.

Sherri Nelson, with the ND Dual Sensory Project, has a variety of resources and services available for professionals and families whose children qualify. These services involve making adaptations within the family routine to increase learning opportunities for the child, and providing resources and support to the family in very personable fashion, making it easy for families to ask questions.

Another example of collaboration is with Cindy Williams, consultant from ND Vision Services/ School for the Blind. Cindy provides Functional Vision Evaluations on children in our region who have diagnosed visual impairments. She provides a wealth of information assisting staff in identification of best learning environments for children, adapting and changing environments to promote the child's learning.

A third service is provided by Carol Lybeck and her staff from the ND School for the Deaf Outreach services. They support families with children who have a diagnosis of hearing loss. Carol and her staff collaborate and share resources with KIDS staff to support children and their caregivers. Carol and staff have provided community support to show how to use the child's environment to enhance hearing and support learning across all settings.

North Dakota has a variety of resources and support services for children with vision and hearing difficulties. I believe we collaborate very well together for families, but there is always room for improvement. We need to continue to communicate while working to utilize the rich resources we have available through the ND State School for the Deaf and ND Vision Services.

Ramona Gunderson, M.S. Ed/ ECSE
Region IV KIDS Coordinator
Infant Development Program





Carmen Grove Suminski,
Superintendent NDVS/
School for the Blind & ND
School for the Deaf

Warmest Greetings!

Welcome to this issue, and I am hopeful that you are enjoying the summer months!

My appreciation to Sherri Nelson and to Nancy Skorheim who assume the leadership with the Dual Sensory Project! Also, I extend appreciation and thanks to parents and families and to personnel with all related agencies.

It has been a good year at NDSD. I have had an opportunity to learn and grow as a person. My thanks to the NDSD staff, students, and families for the warm welcome. A Campus Master Plan is near completion as is the Future Services Plan for NDSD. The Future Services

Transition Team met in Devils Lake on June 16-17. Membership of this team includes NDSD parents, alumni, legislators, staff, local education personnel, Human Services, University personnel and community members. This plan will outline a comprehensive statewide services plan. With continued collaboration and partnerships, we can make a difference for the persons who are deaf and hard of hearing in the state of North Dakota. This has been a most beneficial experience. Extensive information is available on the NDSD website at www.nd.gov/ndsd

I look forward to attending the board meeting of the Council of Schools for the Blind in Freemont, California in July. In April I had the opportunity to attend the annual CEASD Conference in Council Bluffs, Iowa with Carol Lybeck, NDSD Outreach Coordinator. It was a pleasure to be welcomed by professionals in the field from throughout the United States.

Please contact me at csuminsk@nd.gov or at the School for the Deaf, 701-665-4410 or 800-887-2980 or at ND Vision Services/School for the Blind, 701-795-2708 or 800-411-1181.

Perkins Training & Educational Resources Program is proud to announce a new webcast, CHARGE Syndrome: The Impact on Communication and Learning. This insightful webcast explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha Majors, who has worked with many children with CHARGE in the Deaf-Blind Program at Perkins, offers guidance for educators in developing an effective educational program that will improve the emotional well-being and success in learning for students with this syndrome. <http://www.perkins.org/resources/webcasts/>

ND Dual Sensory Project
Technical Assistance Team

ND School for the Deaf

Carol Lybeck => Devils Lake
Linda Ehlers => Fargo
Position Open => Grand Forks
Tami Iszler => Bismarck
Nicole Swartwout => Minot



ND Vision Services
School for the Blind

Dianne Giessinger => Minot
Linda Kraft => Fargo
Lanna Slaby => Jamestown
Cindy Williams => Grand Forks
Mary Verlinde => Bismarck
Katrina Wendel => Grand Forks
Ken Dockter => Grand Forks
Paul Olson => Grand Forks
Pat Hill => Grand Forks
Deb Johnsen => Grand Forks
Candy Lien => Grand Forks
Kathy Grzadzielewski => D. Lake
Tracy Wicken => Grand Forks



Technical assistance request forms are located at www.nd.gov/deafblind/ or call 1-800-421-1181

DISTANCE CONSULTATION OPPORTUNITIES

By Sherri Nelson

With our current grant, we have explored ways to be more efficient and effective in our work with families and professionals across our rural state. It can be costly and difficult to schedule Technical Assistants to provide onsite consultations to individuals and teams across the state, therefore, we have explored resources to assist with distance consultations.

The ND Dual Sensory Project and ND Vision Services have purchased *Flip Video* cameras that can be utilized to record footage of activities in the home or at school and send this to the Technical Assistance staff for consultation. Webcams are also being considered to send live footage of a student during activities, when needed.

Distance consultation is a new and unique endeavor for our Project, however, we are excited to explore the opportunities and learn how we can expand our services provided by the staff from the ND School for the Deaf and ND Vision Services/School for the Blind. Further training and information regarding distance training/consultation was shared at the Office of Special Education (OSEP) Project Directors meetings that was held in Washington DC in July. Project staff attended this meeting.

The National Coalition on Deaf-Blindness is a 2,000 member organization of parents, professionals, consumers, and agencies serving the population who are Deaf-Blind. They have been advocating for the needs of children who are Deaf-Blind since 1987. The Coalition is seeking a \$5 million increase above the President's FY11 budget request to address the resource needs of children who are Deaf-Blind and their families.

The state Deaf-Blind projects that support the Deaf-Blind community have not had a budget increase in over 20 years, despite the doubling of the population of children who are Deaf-Blind over the same time period.

In FY10, the national technical assistance and dissemination program at the Dept of Education received \$49.9 million for all disability technical assistance, of which \$12.8 million is designated for Deaf-Blind programs and services. At a time when remarkable advances in medicine and technology are enabling many more of these infants and children to survive and live longer, it is important for Congress to recognize the need for increased support. Because of the continuing budget

shortfalls, however, these children are receiving fewer services, and programs providing the services have to operate with fewer well-trained personnel.

The request for \$5 million is urgently needed to help states improve their services for families, to support the activities of the national technical assistance and dissemination center on deaf-blindness, and to strengthen personnel preparation programs.

For more information about the National Coalition on Deaf-Blindness contact:

Steven Rothstein at Steven.Rothstein@Perkins.org or Betsy McGinnity at betsy.mcginny@perkins.org

EVERY MOVE COUNTS CLICKS & CHATS emc3

By Sherri Nelson, Project Coordinator

Lanna Slaby, Vision teacher from NDVS/SB, and I participated in this workshop by Jane Korsten at the Anne Carlsen Center in June, 2010. I had previously heard Jane speak back in the early 1990s when I was working with the Infant Development Program. I remember the impact her message had upon my beliefs about communication at that time. As an audiologist with a background in Speech Pathology and Elementary Education, I have always been passionate about communication. Once again, Jane gave us plenty of food for thought with an outstanding presentation for two days.

The message for day one was “Everyone communicates in some way. It is our challenge to recognize that communication and respond to it!”. We talked about the theories and practices with Piaget, Van Dijk and Sternberg. We learned about the essential need for co-occurrences to develop the concept that the world is controllable; those with physical/sensory/motor differences seldom, if ever, experience co-occurrences; and that 100,000 co-occurrences need to be detected, associated, and remembered. Infants under 4 months of age learn to associate their movements with a consequent event. If there is a delay of more than 2 seconds between movement and consequence, infants as old as 9 months do not learn. Three month old infants remember response-consequence associations for at least one week and learning can be reactivated for up to 3 weeks. WOW, the power of early intervention and stimulation!

Assessment was discussed throughout the two days. Too many of the formal assessments identify the disabilities rather than the abilities! Focus is often on typical development when we already know things aren't typical. This often leads to lack of ability to detect small increments of growth, which is essential for the kids we work with.

The *Every Move Counts* assessment is communication based; not developmental; identifies abilities rather than disabilities; focuses on skills relevant to building a functional communication system; detects smaller increments of growth; and is dynamic and ongoing. The assessment components include a Sensory assessment, ongoing sensory probe, Communication component, Symbol System, Clicks, and Chats. Please refer to www.everymovecounts.net for further

information.

“If you always do what you’ve always done, you’ll always get what you’ve already got!”

Jane reinforced the idea that a hearing baby must be hearing speech & language for 4,380 waking hours before expressing themselves @ 18 months. If you only provided speech therapy twice a week for a child for 20-30 minutes, it would take 84 years to achieve that same stimulation! By the time a child is 9-12 years old, they have been exposed to speech & language for 36,400 hours which would be equivalent to therapy 2 times/week for 20-30 minutes for 701 years! The ability of co-occurrences to influence early cognitive development depends on their consistency and frequency!

The second day was full of discussion on the implementation of switches and symbols for communication. At the conclusion of the day, the group discussed DATA—a four letter word! “Not everything that counts can be counted and not everything that can be counted counts!” Remember your rationale for taking data...is it periodic or episodic? Staff centered or student centered? Tool based or activity based? What will it look like? What is needed? How much is enough? What is the goal?

The new manual represents an update of the original work. The goal of both is the identification and understanding of communicative intent of movements and selection of strategies for building on those movements. It also integrates assistive technology from beginning switch use to dedicated AAC.

“Empowerment and participation come with the ability to experience the world and communicate.”

OUR TEAM

Our team is here to serve families and professionals of individuals who are Deaf-Blind, birth through age 21. Please get in touch with us if you have questions, or feel we could be of assistance!

HOW TO ACCESS OUR SERVICES:

ND Dual Sensory Project	North Dakota School for the Deaf	ND Vision Services/
Sherri Nelson, Project Coordinator	Outreach Teachers 701-665-4400	School for the Blind
701-795-2730 or 800-421-1181	or 800-887-2980	Outreach Teachers
		701-795-2700 or 800-421-1181

RELATIONSHIP BASED COMMUNICATION STRATEGIES

By Sherri Nelson, Project Coordinator

We had the pleasure of having Jennifer White come to North Dakota for two days to share her ideas with parents of children with hearing and/or vision impairments and professionals who work with their families. Jennifer owns a company in Seattle that works with individuals with various disabilities called “Able Opportunities”. She has experience of over 30 years working in the schools and adult service agencies collaborating with teams to provide optimal service and clear choices to individuals with a broad spectrum of disabilities. She has extensive experience playing and working in the Deaf and Deaf-Blind communities in the states of Washington and Alaska.



During the first day, there was extensive conversation about building relationships with others through communication. Words and language are used to communicate, and it takes skill to find a “shared language” with children who have vision and/or hearing impairments. We must learn to read their movement, touch, rhythm, and body language. To have conversation requires practice, good intentions, and examination of our interactions. We typically start a conversation with our eyes or body language, so if we are working with a child who is blind we already have to modify that process. As teachers and parents, we need to discover a way to open up dialogue with a child and welcome them into a conversation.

Further discussion focused on our personal file cabinets of life experiences, drawing upon what we know, and creating some new ideas and strategies that will work for children who are dual sensory impaired. The group participated in numerous exercises focusing on sensory input or lack thereof—eliminating vision, audition, and language through various role-playing sessions.

It was particularly challenging for the group to identify the



mutual topic through joint attention without talking or signing! We had to build from scratch our framework of how to convey the information, organize and/or revise it, in order to establish meaningful output for the partner. In order for the reciprocity of exchange to continue, there needed to be adequate “wait time” for the partner’s response. This was a very powerful concept for most of us to grasp and apply to our work with students.



From the simulations, it was clear that the dual sensory student needs affirmation that they have been heard or seen, and through touch, they must receive immediate feedback. They must understand that they are not alone, someone has joined them in conversation. The reality of how much time is spent “waiting” for instruction to occur or the conversation to continue, was reinforced through these activities. For communication to be effective, we must provide the student with continual stimulation and direction. Children need to feel safe and secure in their relationships. They need to trust their partner. We also discussed the need to know the interests of the child—such as objects, sounds, or smells, as a way to establish a conversation topic to initiate communication.



Tactile strategies and tangible symbols were presented as a means to engage in conversations. Through conversations we can teach children, demonstrating the social practice of being engaged with others. Through the use of Hand Under Hand instruction, sequence boards, calendars, labeling strips, and choice boards, we can understand how the child interacts with their world. And it is through this relationship based communication that we can teach the child to partner with others to enhance their recreation and leisure in their future!

The group demonstrated their carpentry skills with hands-on opportunities to build labeling strips, choice boards, and tangible symbols at the workshop (see photos).



HELEN KELLER

Born: June 27, 1880

Died: June 1, 1968

Became Deaf-Blind: 19 months

Met Anne Sullivan: March 1887

Number of US Presidents Met: 13

Number of Books Authored: 12

Schools Attended: Perkins Institute of the Blind, Wright-Humason School for the Deaf, Horace Mann School for the Deaf, and Radcliffe College

Membership & Causes: American Foundation for the Blind, American Braille Press, Women's Suffrage, Peace/Pacifism, Helen Keller International (Co-founder), American Civil Liberties Union (Co-founder), US Socialist Party/Industrial Workers of the World



Helen Keller's fame and appeal are nearly universal-an historical figure whose experience and life's work transcend her disability and place her among the twentieth century's most notable personalities. The Described and Captioned Media Program has created a new webpage at: <http://dcmp.org/helenkeller> to help teachers, families, and students locate resources that chronicle the life and work of this truly amazing woman. From her 1955 Academy Award winning biography, Helen Keller In Her Story, to the Emmy Award winning classic, The Miracle

Worker, our collection truly has something for everyone!

In Depth Biography:

The American Foundation for the Blind (AFB) provides a comprehensive Helen Keller Biography as well as Chronicles of Helen Keller's Life that offers a year-by-year account of Helen's life and accomplishments. See the American Foundation for the Blind website for further details.

The AFB, the organization to which Helen Keller devoted a great deal of work, provides a collection of information and other content about Helen, including: The Helen Keller Archive-the most comprehensive source of Helen Keller related material on the internet; The Helen Keller Kids Museum-part of AFB's Braille Big Program; a collection of articles, photos, and more focusing specifically on Helen's teacher, Anne Sullivan.

Seven decades worth of photo's chronicling Helen's life an work (including some photos featuring other famous figures such as President Calvin Coolidge and Alexander Graham Bell) are available from AFB. Many photos of Helen are also available from the Library of Congress Photo Archive.





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ND Vision Services Supt, &
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Ramona Gunderson

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Linda Ehlers

Deaf Outreach

Nicole Swartwout

Deaf Outreach

UPCOMING EVENTS

- ★ FVND is happy to announce **The FVND University**. We now have 2 online workshops. Our first online course is in becoming a mentor support parent to other parents through our ND Parent to Parent Program. The second is Learning to be a Health Advocate. We are very excited about offering online workshops to families and providers. <http://fvnd.mycourse.com/>
- ★ OSEP/NCDB Topical Workshop, Washington D.C., **November 17-19, 2010**. <http://ncdb.org>
- ★ TASH Conference 2010, Denver, Colorado, **December 8-11, 2010**. <http://www.tash.org/2010tash>
- ★ Zero to Three 25th National Training Institute, National Center for Infants, Toddlers, and Families, Phoenix, Arizona, **December 9-11, 2010**. <http://www.zttnti.conference.org>
- ★ Council for Exceptional Children Convention (Expo), National Harbor, Maryland, **April 25-28, 2011**. <http://www.ccc.sped.org>
- ★ International CHARGE Conference (10th), Orlando, Florida, **July 29-31, 2011**. <http://www.chargesyndrome.org>

“CHARGE Syndrome: Keys to Successful Education and Development”

Sioux Falls, South Dakota

September 16, 2010 9:00 am to 4:00 pm

David Brown has been a special education teacher for 34 years and he has a credential in teaching students with deaf-blindness. He worked as an Itinerant Teacher for Sense (the national deaf-blind association) in England for 18 years before moving to California in 2000. He currently works for California Deaf-Blind Services. He has special interests in CHARGE Syndrome, early intervention, assessment approaches, multi-sensory issues, and in the collaborative interface between education and therapy.

There are many factors that make high stress inherent for children with CHARGE Syndrome. The difficulty the outside world has in understanding these children only increases the stress factors further. This presentation will examine the sources of stress, both internal and external, and suggest ways in which the emotional health of each child can be treated as a priority. Research and practice in the fields of medicine, early intervention, and education provide information that can help us understand learning and behavior characteristics associated with CHARGE Syndrome. Traditional views of educational goals and priorities will be challenged. Multi-sensory issues will be a specific focus as we discuss effective strategies to provide behavioral support as well as other issues that have an impact on children from infancy to young adulthood. Addressing these issues systematically and consistently can assist in the transition from school to adult life.

ND Department of Public Instruction
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Devils Lake, ND 58301

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