

2/25/14 ND DUAL SENSORY ADVISORY BOARD MEETING NOTES

Introductions of Members Present: New Members: Pam Smith-Adult Services NDSD and Eden Neva-High School student who is on the Census, Kari Chaisson –UND Vision Program, Paul Olson-NDVS/SB, Ramona Gunderson – Anne Carlson EI -Grand Forks, Kristen Vetter-Adult Services NDSD, Lilia Bakken – Interim Supt. NDSD, Connie Hovendick-Lake Region SPED, Nancy Skorheim-DPI, Linda Ehlers-Outreach/PIP NDSD, Angie Villorreal – Anne Carlsen EI –Fargo, Eden Neva-student from West Fargo, Lanna Slaby – Outreach NDVS/SB and Sherri Nelson

Census Updates for 2013—low numbers in the Birth – 3 category, and the 18+ at this time. 15/29 are currently in the 6-13 age group. An increased need to start work on Transitioning these students to high school/post secondary education/independent living opportunities! The focus of this grant! List sent out to members. The majority of the students are from Jamestown, Grand Forks, Fargo, and Minot.

THE 2012 National Child Count---September, 2013

The first and longest running registry and knowledge base of children who are DB in the world. Begun in 1986 it represents nearly 30 years of collaboration between the NCDB, the state-DB projects and OSEP for the United States and the Pacific Trust territories, the Virgin Islands, and Puerto Rico.

It has been designed, revised and is the common vehicle to meet federal guidelines for the state and national projects. It is utilized to identify national and state technical assistance needs for children and youth who are DB, their families, and the service providers who serve them.

It is conducted each year to supplement OSEP's Federal Part C and Part B Child Counts. This December 1 count is collected for all reported as having vision and hearing losses as well as those with additional disabilities. Nationally over 90% have one or more additional disabilities. A majority of the children who are DB or who have intervention needs for deafblindness are not identified on the SPED Child Counts under the category of DB. For 2012 a total of 9,525 children and youth were on the DB Child Count.

For 2012 across the US—555 Birth – 2 infants and toddlers identified, as well as 8916 children and youth(ages 3-12). An additional 54 students were reported in those states who provide services beyond the age of 21. Thus a total of 9,525 infants, children, and young adults were identified. This is a 1.46 % increase from the previous year.

In contrast, WESTATE 2012 reports that 1,587 students (3-12) were identified as DB on OSEPs Part B Child Count. All Part C infants and toddlers were reported as developmentally delayed or

at risk. This is a 80% + discrepancy between Part B& C and the national DB Child Count. This creates an under-identification of Deaf-Blindness and this has been a consistent problem for many years. It is critical to identify early and provide intervention services for those unique needs of students who are DB.

In reviewing the Child Count info, it is notable that children who are DB are highly diverse. They are varied as the number reported and the nature and extent of DB in children can be easily misunderstood. These children represent one of the lowest incidence, yet most diverse group of learners receiving early intervention and special education services. They are an extremely heterogeneous group whose sensory losses are often accompanied by additional physical or cognitive disabilities, complex medical needs and/or behavioral challenges.

Data collected includes the IDEA 618 requirements plus info for state technical assistance including: race/Part B & C categories, EI setting, Educational setting 3-5, 6-21, Part C exit status, gender, etiology, documented vision and hearing losses, CVI, Central Auditory Processing, Auditory Neuropathy, other health issues or syndromes, living setting, and the use of corrective lenses, listening devices, assistive technology or cochlear implants.

Emerging trends: overall count increased by 138 from last year, a slight decrease in the birth – 2 yrs #s, and less than 100 infants (birth – 1 year) included on the count. The prevalence of CHARGE Syndrome continues to increase-- 848 children. The prevalence of Usher Syndrome reached a peak in 2007 and has decreased the past 3 years. The # of Hispanic/Latina has increased over the past 6 years. The # of children with cochlear implants from 167 in 2005 to 834 in 2012 (five fold increase). In 2005, over 20% of children had no additional disabilities and that is decreased to 10%; in 2005 13% had 4 or more disabilities and now over 42% have 4 or more diagnosed disabilities. The % of preschoolers in regular early childhood settings has more than doubled in the past 10 years—now over 33% (was 15%). Over 60% of school age children are receiving their education in their local schools, with 65% of elementary school aged children served at least a portion of their day in regular classrooms in their local school. 26% participate in regular curriculum and participate in statewide assessments tied to regular grade level standards!

This continued trend toward educational placements in inclusive settings, especially at the preschool level, is significant and positive for children and families. However, it has profound implications on the needs for information, resources and access to expertise in Deaf-Blindness at the local level.

Currently 92% of children are living at home with their parents, extended family or foster parents. Only 2.3% are living at a residential facility. Therefore providing supports to families is a critical component of the services needed for children who are DB.

The #s of students receiving a certificate of completion or diploma has grown from 160 to 248 over the last 6 years. Therefore the need for transitional services, and postsecondary education supports for this group. Technology has been critical for these children—over 45% use some form of AT at this time.

Library Materials: there were over 650 reported materials purchased for the DB Library. Currently the DB Library has been moved back to the ND Vision Services/School for the Blind due to space/remodel and utilization issues between the School for the Deaf and School for the Blind. Currently Donna Metzger and I are completing an inventory of all materials. We are “weeding” out the materials that are outdated and discarding materials that are not utilized. Many of the VHS tapes from previous trainings from the 1980s are being discarded. We hope to complete this process in a few weeks. All materials will be cataloged and available over the statewide ODIN system. I have a list of children books about people with disabilities that I would like to encourage staff and students to be aware of. Thanks to Susan, the librarian at NDSD, for cataloging all the resources that were purchased since 2006!

Newsletters: The most recent newsletter went out for Fall of 2013. This issue highlighted the family supported events of the CHARGE Conference---two families and myself attended. Also staff trainings supported by the Project including the Building for Tomorrow Family Weekend with Vision Services, the West Regional Early Intervention conference in Jackson Hole, WY (2 staff sent), visit to Annie’s House in Bottineau, the Texas Symposium in Austin, TX (2 staff sent), Training on “Making the Curriculum “Fit” with the IEP in Sioux Falls, SD, and the Deaf-Blind Project Directors meetings in Washington DC. Over ½ of the newsletters are sent electronically. Our goal is to have most of the newsletters sent in this manner in the future. I have been working with adm staff from NDSD on getting email addresses for most patrons.

GRANT APPROVED for 2013 – 2018 The ND Dual Sensory Project grant was submitted and approved for October 1, 2013. The goals for the Project are focused on: 1) Promoting early and appropriate identification of children who are Deaf-Blind; 2) Develop a quality approach to Technical Assistance for families and professionals; 3) Implement onsite and long distance technical assistance; 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 including disseminate information and resources statewide on DB.

Changes from the last grant: The purpose of the ND Dual Sensory Project will help State education agencies, local education agencies, Part C lead agencies, early intervention services providers, teachers, service providers and families to address the educational, related services, transitional and early intervention needs of children who are DB to ensure that these children will graduate from high school ready for competitive employment, postsecondary education or independent living options!! Priorities include: training and information for professionals and

families, improved educational outcomes, implementation of the conceptual framework, evidence based practices, services of high quality, intensity and duration and collaboration with the National Center on DB. As you can see by our Census data, the need to look at transitional services supports the grant priority!

FINAL REPORT FOR THE 2008-2013 GRANT The final report for the final year of the grant and the summary of the grant cycle was submitted in December, 2013. It is felt that the Project has provided numerous training opportunities for staff and families over the past five years. Staff has been informed of many national happenings through the use of multi-media including webinars, Skype, email, workshops, and distance trainings. The Project impacted over 40 students and their families, and the service providers that serve them. The Project made a significant contribution toward increasing knowledge and understanding of the unique and complex educational needs of students who have dual sensory impairments.

Barriers that are faced within our state: consolidation of school districts, reduced state educational funding, the rural nature of the state—the need to travel great distances to see one child in a local school district, travel conditions during the winter, the technology capabilities of some of the school districts and/or family homes, lack of interveners (trained staff in the field of DB), lack of data on post-secondary outcomes for students who are DB, and the influx of families on the western part of the state compounded by lack of housing and professional staff to accommodate this need.

**Eden came into the Grand Forks setting and introduced herself to the team. She talked about her week at NDVS/SB and also what she is planning to do this summer. She talked about her swimming.*

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

A multidisciplinary team including a parent (Sherri Nelson), outreach specialists and teachers of the Deaf (Pam Smith, Kristen Vetter, Bambi Lambert(Fargo), and a postsecondary disability services coordinator (Kathleen Peterson from UND) attended the Summit in Denver in November, 2013. During the Denver 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. Following this summit, the team decided our first step was to gather information from a survey. We wanted to know what support services were being provided for D/HOH and what the needs were for agencies across the state. Information obtained would be used for improving educational programming, employment opportunities, services and outcomes for ND individuals who are D/HOH. Over 500 surveys were mailed out to schools, VR, medical facilities, Human Service Centers, law enforcement agencies, IPAT, and other support agencies. Over 150 surveys have been returned and data is being aggregated and discussed.

In January, 2014, the second 3 day Summit was attended by the ND team of Pam Smith, Kristen Vetter, Bambi Lambert, Misty Risky-Leuthardt (VR—replacement for Kathleen Peterson from UND), and Sherri Nelson. There were 231 individuals from all 50 states that attended this meeting. Breakout sessions, large and small group discussions, and state team meetings were arranged. Summit 2014 was designed to provide participants with 3 components needed to create change—knowledge, tools, and time.

An action plan was developed by our state team. The goal was that D/HOH individuals will improve their independence across settings through self-advocacy and self-determination. Based upon the data that we collected we will prioritize the needs and provide trainings to stakeholders, including students across ND. We will be planning a state-wide transition training opportunity specific to D/HOH for this fall that will align with the ND transition focus.

The training will include breakout sessions lead by Deaf Adults with varied backgrounds, and experiences and professionals. At this time, parents and service providers will be invited to learn about the transition process and possible agency supports. Pre and post training evaluation will be developed and completed by attendees. Follow-up evaluation will be completed 3 months after to see how this activity impacted their independence.

Additional goals will be to post transitional resources on the Adult Services website at NDSD, and publicize the use of PEPNET 2 resources for families and professionals across ND. There is a critical need for postsecondary data for D/HOH individuals in our state. This will be discussed further with administration from NDSD and other appropriate agencies. Misty has resigned from her position with VR and so the team will be looking for another VR representative.

NEEDS SURVEY AMONG STAFF Training for the Dual Sensory Project: A Needs survey was sent out to the NDSD and NDVS staff in October, 2013...responses from 10 staff were received back, 7 from NDVS and 3 from NDSD. The topic of trainings that were a priority included IEP/Common Core Standards (Aligning IEP goals with CCSS), Active Learning from the Penrickton Center and Technology—how to put technology into the classrooms when schools

won't provide it. Other topics of interest included: Expanded Core Curriculum, Secondary Transition of DB students, cochlear implants, how to work with children with limited mobility, communication, Insite training, and mental health.

Transition Communities of Practice: I serve on the Region IV and Region V committees. In region V we have been working with Joan Karpenko from Family Voices on "Teen Night Out" opportunities for teens ages 14 – 21 to gather in a social setting and enjoy a fun time together. On Friday, the group of over 25 kids went to the Fargo Force hockey game together. Other events have been held each quarter.

I will be working with Paul Olson and Lilia Bakken to develop a Professional Development plan for further trainings on deafblindness. The Project continues to work closely with the National Center on webinars, sharing resources, and trainings.

***There was some discussion regarding the shift from OSEP of looking at outcome-based data. The reports and new grant reflect the need to look at the IMPACT of what we do with the students, families and professionals, not what we are doing. Kari talked about the changes that are occurring at the Higher Education levels regarding this concept also. The National Center is providing support for the understanding of this paradigm shift.*

New office space: 3 NDS staff and 2 NDVS/SB staff share office space in Fargo

New address: 1321 S 23rd St., Suite A, Fargo, ND 58301 #701 239-7376

The Project will currently be supporting:

- 1) A staff member to complete on online workshop, "Augmentative-Alternative Communication Strategies" (March 31 – May 5, 2014)
- 2) A staff member from NDVS to attend the National CEC conference in April in Philadelphia, PA.

I am looking for anyone interested in paraprofessional training for an Intervener. If you know of a para interested in some training, let me know!

*** A training was scheduled to be held in December, 2013 on Cortical Vision Impairment, at NDVS/SB but due to weather, Christine Roman postponed her trip. Paul is hoping that this will be rescheduled next fall. The Family Weekend is planned for NDVS in April in Bismarck. Linda E reported on the training that was held on Visual Phonics this fall. 30 participants from across the state attended. The Family Learning Vacation for NDS will be held in May, 2014. The featured speaker is a mom with two grown children with Usher Syndrome. Pam reported that Michael Harvey, an expert regarding mental health and deafness, came to ND in the fall to talk*

to a group of over 80 people from across the state. It was well received and NDSD hopes to do something each year on this topic!

Kari talked about the UND Vision Masters Program. There will be a new cohort of students starting soon, so if you know anyone that is interested have them contact her. They have worked with a big group from Alabama (I think that's the right state...) and that was a very positive situation.

Paul talked about having Connie Hovendick come to NDVS/SB and talk to his staff about issues relating to work with Special Education.

Ramona's talk was cut off by Polycom due to time constraints, so it is pasted below:

Hi Sherri,

I thought I'd finish what I was trying to say yesterday before the system went down on us. We acknowledge the Deaf/Blind Sensory Project and know it can be very significant for families.

We seem to have difficulties getting families to want to be a part of the project if we think their child will qualify. Just to let you know our current struggles;

-one family is very inconsistent- once we are in the home it has been impossible for them to sign anything to allow someone else into their lives

-the second family has been disappointed that we don't do more of a direct therapy model and has kept us on only for the MA. Cindy has seen this family once, and I'm hoping that maybe she will go out or call to talk to the family about this project and what it can do for them and their child.

-Ezra H- I was under the impression by the EI person that Cindy Williams was going to refer this little one but I didn't see him on your list.

Again, there are many circumstances that involve getting families involved. The best scenario I think would be to have one of the state's providers following up to discuss referral with our families after we have mentioned it.

Let me know what you think.

Ramona Gunderson, M.Ed
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Thanks to all who attended the Board meeting! I will be sending these notes out to all members.....we will plan to meet again next fall! Enjoy the SPRING and SUMMER! Hope they arrive soon 😊 Sherri