Each day infants are discharged from the hospital at birth without receiving an initial hearing screening. By missing this critical opportunity, children are left out of the early identification and intervention process, thereby, potentially delaying their overall development. Improvements to state Early Hearing Detection & Intervention (EHDI) programs are credited to national recommendations, guidelines, and legislation. Statewide, North Dakota is doing its part to develop more effective EHDI models and address ongoing issues. One example is by using the data from the online statewide reporting system, OZ eSP, to show ND’s hospital participation and program implementation. ND EHDI is excited to share 2006 performance results and data from the 2006 Annual Performance Report.

Of the twenty-three birthing hospital partners in ND, six experienced changes in birthing capabilities or reported no births in 2006. By comparison, 17 of the 23 hospitals used the online reporting system consistently and 18 participated fully in the 2006 ND EDHI program. Four major cities and five hospitals accounted for the majority of ND births in these more populated areas. Hospitals experiencing more than 150 births per month are considered “large” hospitals and are not compared against “small” hospitals (<150 births per month). Data presented are composite data and are anonymously compared. Eleven indicators were chosen to demonstrate performance of the ND EHDI implementation for the past year; however, only three areas are discussed next.

ND compared its percentage of infants who did not pass (refer) their birth screen (OZ eSP) with the national benchmark and found that ND is very close in meeting this goal. The national target suggests that, of completed birth screens, less than 10% should have a refer result. Last year small hospital data indicated that 10.95% of infants screened, at birth, needed additional testing. Similarly, large hospital data indicated 10.56% of infants needed additional tests and the state averaged 10.63% overall. These data assist EHDI staff and its partners to identify training or equipment needs, thereby, decreasing this percentage.

Tracking and follow-up of infants who do not pass, needing an outpatient screen, is an area of concern nationally and statewide. This is clearly emphasized by data presented through the OZ eSP system as well. Small hospital data indicate 52.18% of infants who needed additional testing actually returned for a second-stage screen. Large hospital data showed 54.90% of infants returned. The goal is to eliminate loss-to-follow-up completely and assure that all infants who refer will actually return for additional testing. A 100% return rate for outpatient screens may seem unrealistic but research has confirmed that the earlier hearing loss is identified in a child’s life the more early intervention positively effects the child’s development. By informing families of the importance of returning for an outpatient screen and providing support, the return rate will increase. Hospitals may need to employ new
methods of appealing to families or continue to work with ND EDH project staff to assist hospitals and audiologists to connect with community partners.

One such partner, assisting ND EHDI efforts to reduce loss-to-follow-up, is the Right Track Program. Right Track is a program funded through the Department of Human Services to provide parent education and necessary referrals to supporting programs. Another provider willing to assist is the ND School for the Deaf, Parent Infant Program (PIP). PIP is a home-based program that provides parent education to families of children birth to three with a diagnosed hearing loss. PIP staff agreed to provide follow-up to families whose infant has not passed two rounds of hearing screenings. These providers assist hospitals by encouraging families of infants to return for any necessary hearing screenings.

Tracking and follow-up with infants who need a diagnostic evaluation is another area of focus for EHDI programs on a national scale. Last year, 57 infants were referred for additional testing (12 by small hospitals; 45 by large hospitals) and only two were identified with having a hearing loss according to data reported in OZ eSP. In order to determine performance in this area, the number of infants identified with a hearing loss in ND was compared with the national incidence level where 2-3 infants per 1000 are identified with having a hearing loss.

Vital Records reported that our partner hospitals birthed 9,587 infants in 2006 (1,631 by small hospitals; 7,956 by large hospitals). Using this metric, ND small hospitals should have identified 3-5 infants with hearing loss in 2006. Large hospitals should have identified 16-24 infants. According to the national incidence level, ND is under-identifying infants with hearing loss by small hospitals; 45 by large hospitals). Using this metric, ND small hospitals should have identified 3-5 infants with hearing loss in 2006. Large hospitals should have identified 16-24 infants. According to the national incidence level, ND is under-identifying infants with hearing loss.

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(Continued from Page 1 – Kimberly Witt)
This webcast will discuss employment barriers and strategies for individuals with psychiatric disabilities and criminal histories.

A Bit of Disability History

April 4 marks the birth date of Dorothea Dix. Born in 1802, Dorothea has been described as “the most effective advocate of humanitarian reform in American mental institutions during the nineteenth century.” Dorothea was a major influencer in the founding of 32 hospitals for people with mental illness, 15 schools for people with mental retardation, a school for the blind, and numerous training facilities for nurses across the United States. She was also influential in changing the treatment of people with mental illness in Europe. Although Dorothea did not play a role in the direct understanding or the nature of mental disability, her influence the government made her one of the most politically involved women of her time. The contributions Dorothea made toward the better treatment of people with mental illness helped to pave the way for social and medical reform that is still felt today.

Source: webster.edu/~woollff/dorotheax.html

NEW FACES AT NDCPD

Tanya McGill
NDCPD welcomed Tanya McGill in March as an Administrative Assistant to the Executive Director. Tanya is from Plentywood, MT; she moved to Minot with the Air Force and was medically retired from the military in 2002. Tanya is a May, 2006 graduate of MSU and is currently working toward a master’s degree in Management. Tanya has a daughter who is 10 years old.

Mary Olson
Mary Olson joined the NDCPD team in March. She provides office support for the NW Infant Development Program based in Williston. Mary grew up in Watford City, ND but has lived in Williston for many years. Mary has background experience as a medical technologist and was previously employed at the James Memorial Center for Visual Arts in Williston. She is married with three daughters.

Employment Related Webcasts, 2007

| April 16 | Employment for Individuals with Disabilities with Criminal Records
| Dennis Born, Director, Supported Employment Consultation & Training Center (SECTC) |
| This webcast will discuss employment barriers and strategies for individuals with psychiatric disabilities and criminal histories. |

| May 15 | Transition to Meaningful Adult Roles: You Can’t Put a Square Peg in a Round Hole |
| Marilyn Henn, National Speaker on Transition |
| This presentation covers the journey and the outcome of Marilyn and her daughter, who has severe autism, over the past 30 years in words and video. |

| May 22 | Organization Change: Examining Successful Case Studies |
| Karen J. Lee, Executive Director of Employment Supports, Via of Lehigh Valley |
| This webcast focuses on organizational change based on the experience of SEEC and how they transitioned to provide customized employment. |

| June 12 | Customized Self-Employment |
| Corey Smith, Director of Employment Supports, Lehigh Valley |
| Entrepreneurs as a career choice is an important employment option for individuals with disabilities. Also discussed will be resource ownership. |

Kathy Erickson Retires

Kathy Erickson recently retired after almost 20 years as the Director of the Pathfinder Family Center. We recently asked Kathy to look back on her efforts to help ND families.

What progress have you seen in educating children with special needs?
I believe that some of the progress for children with disabilities has occurred as a result of teachers learning and using best practices. Understanding of “active parent involvement” increased as parents began to help develop their child’s education plans. Parents who work with their children at home make a tremendous difference.

What can you share with new parents?
I have observed more parents taking a “meaningful” role in their child’s development, related services and IEP’s. When my daughter was young, parents felt the pain of critical attitudes toward children and adults far more often. Attitudes toward disability have evolved and been influenced by prior generations. I wonder if those same attitudes are influential today in decisions made with eldercare.

What advice can you share with new parents?
I encourage new parents to provide the loving care that all infants deserve; not to focus on the “what ifs”, but to learn as much as possible about the impact of the condition, and ways to care for their infants, and to participate in a support group to learn from other parents.

What do you believe are the most important issues facing families and schools today?
I am still stuck on the need to focus on a good evaluation of progress and what works best for each child. I believe that, with a concerted effort between home and school including the child, we can really make a difference in each child’s progress.

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I am still stuck on the need to focus on a good evaluation of progress and what works best for each child. I believe that, with a concerted effort between home and school including the child, we can really make a difference in each child’s progress. In today’s busy world, fewer children and youth experience that level of effort.

What important lessons have you learned in helping families?
The most important thing I have learned is not to take anything at face value. Read, research, and re-read what is going on for whatever applies to your situation. Make sure that all players in a dispute are thoroughly aware of any extended circumstances. Approach any situation as knowledgeable and FAIRLY as possible, and state that as your intent in the first meeting.

What are some of the challenges that have impacted your work?
It has been a rather long and bumpy ride. Sometimes I wonder where I found the courage to invest my “working years” totally in a position that was federal grant dependent. There have been times when the stress of trying to get people to “yes” in the best interests of a child, has proved very difficult. I believe if I had the years to do it over, I would work even harder at training parents to know their rights, and to communicate in ways that encourage others to cooperate more easily.

What are some future trends that hold promise for helping families and professionals?
I am interested in “communities of practice” that provide gradual levels of training for parents, beginning with learning about a disability at birth, then what can be done in the home and finally how to access what is available in the community. There are obvious challenges to implementing this approach because of working parents, distance, and coordination. The most likely answer is to encourage use of online interactive training. This could be done through Head Start programs, county libraries, social service programs, clinics, and medical facilities. It would take a highly collaborative effort but what other alternative is there?
The North Dakota Center for Persons with Disabilities (NDCPD), in collaboration with the ND Center for Rural Health’s Family to Family Network (F2F) and Family Voices of ND, (FVND) will conduct a strategic planning process under the title of ND Family Support Coalition (FSPC). This plan will guide the implementation of future Rural Health Network Development grants for Family Support. The FSP Coalition anticipates achievement of two outcomes: 1) establishment of a collaborative network of rural health/human services partners, and 2) development of a comprehensive written strategic plan for family support services for rural North Dakota families.

While individual coalition members operate with their own strategic plans, the fact that there is no overall plan is a challenge to the ultimate development of a statewide family support system. The shared vision will accommodate the different program focuses, philosophies, funding streams, and other factors. There is a shared orientation to working with and assisting families; however, each organization accomplishes this in their own way. The planning process will need to be respectful of traditions and methods while guiding the members towards creating a common voice for family support organizations. This grant will provide the time and additional resources necessary to create and operate a network along with developing and implementing a strategic plan without subtracting resources from each agency’s primary mission. Through this project, ND citizens with special healthcare needs and their families will have greater access to coordinated, quality health services which may prevent or somewhat alleviate secondary disability conditions. Our focus is clearly on establishing a plan for a more coordinated public health infrastructure for children with special healthcare needs.

The North Dakota Center for Persons with Disabilities (NDCPD) is a member of the Association of University Centers on Disabilities (AUCD). AUCD is a national network of interdisciplinary centers advancing policy and practice through research, education and services for and with individuals with developmental disabilities, their families and communities.

The E³ project at NDCPD has collaborated with five departments on the Minot State University campus to employ five people with disabilities in part-time positions. Employment began February, 2007 and is targeted to continue through August, 2007. However, each department has the option to continue employment beyond the grant project. The five departments collaborating with the E³ project include the College of Business, Graduate School, Alumni Office, Rural Crime and Justice Center, and Enrollment Services.

Staff from the E³ project are working with two community agencies, REM and Community Options, Inc., to find workers with disabilities who are seeking employment. Workers are then matched to a MSU department based upon interest and skill. Current workers have mild to moderate intellectual and physical disabilities. The work provided by these workers is a valuable asset to the workplace. The MSU Human Resources Office, which is not part of the E³ project, has employed a person with disabilities for the past year and a half. According to Wes Matthews, Director, “The experience has been extremely positive.”

The long range goal of the E³ project is to provide data to the MSU campus and other campuses regarding the validity of tapping into this resource of workers within communities. We hope to expand this project beyond MSU and invite other campuses across the state to join in and include persons with disabilities as part of their workforce.

If you are interested in learning more about the project, please contact Rich Berg at NDCPD, 1-800-233-1737, ext. 4349, or email him at rich.berg@minotstateu.edu.