

SUMMARY OF ADVISORY COMMITTEE MEETING
Virginia Early Hearing Detection and Intervention Program
Virginia Department of Health
February 9, 2007
FINAL

The following persons attended the meeting of the Virginia Early Hearing Detection and Intervention (EHDI) Program Advisory Committee: Barbara Allen, Jeannine Beden, Brian Campbell, Craig Derkay, Mary Ann Discenza Darlene Donnelly, Leslie Ellwood, Nancy Ford, Ruth Frierson, Fredia Helbert, Claire Jacobson, Loucendia Lambert, Sue Lau, Debbie Pfeiffer, Barry Strasnick, Beth Tolley, Dana Yarbrough, Pat Dewey, and Shirley Trammel – guest.

Announcements and Updates

- Susan Lau, the Surveillance and Evaluation Coordinator, has accepted another position. Her contributions to the EHDI Program have been significant and she will be missed.
- Debbie Pfeiffer announced the start of a new program, the Center for Early Literacy Learning (CELL). It is funded by the U.S. Department of Education, Office of Special Education Programs. CELL is a research-to-practice technical assistance center. It's goal is to promote the adoption and sustained use of evidence-based early literacy learning practices by early childhood intervention practitioners, parents, and other caregivers of young children, birth to five years of age, with identified disabilities, developmental delays, and those at-risk for poor outcomes. CELL is a major initiative of the Center for Evidence-Based Practices at the Orelena Hawks Puckett Institute. To learn more visit the CELL Website <http://www.earlyliteracylearning.org/> or by contacting Dr. Tracy Masiello at tmasiello@puckett.org.
- Beth Tolley reported that additional early intervention staff have been recruited to be part of the Work Group, formed in 2005 to address the needs of Virginia families with a newly diagnosed infant who is deaf or hard of hearing. The next meeting will be held on February 28. The focus will be on developing a fact sheet that addresses the supports and services needed by infants and toddlers who are deaf or hard of hearing, to be used by early intervention providers.
- Fredia Helbert announced the Speech Hearing Association of Virginia (SHAV) conference will include presentations on the national prospective of newborn hearing screening as well as communication with families. Grant funds are being used to support an audiology speaker from North Carolina, Dr. Jack Roush.
- Debbie Pfeiffer announced there would be an INSITE Training Program this summer. INSITE (In-home Sensory Impaired Training and Education) program offers home-based support and resources for families with infants, toddlers and pre-schoolers, age birth to five, with sensory impairments and additional disabilities (MDSI). The training is for people working with these babies who have dual sensory impairments. It will run July 23 – 25, 2007 and August 22-24, 2007. Mark Compano, Director of the Virginia Deaf-Blind Project, is organizing the event to be held in Staunton, Virginia. EHDI grant funds are being used to support this training. VDOE also is supporting the training.
- Barry Strasnick reported on a public/private partnership called Collaboration for Hearing Education and Research, CHEAR, a preschool, oral, deaf education program for children aged 1-6. Eastern Virginia Medical School and Old Dominion University (ODU) are collaborating on this project. Funds must be raised for the project, which may eventually include a loaner hearing aid bank, rotating externships for teachers and therapists, development of core curricula, and on-line training. The goal for the first year is to enroll ten children. Carolyn Brown, from the Carolina Children's Communicative Disorders Program at the University of North Carolina, is retiring this year and has volunteered to be a consultant. Program outlines and budget development will occur over the next few months.

- The Joint Committee on Infant Hearing (JCIH), established in late 1969, has drafted the 2007 Position Statement. The Joint Committee is comprised of representatives from the American Academy of Pediatrics, the American Academy of Otolaryngology and Head and Neck Surgery, the American Speech Language Hearing Association, the American Academy of Audiology, the Council on Education of the Deaf, and Directors of Speech and Hearing Programs in State Health and Welfare Agencies. The 2007 document addresses principles and guidelines for Early Hearing Detection and Intervention Programs and covers topics such as screening and assessment protocols, communication with families, data management, roles and responsibilities, medical protocols, and intervention. The final draft has been submitted to member organizations for review and approval. Once approved, it will be printed and distributed nationwide. In the past, the Virginia EHDI Program has patterned its guidelines and protocols on the recommendations of JCIH. The impact of the updated guidelines on Virginia EHDI include need to revise the list of risk indicators to be tracked, changes in screening protocols for regular nursery versus intensive care nursery infants, and changes in recommendations for tracking of infants who are at risk for late-onset or progressive hearing loss.

Report from Virginia Department of Health

- Dr. Dan Montero resigned from the Advisory Committee at the end of last year; he has moved out of state. He requested that the Virginia Academy of Family Physicians identify a replacement.
- Virginia has the opportunity to work with the National Center for Hearing Assessment and Management (NCHAM) on a project call ECHO – Early Childhood Hearing Outreach. This is a project that focuses on hearing screening and follow up for children in Early Head Start/Migrant programs. Four audiologists and one RN have volunteered to be on the ECHO team. As of this date there is a commitment from four programs. The ECHO team provides training and technical assistance to at least five Head Start programs serving children 0-3 years of age. Those programs are provided with OAE equipment, protocols and screening forms and, in turn, submit screening and follow-up data on all children screened throughout the year. The ECHO Team and grantees are provided direct support from the NCHAM ECHO Team during the first year with the intent that they sustain and expand this effort during the years that follow.
- VDH was approached recently by the Partnership for People with Disabilities regarding collaboration on a Centers for Disease Control and Prevention (CDC) grant that would examine the issue of children with hearing loss and an additional condition, or comorbidity. VDH is in a unique position for collaboration because both the birth defect and EHDI data are in the same database, there is access and linkages to birth certificate data, and the birth defect and EHDI programs can benefit from the results of the proposed study. The letter of intent described the goals and objectives of the proposed project; CDC will review the submissions and “invite” selected full applications.
- VDH has submitted a request to Health Resources and Services Administration to use unspent funds from the first grant year. VDH will use the funds to continue support for the Hearing Aid Loan Bank, translate and print new resource guides and directories, produce posters for medical offices, and refresh the supply of penlights for conferences.

Report from Department of Medical Assistance Services

Brian Campbell of DMAS reported that DMAS has been working on a thorough evaluation of its hearing aid program and the claims system for about a year and a half. They have developed a plan that will revise the system for hearing aid reimbursement. He has obtained input from SHAV and several audiologists in Virginia. The revised plan was presented to the Budget and Fiscal Departments. They propose to unbundle the rates and pay a separate fitting and dispensing fee. Fitting fees would be allowed per new device and repair; dispensing fee would be allowed once per new device. A new hearing aid procedures manual has been drafted. Once the funding has been obtained, payment schedules will be added and the manual will be disseminated to providers. If approved, the changes will go into effect in 2008. The improvement in

number of hearing aids approved has been significant. In 2005 ten hearing aids were approved; in 2006, 51 hearing aids were approved. Because of past issues, the number of Medicaid providers has been greatly reduced. There is only one provider in Northern Virginia currently submitting claims for hearing aids.

Update from Partnership for People with Disabilities

Dana Yarbrough reported on developments with the Guide By Your Side Program. Applications were received and reviewed, and telephone interviews were conducted in September. Fourteen guides were trained in October. The Family Guide Resource Tool Kit was created for use by the guides. In January, VDH put out a press release about the project; there have been several newspaper articles written as a result. A Web site has been established and will be fleshed out soon. Systems are in place to provide ongoing communication with the Virginia Department of Health, early intervention and other agencies. An important part of the program is ongoing evaluation. A follow-up survey was designed for parents to report on their satisfaction with the parent guide, resource materials, and services provided. For January 2007, 13 referrals were received and 9 families matched. The next Family Guide orientation and training will be held in the fall of 2007. Finalized material will be available at the May meeting.

Update on Revision of Protocols for Audiological Assessment.

Claire Jacobson led the review of the draft protocols. The current protocols were approved in September 2004. Discussion and decisions included:

- Once completed, the revised protocols will be included in the list of VDH guidance documents, disseminated to providers and placed on the EHDI Web site.
- Bone conduction auditory brainstem response (ABR) must be done to make a confident diagnosis of hearing loss. Members felt that Virginia should continue to follow the “exceptional model of evidence-based practice” and not reduce our testing requirements to lower standards.
- Once this recommendation is in place, facilities must have both air and bone conduction ABR capability in order to be on the list of approved assessment sites. Members were advised that this would probably reduce the number of sites that could be on the list.
- Barry Strasnick stated that, from a legal standpoint, the risk indicators in Virginia’s protocols should be consistent with the JCIH recommendations.
- All references will be documented in a bibliography.
- Once the JCIH recommendations are final, this document can be completed.

Report from Follow-Up Coordinator

Ruth Frierson reviewed the two new brochures that have been developed. The first replaces the brochures that are provided to hospitals for parents. The other is a new brochure designed to be sent to families of children diagnosed with a hearing loss and reported to VDH. Members were invited to provide comments on the content of the hearing loss brochure.

Report from Surveillance and Evaluation Coordinator

Sue Lau provided a update of activities conducted since the last meeting.

- Hospital reporting is improving. In 2004 the elapsed time between data entry and discharge was 24 days; in 2006 it was reduced to 14 days.
- The EHDI Website has been redesigned and information and links have been added. Go to www.vahealth.org/hearing to see the results.
- A survey was mailed last fall to 362 parents of a child with a hearing loss born in 2005 and 2006. Responses are still coming in; the return rate is 22%. The results will be analyzed and a report written and disseminated.
- Response highlights:

- More than half took two weeks to a month to get an appointment; more than a ¼ of them took two months to get a retest; ¾ had to be retested at least two or more times before definitive results obtained.
- About 2/3 of the children were referred for Early Intervention. Of those who were referred to Early Intervention quite a few said no one contacted them after the referral was made.
- Families were asked if they received information and was it timely. More than 1/3 reported not receiving information on grief and acceptance or about importance of referral to an ophthalmologist. The majority were satisfied with the timeliness.
- The last question on the survey addressed bias. Very few respondents thought they received biased information.
- Sue Lau recommended that EHDI continue to send the survey, perhaps within a few months of receiving the report of hearing loss. This would help to identify issues and barriers on an ongoing basis.
- CDC has designed a new survey. Their Data Committee has worked over the last two years to design the questions and write the definitions and explanations. The purpose is to be able to look at EHDI data across states in the same way. The report for 2005 births is due March 5. The data requested is similar to what has been reported in past years, but there are distinct differences. For example, in the past states reported the number of children born in a given year that had a hearing loss and reported to the EHDI Program. Now the CDC also wants information on the number of babies who failed their initial screening and then were found to have hearing loss. CDC is asking programs to report number of ears with hearing loss, not the number of children. VDH has designed the reports in the new database in order to be able to report these data in future years.

Next Meeting

The next meeting will be held on May 11, 2007 at the offices of the Virginia Hospital and Healthcare Association in Glen Allen.