

# Communicating the Need for Follow-up to Improve Outcomes of Newborn Hearing Screening

## Why This Working Group?

Each day in this country, approximately 33 children are born with a significant hearing impairment<sup>1</sup> [<http://www.nidcd.nih.gov/strategic/strategic.htm>]. The early identification of children with hearing impairment is an important public health objective in the United States. Currently, many of these children are not identified until they are two years old or older despite advances in the technology available for the early detection of deafness and hearing impairment. The consequences of a late diagnosis of a hearing impairment may be significant delays in spoken language and literacy.<sup>2</sup>

As part of its ongoing support of research on early identification of hearing loss and intervention, the NIDCD has held three Working Groups, in 1993 [<http://www.nidcd.nih.gov/health/inside/wtr00/pg2.htm>], 1997 [<http://www.nidcd.nih.gov/news/ru/97/recomnd.htm>] and 2000 [[http://www.nidcd.nih.gov/funding/hb/earlyid\\_00.htm](http://www.nidcd.nih.gov/funding/hb/earlyid_00.htm)], to address issues related to newborn screening including examining acceptable protocols for use in state-wide universal newborn hearing screening programs, research opportunities offered by neonatal hearing screening programs in the areas of diagnostic strategies for characterizing the hearing impairment and intervention strategies for remediating hearing impairment, and critical research needs.

A recommendation of the third workshop was to examine the health care delivery systems issues and related communication issues with the goal of determining methods to resolve the problems of infants who do not return for follow-up evaluation after an initial assessment of hearing impairment has been made. These infants are considered “lost to follow-up.” Follow-up refers to the re-examination of an infant (e.g., a patient), following detection of deafness or hearing loss, for diagnosis, intervention, and treatment.

To that end, a working group was convened on July 23, 2001, entitled “Communicating the Need for Follow-up to Improve Outcomes of Newborn Hearing Screening,” to define the issues involved and develop recommendations for hearing health professionals on communicating follow-up. Dr. Marin Allen and Dr. Amy Donahue served as cochairs. The working group consisted of experts in the fields of pediatrics, otolaryngology, audiology, speech and language, ethics, newborn screening programs, health communication, nursing, state health education, special population communication, child health, telemedicine, and epidemiology. These experts provided information and recommendations on topics ranging from current practices, practical issues of the infant hearing screening and follow-up decision-making process, differences in hospital and other newborn nursery systems across the United States, what parents need to know, how and what to communicate, and what impedes or aids successful follow-up. A full list of the members and their institutional affiliations are shown at the end of this document. The discussion of the working group is summarized in final recommendations in this document.

## The Working Group

### Introduction to the Meeting

Dr. Marin Allen, Chief, Office of Health Communication and Public Liaison/NIDCD welcomed the group and reported that the Institute’s Director, Dr. James F. Battey, Jr., was unable to attend the meeting but he wanted to thank the members for their participation. He had been very involved in the

development and direction of the meeting and concerned about the early identification of hearing loss.

Dr. Allen noted that, as the universal newborn hearing screening initiative moved from the initial stage of conception and discussion to an implementation stage in most states, NIDCD became aware of numerous programmatic issues emerging for professionals in related fields. The information provided to parents, screening procedures, professional roles and functions, standards of care, quality of intervention services, funding sources, hospital practices, continuity of care processes, and tracking programs all lacked consistency across interstate and intrastate systems. The NIDCD thought it was important to pursue the recommendation from the third Early Identification Working Group to find strategies and tactics for use with infants to improve outcomes through follow-up after hearing screening to facilitate the effectiveness of the initiative. Dr. Allen also noted the importance of fostering health literacy in these efforts, with regard to both language use and comprehension level in preparing material for parents and other audiences.

## **Background**

Amy Donahue, Ph.D., Chief, Hearing, Balance/Vestibular Sciences Branch/NIDCD provided background information on the NIDCD Early Identification Working Groups (1993, 1997, 2000), newborn hearing screening programs, and the variation in implementing legislation in states. She also outlined the broader challenges of the screening, diagnostic assessment, and intervention processes that have begun to surface with the implementation of screening programs to date.

## **Panelists Identify Areas of Concern and Expertise (in order of presentation)**

Anne Thomas, Associate Director for Communication/NIH, explained NIH's congressional mandate to disseminate research results. She provided an overview of health communication, health literacy, and how NIH communicates with a variety of audiences.

Issac D. Montoya, M.D., Chief Executive Officer, Affiliated Systems Corporation, discussed cultural and socioeconomic issues of communicating with parents and provided information about working with some specific special populations, and outlined potential opportunities to address certain issues through existing resources.

Bobbi Stettner-Eaton, Ph.D., Executive Director, Federal Interagency Coordinating Council (FICC)/U.S. Department of Education discussed the Individuals with Disabilities Education Act (IDEA) and the coordination and transition of children from the infant and toddler programs to preschool programs.<sup>3</sup>

Judith S. Gravel, Ph.D., Professor, Albert Einstein College of Medicine [<http://www.aecom.yu.edu/home/>], discussed New York State Demonstration Project and communication methods and follow-up strategies used in well baby and neonatal intensive care units.

Patrick E Brookhouser, M.D., Director, Boys Town National Research Hospital [<http://www.boystownhospital.org>], discussed critical differences between communication in rural and urban areas, the culture and day-to-day operation of well-baby nurseries, and communicating the importance of screening to professionals and parents in well-baby nurseries.

Carolyn Lund, RN, MS, FAAN, nurse with the Intensive Care Nursery of Children's Hospital in Oakland, CA [[childrenshospitaloakland.org](http://childrenshospitaloakland.org)], outlined the process of health service delivery in a neonatal intensive care unit and identified some continuity of care issues.

Vicki Freimuth, Ph.D., Director, Office of Communication/Centers for Disease Control and Prevention,

discussed communication frameworks and principles for outreach to various audiences, especially parents.

Mary Pat Moeller, M.S., Director of Childhood Deafness, Language & Learning/Boys Town National Research Hospital, discussed the early processes and factors that appear to affect both choices and outcomes.

Jacqueline E. Jones, M.D., Professor of Clinical Otorhinolaryngology and Director of Pediatric Otolaryngology Service/Cornell University Medical Center, provided the practicing physician's viewpoint on the issues. She discussed the importance of identifying all relevant audiences and their differing needs related to education.

Hallie W. Morrow, M.D., M.P.H., Program Medical Consultant/Program Standards and Quality Assurance/California Department of Health Services/Children's Medical Services Branch, described the California newborn hearing screening program and stressed recognition that two different populations, neonatal intensive care infants and well babies, need to be addressed. She discussed the differences across systems with regard to both operations and professional functions.

John M. Lorenz, M.D., Professor of Clinical Pediatrics and Director of Network Nurseries/Children's Hospital of New York, discussed New York's recent efforts to increase newborn hearing screening. He outlined models of providing care for infants and tracking their care.

Dena S. Puskin, Sc.D, Director, Office for the Advancement of Telehealth/Health Resources Administration, discussed the use of telecommunications and advanced computer technology to improve the delivery of health services in remote areas and in inner cities (when funding is available) and to support the education of health professionals at a distance. She described the issues associated with providing screening and follow-up services to individuals with little or no access to clinics/health centers.

John McGrath, Ph.D., Director, Office of Science Policy, Analysis and Communication/National Institute of Child Health and Human Development/NIH, discussed the importance of engaging parents in the screening process, use of alternative care providers to conduct screenings, and opportunities to forge public-private partnerships to disseminate information in various health education campaigns.

Robert B. Mehnert, Director, Office of Communications and Public Liaison/National Library of Medicine/NIH, discussed current methods used by NLM to disseminate information to various audiences including physicians, nurses, and allied health professionals.

Dan O'Neal, R.N., Chief, Office Of Science Policy/National Institute of Nursing Research/NIH, discussed the complexities of working with numerous professional organizations to communicate information to professionals and the public and the importance of nursing professional organizations to the communication process.

Thomas F. Tonniges, MD, FAAP, (via teleconference) Director, Department of Community Pediatrics/American Academy of Pediatrics, provided background information on the medical home concept and discussed its role for children and families with hearing loss.

June Holstrum, Ph.D., Coordinator, Early Hearing Detection and Intervention (EHDI) Program/Centers for Disease Control and Prevention, discussed screening and tracking aspects of state-level programs funded by CDC's EHDI program.

## **Important Overarching Issues**

Research shows that numerous factors influence the outcome of infants identified with a hearing loss including the following:

- Level of family involvement
- Strength and quality of family communication with infants
- Age of identification of hearing loss
- Early intervention
- Stress on families that occurs when a hearing loss goes undetected for a long period of time
- Parental confidence in managing the infant
- Family access to appropriate support systems
- Family's perception of support (informal as opposed to formal)
- How optimistic parents feel about their child's future
- Family's perception of being in control of the decision-making after diagnosis
- Relationship between the interventionist and the family
- Access to services
- Number of demands on parents
- Quality of the intervention (access to an appropriate level of services)

There are an insufficient number of health professionals qualified to perform various screening and intervention procedures.

Factors that vary significantly across interstate and intrastate systems include the following:

- Professional roles
- Standards of care
- Quality of intervention services
- Hospital practices and procedures

## **Identification of Barriers to Follow-up<sup>4</sup>**

Certain birthing options, e.g., alternative birth centers, are often not covered by state legislation requiring screening.

- The lack of continuity in service provision and tracking within the primary care system, an insufficient number of doctors, high caseloads, and frequent rotation of doctors all contribute to lost to follow-up status of many infants.
- Access to care difficulties, e.g., transportation problems, exist in both inner cities and rural areas.
- Information given to parents about hearing screening and follow-up is insufficient. Causes include the following:
  - Care providers not having access to the parent(s) for several days if a newborn is transferred from the birth hospital to a Neonatal Intensive Care Unit (NICU) in another facility
  - In some programs only parents of high-risk infants receive information about screenings

- Parents may not know or reveal information about the clinic/physician the infant will be seen
- Language and literacy barriers exist. For example, there are currently 329 languages spoken or signed in the United States and less than 60% of the population in some U.S. cities have English as a first language.
- An internal professional concern was expressed about an increased number of otolaryngologists in specialty fields such as facial plastic surgery or head neck cancer rather than general otolaryngology. Some otolaryngologists, particularly those in smaller communities and in rural areas, tend to see fewer children with a hearing impairment or who are deaf. This can result in a need to know more about hearing screening. For example, need for knowledge to accurately diagnosing and treating differently degrees of hearing loss, conduct genetic evaluations and counseling, and evaluate children under school-age and fitting a hearing aid on those same children need to be developed for some.
- There are insufficient funding sources for tracking follow-up care in screening programs; funding for screenings is often only available for low-income populations in state programs.
- A wide variety of practitioners deliver primary care to underserved populations; the links to those services are inadequate.

### **Specific Recommendations for Improvement**

- To reduce the number of children lost to follow-up, health care professionals:
- Need to be encouraged to accept responsibility for appropriate follow-up and care after screening
- Need to consider a community pediatrics or medical home viewpoint
- Need to consider linking children to a medical home at the time at the time of delivery
- Need to use existing systems, such as metabolic screening, to build on for hearing screening
- Need to integrate health information systems to ensure essential information about each child is both available and timely for professionals
- Must become involved in hospital-based programs such as planning and advisory committees and need to increase primary care provider education about their role in providing a medical home
- Need to link payment for providing care of the child in the hospital to ensuring all appropriate follow-ups were received

### **Specific Considerations for Health Communication Professionals**

- In messages to physicians and professional associations, frame hearing screening and follow-up as part of a “continuum of care” rather than an initiative/incentive in and of itself
- Enlist the support of nursing organizations to co-sponsor evidence-based information that’s

intended to change curriculum, accreditation mechanisms, and practice for their members.

- Conduct outreach to teachers about incorporating hearing and identification of hearing loss into school curricula.
- Establish appropriate public-private partnerships to assist with the financial aspects of educational outreach to the public and professionals.
- Use other than general news media to assist with getting the message out to a broader audience.
- There is a limited population that need newborn screening, general mass media mechanisms of communication.
- In developing programs and communicating information to professionals at all levels about the identification, assessment, and management of children with hearing loss:
  - Use evidence-based practice guidelines developed by other states as a reference, e.g., New York Department of Health has a series of six clinical practice guidelines to cover children 0-3 with disabilities, including one on hearing loss.
- Messages to the public/parents should:
  1. Emphasize the critical period of language development.
  2. Explain that hearing screening is non-invasive.
  3. Explain what questions parents should be asking professionals about screening.
  4. Explain that hearing can be tested at any age and hearing tests should be done on a regular basis.
  5. Avoid terms such as “fail” in the explanation of the screening results.
  6. Tie messages about hearing screening to something people know and value such as the importance parents place on the baby’s first words, e.g., through messages such as “Do you want your baby’s first words to be on time?”, “Be sure his hearing is okay.”
  7. Educate about assistive devices available, the types of physicians and professionals involved with hearing health and their competency requirements, what to expect from an audiology assessment/evaluation, a pediatric hearing aid evaluation, the types of equipment the practitioner should have, and what the early intervention system does to help them with choices and decisions.
  8. Address parental needs in ways that attend to cultural, ethnic, racial, socioeconomic, and service availability issues so parents will be motivated to bring their children in for screening.
  9. Emphasize that screening is part of the package of services they need (others include heelstick<sup>5</sup> testing, immunization, information on what to do if their child gets sick in the middle of the night, etc.).

- Use nontraditional methods of outreach to parents such as closed circuit television programs/spots that can be provided to hospitals free of charge, prenatal/childbirth education classes, obstetric providers, state child health contractors, state/county prenatal services programs, grandparents/aging groups, lay health workers along U.S. border regions, and peer educators, alternate birth centers, and WIC<sup>6</sup> programs.<sup>7</sup>
- The communication framework must be clear about the types of audiences being approached to ensure knowledge is adequately imparted. There are three groups of children who need to be addressed: those who passed a screening, those who haven't been screened; and those who did not pass the screening and did not return for follow-up.
- Seek out partners in the education arena versus partners who are only health-based. For example, use individual preschool programs: Early Head Start programs; Transitional Assistance to Needy Families (TANIF) program; high school-based child development centers; and inter-agency coordinating councils as well as Parent Training and Information Centers and Family Voices coordinators (funded by the U.S. Department of Education) in each state to educate families about screening under the Individuals Disabilities Education Act, which requires all children suspected of having a disability to be identified, located, and evaluated so intervention services, when necessary, can be provided from infancy through age 21.
- Increase availability of just-in-time information for practitioners so it is useful to them at the point when they are making decisions. Develop approaches to information for the various kinds of professionals.

### **Specific Messages for Parents**

- Parents should work with hospital/facility staff to arrange for a follow-up appointment when a baby is identified as having a hearing loss.
- Parents should ask the hospital/facility staff to arrange for them to talk to a hearing health professional if they are informed their child did not pass the initial hearing screening.
- Parents should ask for written information about the screening process and about support resources for families that are available in their state.
- Parents need to be aware of their responsibility for their infant's care, e.g., notify doctors and specialists if they change addresses or phone numbers and show up for follow-up appointments or contact the care provider to re-schedule the appointment.

### **Specific Considerations for Professionals**

#### Scientists

- Additional mobile testing devices are needed, e.g., a small device that can do at least auto-acoustic emission screening.
- New technology is needed to reduce the false-positive results that can cause mixed messages to parents and health professionals resulting in reduced credibility of the screening program.
- Technology for follow-up services, including intervention when necessary, needs to be adequate

for use in rural settings.

#### Specific Messages for Physicians/Professional Associations/Hospitals

- Families with children who are hard-of-hearing may not be receiving adequate information about use of amplification devices early to develop spoken communication better.
- Well-baby nursery environments have obstacles that must be addressed.
- Limited staff have access to newborns to prevent exposure to germs.
- Infants are perceived as being “well.”
- The primary focus is on getting the mother ready to take the infant home.
- The physician may have seen the infant before the screening occurs and may not see the infant again prior to discharge.
- Mothers have multiple concerns with limited or no insight into the importance of hearing screening.
- Communicate screening results accurately and carefully to parents to ensure they understand the importance of the results and are motivated to return the infant for follow-up services.
- Explain speech developmental milestones so they and hearing screening into regular well-baby care.
- Standard protocols for interpreting screening results and communicating those results to others should be developed.
- Some physicians need to be aware that mild, moderate, and high frequency hearing loss cannot be identified through behavioral observation alone or singly based on the child’s history, though the absence of babbling at 10 months of age has been shown to be a marker.
- Physicians should require office staff to be responsive to families in order to assist parents with getting children through the health care system.
- Make the screening process interactive for the entire family when possible, e.g., conduct hearing screenings on other family members when the infant is brought to a facility for a screening.
- Take advantage of opportunities to cross-train people to perform some screening tasks in areas where resources are lacking in the community such as technicians operating under the supervision of a rotating technologist and paramedics and emergency medical personnel and use technology where possible or to accommodate the flexibility of discharges in well-baby nurseries (round the clock, evenings, and weekends) use mid-level care providers such as volunteers, nurses, clerks, nurse aides/assistants, lab technicians, or respiratory therapists to conduct the first level of screening. Ensure the secondary testing is appropriately done.
- Physicians must be careful when suggesting communication or devices/equipment options to parents. While it’s ideal to inform parents about a wide array of options, school districts often

can't provide all of them.

- Decisions about a communication mode for a child who is deaf is a highly personal family decision. Processes should be developed to empower families with their decision-making authority, e.g., parents given time to explore options, see developmental evidence, and utilize informal support mechanisms before choosing a communication mode. Studies indicate parents feel burdened by strong opinions about communication choices.
- If the newborn doesn't pass the initial screening, explore the possibility of using audiologists already in the facility to do a definitive ABR before the baby leaves the hospital.
- If newborn hearing screening services or follow-up services are outsourced, oversight should be such that the highest quality services necessary can be ensured.
- The use of incentives may be appropriate, such as travel vouchers, to encourage parents to return for follow-up care.
- Hearing screening should follow the example of other types of screening such as heel stick testing or vision screening, and be seen as one entry point into a comprehensive child health care system.
- Provide a family-centered practice so families can be coached to become the primary interventionists with their infants. Avoid the child-focused model where clinicians come to the home and work directly with the infant rather than empowering the family to have positive interactions with the baby.
- Professionals need to either become knowledgeable about the state or local system for early identification of hearing loss and resources that are available for families or be able to refer parents to other professionals who have the skills to facilitate moving families into the screening process and are knowledgeable about early intervention systems and resources available to families under state supported systems. This is particularly true in rural areas where services may be more limited.
- Evaluate children according to established guidelines.
- Develop discharge questionnaire addressing practical contact issues such as whether the baby will have the same name after discharge and phone numbers for extended family members.
- Use existing services for families who cannot get into a facility for follow-up, e.g., if home health nursing is used for well-baby checkups, the hospital audiology program could extend the checkup to the screening process.

### **Suggested Models for Investigation**

- State metabolic screening programs: Physicians are responsible for doing the follow-up but not for knowing whether the state receives the test results.
- Retinopathy programs: Strategies used include making the appointment with the ophthalmologist before the child goes home and the ophthalmologist takes responsibility for finding out what happened if the child doesn't show up for the appointment.

- Great Valley Community Health Center for Latino/Latina Families: One obstacle noted was that a high percentage of the families don't have the same phone number more than 3 months at a time. The Center modified practices so that when families came in, they screened them for everything while they were there.
- Program for drug users: Population is indigent, homeless drug users. Currently, 550 welfare mothers are being followed in year 4 of the project and the follow-up rate is 97%. This project is housed in the community where the clients are. The Center is furnished in a culturally appropriate way. Refreshments are served to moms and toys and a safe area are provided for kids while the mom's being interviewed. They create interactive activities for moms such as an audio system with a computer and a touch screen mechanism for answering questions rather than using a trained interviewer. They also take pictures for the client's file to ensure the validity and security of the process and take pictures of the infants to give to parents because parents often don't have other means to get a baby picture.
- Hospital labs have a system related to compliance for handling a large volume of data. Labs receive doctors' orders, draw blood, keep track of whether a child was actually tested, maintain information such as the age of the child when tested, test results, and send a copy of the results to the physician who ordered the test.
- Ultrasound model: when ultrasound first came out it was not recommended routinely but many women had it done and got a picture of the results to show family members. With this model, it was a clear desire on the part of parents that made the test almost routine today.
- Small study on immunization in rural Nebraska: The study looked at when children got their first immunization. If children was connected to their primary care practice by three months of age for their first shot, they then ended up-to-date on the rest of their immunizations by the time they started school. If they didn't make that connection, then they tended to not be connected to a system of care.
- HRSA-funded state early identification programs: Currently in the process of obtaining data for state profiles by using a series of questions each state fills out. It asks what type of screening is going to be done, what type of equipment will be used, what the protocols are, whether second stage screening is done, whether those services are located in the hospital, how follow-up is done, what the follow-up rates are within and across states, what the program components are, how the program is funded (including screening, diagnostics, and interventions).
- Massachusetts early identification screening program: They're getting approximately 80% back for follow-up through the use of electronic birth certificates (EBC). In this state, the EBC is maintained by the state health department. Information is updated automatically as it's sent by hospitals/physicians. Responsibility for follow-up is divided. All infants who do not pass the screening are referred for follow-up. The hospital is responsible for notifying the primary care physician about the referral and the family about the appointment. If the state health department doesn't get information from the referral back within a couple of weeks, they start making calls to the primary care physician and the family. If they still don't get anything, they then send a public health nurse to check on the family. This program is adding a web version of their electronic tracking.
- New York Demonstration Program: Dealt with a communication breakdown in the Bronx about transitioning between hospital-day screening and enrollment in the early intervention program

that could have resulted in a loss of children being followed-up. The program developed an extensive plan on how the communication process would take place and who was responsible for what to alleviate this concern.

- RSV prophylactic treatment (concerns a program that administered monthly shots to infants in a clinic): Even with motivated parents, it was necessary to set up a “shot clinic” where services could be provided from 8:00 in the morning till 10:00 at night. For follow-up to hearing screenings, rescreening services could be offered and parents could come in at their own pace (e.g., every Thursday we have rescreening available at a particular place).
- Inner city ophthalmologic screening for diabetic retinopathy: The disease is a significant health problem in the elderly population. Treatment is often made more difficult because of patients’ age and disability. These factors affect the ability of a patient to utilize public transportation to get to a clinic for treatment.
- Use existing well-developed resources to develop follow-up screening programs and tracking mechanisms, e.g., use labs responsible for PKU, bilirubin, and glucose screenings in hospitals to conduct hearing screenings. The advantages include familiarity with drawing blood from infants, science-trained with a minimum of a bachelor’s degree, comfort-level of staff with technology, great deal of contact with physicians in terms of reporting test results, and existing tracking systems which allow them to go directly into medical records, whether they are paper or electronic records.
- CHES program of the University of Wisconsin: Provides a private network of resources around topics, like asthma, cancer, etc. It’s available through the Internet, but is a controlled information source. Information is electronically provided in different forums, such as chat rooms and expert consultation. Computers are given to low income families and instruction is conducted on how to operate them.
- Heel Stick testing: Link follow-up process to existing state health department mechanisms. Responsibility for follow up should be with the health departments rather than it being a physician-based program because of the current economic burdens on hospitals and physicians.

California Early Periodic Screening, Diagnosis and Treatment Program: This Federal medicaid program ensures that all children under 200% of the Federal poverty level receive preventive health care exams. The local county programs get the results from the EPSDT exams. If there are referrals to follow-up on issues and problems identified during the preventive health care exam, they then contact those families and assist them to get in for the services and track who actually came in. California is now telling the EPSDT program and hearing coordination centers, that when a child that falls through the cracks, who does a no-show to appointments, or the provider can’t contact the family, then that child is referred at the local level for action through public health nurses or community health workers, etc. These individuals, in turn, go out and try to find those families and re-link them back with the system. They’re not limiting it in terms of income.

## Resources

A bibliography<sup>8</sup> [[http://www.nlm.nih.gov/pubs/cbm/hearing\\_early\\_id.html](http://www.nlm.nih.gov/pubs/cbm/hearing_early_id.html)] was prepared for the Working Group. The bibliography emphasizes population studies, reviews of the literature on health communication strategies including compliance and follow-through pertaining to other childhood diseases

and disorders, and material on medical home, including materials from audiology, speech-language pathology, otolaryngology, nursing, sociology, and ethics. The search surveyed literature updated resource material gathered for a previous Working Group (bibliography of the 1993 National Institutes of Health Consensus Development Conference on Early Identification of Hearing Impairment in Infants and Young Children). Selected examples of items include (in random order):

Milligan RA, Gilroy J, Katz KS, Rodan MF, Subramanian KN. Developing a shared language: interdisciplinary communication among diverse health care professionals. *Holistic Nursing Practice* 1999 Jan;13(2):47-53. [PMID:10196902]

American Academy of Pediatrics, Committee on Children With Disabilities. Care Coordination: Integrating health and Related Systems of Care for Children With Special Health Care Needs. *Pediatrics* 1999 Oct;104(4).

Redlener I. Overcoming barriers to health care access for medically underserved children. *Journal of Ambulatory Care Management*. 1993 Jan;16(1):21-8. PMID: 10123427

Kelly MP. Health education, the health promotion movement, and communication. *Journal of Biocommunication*. 1996;23(1):13-7. PMID: 8723547

Freimuth VS, Mettger W. Is there a hard-to-reach audience? *Public Health Reports*. 1990 May-Jun;105(3):232-8. PMID: 2113680.

Cegala DJ. A study of doctors' and patients' communication during a primary care consultation: implications for communication training. *Journal of Health Communication*. 1997 Jul-Sep;2(3):169-94. PMID: 10977246

Brodie M, Flournoy RE, Altman DE, Blendon RJ, Benson JM, Rosenbaum MD. Health information, the Internet, and the digital divide. *Health Affairs (Millwood)*. 2000 Nov-Dec;19(6):255-65. PMID: 11192412

Fong GT, Rempel LA, Hall PA. Challenges to improving health risk communication in the 21st century: a discussion. *Journal of the National Cancer Institute Monographs*. 1999;(25):173-6. Review. PMID: 10854475

Phillips DP, Kanter EJ, Bednarczyk B, Tastad PL. Importance of the lay press in the transmission of medical knowledge to the scientific community. *New England Journal of Medicine*. 1991 Oct 17;325(16):1180-3. PMID: 1891034

Ratzan SC. Health communication ethics. *Journal of Health Communication*. 1998 Oct-Dec;3(4):291-4. PMID: 10977259

Berland GK, Elliott MN, Morales LS, Algazy JI, Kravitz RL, Broder MS, Kanouse DE, Munoz JA, Puyol JA, Lara M, Watkins KE, Yang H, McGlynn EA. Health information on the Internet: accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association*. 2001 May 23-30;285(20):2612-21. PMID: 11368735

Schroeder RE, Morrison EE, Cavanaugh C, West MP, Montgomery J. Improving communication among health professionals through education: a pilot study. *Journal of Health Administration Education*. 1999 Summer;17(3):175-98. Review. PMID: 11184900

Gosbee J. Communication among health professionals. *BMJ*. 1998 Feb 28;316(7132):642. PMID: 9522773

Izenberg N, Lieberman DA. The Web, Communication Trends, and Children's Health. Part 2: The Web and the practice of pediatrics. *Clinical Pediatrics (Phila)*. 1998 Apr;37(4):215-21. PMID: 9564570

Ochs K. Communication in rural health care. *The Kansas Nurse*. 1995 Aug;70(7):4. PMID: 7494390

Duggan A, Windham A, McFarlane E, Fuddy L, Rohde C, Buchbinder S, Sia C. Hawaii's healthy start program of home visiting for at-risk families: evaluation of family identification, family engagement, and service delivery. *Pediatrics*. 2000 Jan;105(1 Pt 3):250-9. PMID: 10617732

Maurana CA, Clark MA. The Health Action Fund: a community-based approach to enhancing health. *Journal of Health Communication*. 2000 Jul-Sep;5(3):243-54. PMID: 11185024

### **Working Group Participants**

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## Notes

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<sup>1</sup>National Institute on Deafness and Other Communication Disorders (NIDCD). *National Strategic Research Plan: Hearing and Hearing Impairment*. Bethesda, MD: HHS, NIH, 1996.

<sup>2</sup>In March 1993, a National Institutes of Health Consensus Conference recommended hearing screening of all newborns. Statewide systems for universal newborn hearing screening have begun to be addressed through legislation, voluntary initiatives, and federal support. Universal screening will result in more infants being referred for diagnosis and intervention. To date [12/31/01], 35 states have passed universal newborn hearing screening legislation and five other states have legislation pending.

<sup>3</sup>The FICC was established under the 1991 Amendments to the IDEA to address interagency service issues to young children with disabilities and their families. To find out more about IDEA see: [www.ed.gov/offices/OSERS/Policy/IDEA25th/](http://www.ed.gov/offices/OSERS/Policy/IDEA25th/)

<sup>4</sup>Although not directly related to communication issues or the NIDCD mission, members of the group indicated that reimbursement issues are a concern. Specifically, the concerns included the necessity of scheduling follow-up appointments before the infant leaves the hospital but insurance providers often not reimbursing providers unless prior authorization was obtained, follow-up services not being covered by insurance because they are not a standard of care, framing follow-up services to insurers as something that will improve an individual's functional status

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and their ability to productively contribute which could ultimately reduce future insurance costs, the necessity of establishing an expedited insurance authorization process for follow-up of infants identified through the newborn hearing screening program and difficulties associated with reimbursement for screening, follow-up, and intervention services having several different sources of funding, such as under education, social services, or health care, at both the Federal and state level.

<sup>5</sup> Blood, obtained by "heel stick," is routinely drawn from newborn infants for testing of blood type and conditions such as phenylketonuria, thyroid function, sickle cell disease, or other blood disorders.

<sup>6</sup> Special Supplemental Nutrition Program for Women, Infants, and Children, commonly known as WIC. WIC provides Federal grants to States for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children who are found to be at nutritional risk.

<sup>7</sup> The limited number of pediatric otolaryngologists in the United States necessitates working with professional organizations to conduct grass-roots education with general otolaryngologists, family practitioners, nurse practitioners, family clinics, and rural pediatricians about conducting hearing screenings, interpreting findings, and the importance of clinical practice guidelines. Creative/unique venues, such as nontraditional entertainment industry/media sources, should also be utilized to reach physicians.

<sup>8</sup> To be added.