BEYOND NEWBORN HEARING SCREENING: MEETING THE EDUCATIONAL AND HEALTH CARE NEEDS OF INFANTS AND YOUNG CHILDREN WITH HEARING LOSS IN AMERICA

"Report and Recommendations of the 2004 National Consensus Conference on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss"

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ABSTRACT

This Report is the summary of the Consensus Conference on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss that was held in September, 2004. It is the product of the leading experts in America today on the topic of hearing loss in young children. The Report represents hundreds of hours of investment of personal and professional time by each participant and the truly collegial and cooperative partnership between and among experts who represent various professional disciplines and different points of view.

This Report is dedicated to the participants and sponsors of the Consensus Conference. We are indebted to them for their support and significant contributions to this endeavor.

In 2002, the Principal Investigators, Dr. Dorothy K. Marge and Dr. Michael Marge, were requested by the Office of Special Education Programs, U.S. Department of Education (OSEP), to conduct a national conference on closing the gaps in services and programs for infants and young children with hearing loss. The Department of Education had evidence that although our Nation has realized tremendous strides in identifying young children with hearing loss during the past decade, the availability and efficiency of services for children with hearing loss were “abysmal.” The next critical step in the provision of appropriate services for these children was either absent or disorganized without a trained case manager and a single point of entry into a system of services. The Department of Education perceived the problem as a crisis that required immediate and full attention by all stakeholders.

With partial financial support from the OSEP, the PIs sought additional support from a number of sponsors that had expressed interest in serving our children with hearing loss. A list of the sponsors is found in Appendix 1 of this Report.

After more than two years of planning, seventy participants representing all phases of the topic were invited to the Consensus Conference on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss, September 10-12, 2004, at the Holiday Inn in Old Town Alexandria, VA. Before the Conference, participants were mailed a packet of materials that included: a. the Conference Program and anticipated outcomes; b. four commissioned papers on various aspects of the topic; c. additional background materials recommended by the participants; and d. a list of participants and their assignments as speakers, moderators, and members of small discussion groups. Of particular concern was the Level of Evidence the participants would use to substantiate their recommendations. In many instances, the Level of Evidence was “conventional wisdom and agreement” or “perceived best practices.” In other instances, participants presented scientific evidence in support of a recommendation to improve services. A subsequent publication, in process, will provide complete citations and levels of evidence in support of each recommendation.

The anticipated outcomes expressed as Recommendations that received total agreement or almost total agreement were categorized as follows:

- Elements of a model educational program of services
- Best approaches to implement a model educational program of services with a recommended research agenda
- Elements of a model health care program of services
- Best approaches to implement a model health care program of services with a recommended research agenda
- Ways in which education and health care may combine and coordinate their efforts effectively and efficiently for the benefit of the child and his or her family.

Based on the written evaluations by the participants submitted when the Conference concluded and based on the subsequent unsolicited responses by notes from participants and sponsors, the Conference was assessed to be highly successful in meeting its objectives, constructive and productive, and established excellent and long-needed cordial working relationships between and among the professions that are committed stakeholders in this endeavor.

After the Conference, a Rewrite Group was formed to assist the PIs in refining the Report of the Conference. Several iterations were written and reviewed by all participants and the results are reflected in this Report.

The Recommendations under each section, Education, Health Care and Education/Health Care Combined, will serve as guidance for initiating a new National Program by pertinent Federal agencies and for serving as a basis for new legislation by Congress and State legislatures to close the gap in services for infants and young children with hearing loss.

One of the most exciting and encouraging products emanating from the Consensus Conference is the high level of interest and commitment by all participants who have dedicated their professional lives in service to our children with hearing loss. After working for years in improving the development of children with hearing loss, there is now a glimmer of hope that at last we may realize a dream of long ago—that infants and young children with hearing loss will receive the best possible services in a timely, facile, and cost-effective manner so that they may reach their full potential as citizens of the United States.

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June 22, 2005

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"Report and Recommendations of the 2004 National Consensus Conference on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss"

Introduction:

This Report provides a review of the planning, conduct and outcomes of the 2004 Consensus Conference on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss. In the following pages, the reader will find:

A. Background of the Problem that resulted in the development and implementation of the Consensus Conference.

B. Information about the objectives, planning process, selection of participants, and agenda of the Conference.

C. Outcomes that are presented in three categories: (1) Recommendations for model educational interventions and proposed research agenda, (2) Recommendations for model health care interventions and proposed research agenda, and (3) Recommendations for ways in which education and health care services may be combined and coordinated for greatest effectiveness.

Background:

Hearing loss is the number one birth disorder in America. Approximately 1 in 1,000 newborns (or 33 babies every day) is born profoundly deaf. Another 2-3 per 1,000 babies are born with partial hearing loss. (National Center for Hearing Assessment and Management; Centers for Disease Control and Prevention).

Infants with hearing loss typically will not spontaneously develop language and literacy because most language development occurs before 18 months of life and lack of typical auditory and/or supplemental visual input during this critical period will irreversibly interfere with the healthy development of language and literacy skills.

The lack of age appropriate language development and literacy skills have substantial negative effects on the child's cognitive and social development which, in turn, interferes with success in school and later life, especially in the development of reading and related activities.

According to White (2004), during the past 10 years, there has been a dramatic increase in the number of babies being screened for hearing loss prior to discharge from the hospital with 90% of newborns now being screened. Currently, 42 states and the District of Columbia require newborn hearing screening by law or voluntary compliance. Even though hundreds of hospitals in the United States have demonstrated the feasibility and cost-efficiency of operating newborn hearing screening programs as the standard of care for babies born in their hospital, about 40% of the newborns are currently screened for hearing loss before being released from the hospital. The results of this screening have revealed that hearing loss occurs in newborn infants more frequently than any other health condition. Only 67% of babies are now screened for hearing loss before 1 month of age. The rest or 33% are undetected until two or three years of age or later (compared to 10% in other industrialized nations).

A small, but important subgroup that is not being well served by current Early Hearing Detection and Intervention (EHDI) programs of the Centers for Disease Control and Prevention are babies who are born at home. With 1-2% of all births occurring outside the hospital, this represents 40,000 to 80,000 babies per year. Only 21 states reported that they had a systematic program in place to screen these births, and those states were only able to screen an estimated 41% of out-of-hospital births. Thus, the vast majority of these babies are not currently being screened for hearing loss.

It is predicted, however, that our Nation is on the path to eliminating delayed detection of hearing loss within the next five years (Creaghead, 2002).

Early detection of hearing loss (i.e., before 6 months of age), coupled with medical, audiological, and educational intervention and treatment, is reported to be highly effective in ameliorating the effects of congenital hearing loss which often reduces the need for long term special education services and substantially reduces the expenditure of public funds (Yoshinaga-Itano, et al., 1998).

Authoritative and respected government and professional groups, including the National Institutes of Health Consensus Development Panel, the Healthy People 2000 and 2010 Reports from the Department of Health and Human Services, the Joint Committee on Infant Hearing comprised of representatives from the American Academy of Pediatrics, the American Academy of Audiology, the American Speech-Language-Hearing Association, the American Academy of Otolaryngology--Head and Neck Surgery, the Council on Education of the Deaf, and the Directors of Speech and Hearing Programs in State Health and Welfare Agencies, have all recommended that congenital hearing loss be identified shortly after birth, with intervention and treatment begun before 6 months of age.

A leader in advancing research and development and recommending a national policy for newborn hearing screening is the National Institute on Deafness and Other Communication Disorders, National Institutes of Health. In a 1993 Consensus Conference, the Institute identified the needs and minimal standards required for a national effort to test every newborn for hearing loss. This valuable input provided the impetus for the current legislative recommendation.

Within Health Resources and Services Administration, the Maternal and Child Health Bureau has sponsored a newborn hearing screening initiative since 1989, which has been based on interagency collaboration and consultation with other federal agencies concerned with infant hearing detection, diagnosis, and treatment/intervention.

Through the efforts of Congressman James Walsh of New York State, legislation was supported in 1999 that provided the first state Universal Newborn Hearing Screening grants in April 2000. In those areas where newborn hearing screening is occurring, the follow-up with appropriate and timely diagnosis and educational and health care interventions continues to be a major challenge. Linkages between screening programs and early educational and health care intervention programs are still not well established. Also, data management and tracking of these infants with hearing loss are still in the developmental stage.

Now that the technology for newborn hearing screening is feasible and cost-effective, we are realizing growth in the number of State programs that have introduced screening. The primary focus to date has been on the identification and diagnosis of the hearing loss. Unfortunately, limited attention has been given to the post-diagnostic educational and health care program needs for these children or to the preparation of professionals who will provide early intervention services for these children and their families. Current trends in the professional preparation across disciplines (e.g. public health, education, medical) emphasize the application of online distance learning technologies. Limited opportunities exist for the application of online technology to address the training needs for professionals to serve infants and toddlers who are deaf/hard of hearing and their families. Only one federally supported program, Collaborative Early Intervention National Training and e-Resource (CENTe-R), at the University of North Carolina at Greensboro is presently developing, field testing and disseminating online materials for graduate level preparation programs across educational disciplines (e.g. deafness, early intervention, early childhood).

In view of these factors, a conference that was focused on the educational and health care needs of infants and young children with hearing loss was urgent and most timely. This resulted in a proposal for a National Consensus Conference from SUNY Upstate Medical University that was submitted to key funding agencies and was financially supported by more than 15 sponsors.

<u>Conference Objectives:</u>

The Conference Proposal identified the following objectives:

1. To identify existing effective evidence-based educational and health care programs for infants and children who have been detected through universal newborn hearing screening to have hearing loss.
2. To identify professional and support staff who should provide educational and health care programs for these children. Related to this objective are a number of issues: Is there a need for modification of Early Intervention and Early Childhood Education curricula in colleges and universities so that future early interventionists and early childhood and related services professionals may be trained in this area of specialization? How will the disproportionate numbers of minorities among young deaf children be managed? Will this require bilingual specialists? What is the most appropriate, expeditious and accessible format for providing training?
3. To address how these children will attain "true access to general education." Identify the parameters of a longitudinal study that will determine effective approaches to the successful education of infants and children with hearing loss.
4. To address the issues regarding educational and health care programs and services for very young children with multiple disabilities where hearing loss represents one of several major conditions.
5. To explore the best manner to track and monitor the progress in education and health care for these children. Should the tracking remain at the State level or is this a federal responsibility? Also, there is a need to address program and service availability in various geographic areas (for example, rural vs. urban).
6. To identify the current and future role of Federal agencies in maximizing services to families with these children through Part C of IDEA. One of the problems with the universal newborn screening is that almost 50% of the children do not return for follow-up after they have been identified with hearing loss. In support of the President's New Freedom Initiatives with its focus on the application of technology for persons with disabilities, the Conference will explore the use of assistive technology for improving the lives of these children. The use of new and advanced hearing instruments, such as cochlear implants, electronic communication devices, digital hearing aids, and computers, will be addressed.
7. To delineate a research agenda for educational and health care intervention.
8. To identify the safeguards that must be in place to prevent abuse of children with disabilities, especially children with communication disorders.

Conference Outcomes:

The Conference Proposal identified the following anticipated outcomes:

1. To identify the current and future roles of Federal agencies in the research, development and implementation of programs to meet the educational and health care needs for infants and young children with hearing loss.
2. To obtain valuable and needed information about the magnitude and scope of the problem.
3. To disseminate recommended practices for developing effective Early Intervention, Early Childhood Education and Deafness curriculum, health care

intervention, and recommendations about protecting the safety and health of children with hearing loss.

4. To identify recommendations about how to effectively track and monitor the progress of these children, either utilizing existing systems or creating a new one.
5. To delineate the need for research that evaluates the various approaches in education and health care interventions for infants and young children with hearing loss.
6. To obtain recommendations for a campaign to raise greater awareness of the value of universal newborn hearing screening for state health and education administrators, educational and medical professional organizations, social service organizations that are dedicated to service of families, and the general public. To obtain recommendations for an intensive parent education program for parents and expectant parents, stressing the value of newborn hearing screening and the follow-up educational and support program.
7. To identify existing programs and resources that can be contacted for additional information and materials for training and informational purposes.

Conference Planning Committee:

A Planning Committee comprised of representatives from each of the sponsoring organizations was established to assist the Principal Investigator in the planning and implementation of the Conference.

Procedure for Inviting Conferees:

Members of the Conference Planning Committee were requested to submit nominations for each of the following categories: educational researchers (specialists in the education of infants and young children with hearing loss, specialists in the education of school aged children who are deaf/hard of hearing in grades K - 3, reading and language specialists); representatives from health and health related specialties (otolaryngologist, pediatrician, audiologist, speech-language pathologist, nurse, assistive technologist); representatives from child psychology, guidance and counseling, social work, and mental health specialties; and representatives from families of infants and young children with hearing loss identified by the infant hearing screening program and advocates for children with hearing loss.

Using a prescribed set of criteria, a final list was derived from those who best met the criteria and who accepted the invitation to participate

Non-federal and Federal representatives from the sponsoring agencies were also invited to participate in the Conference. A list of sponsoring organizations is found in the Appendix.

Preconference Materials:

Prior to the conference, each invitee received a packet of materials that provided background information about the topics of the Conference. Two types of materials were sent: (1) Four commissioned papers by scholars and (2) Selected publications and annotated bibliographies. The commissioned papers covered the following subjects: (a) Scope and magnitude of the problem of testing infants for hearing loss, (b) Background and history of hearing screening programs for infants and young children, (c) Current status and effectiveness of educational and health care services for infants and young children with hearing loss, and (d) Evidence of effectiveness and transferability of model educational and health care services programs for infants and young children with hearing loss.

Conference Program:

"Consensus Conference on Effective Educational and Healthcare Interventions for Infants and Young Children with Hearing Loss,"

September 10 - 12, 2004, Old Town Alexandria Holiday Inn Select, Alexandria, VA.

All events will be held on the 5th Floor Conference Center Area

Friday, September 10, 2004:

3:00-5:00 PM	Registration in Brent Foyer Beverage break in Brent Foyer
4:00–5:00 Brent	Opening Session: Dorothy Marge, Ph.D., Conference Coordinator, Welcome, introduction of co-sponsors, overview of three topics and anticipated outcomes of the conference. Greetings sent by U.S. Congressman James Walsh read by Dr. Robert J.Weber, Chair, Dept. of PM&R, SUNY Upstate Medical University Introduction of the Invited Keynote Speaker, Dr. Michael Marge, Co-Conference Coordinator Keynote Speaker: Anne Ryun, wife of U.S. Congressman Jim Ryun of Kansas, Co-Chair of the Congressional Hearing Health Caucus
5:00 – 6:00 Brent	Panel Presentation: "Parental Experiences with Post-Identification Programs and Services for Their Children with Hearing Loss." Four parents of children with hearing loss. Beth Benedict, Ph.D., Moderator. Panelists are: Jill McMillin, Amber Robles-Gordon and Jackie Busa. They will discuss how they accessed programs and needed services for their children.
6:00-6:15	Break

6:15 – 7:30 Brent	Dinner: Greetings by Alan Spitzer, MD, Pediatrix Medical Group. Dinner Speaker—Karl White, Ph.D., Utah State University, "The Current Status, Problems and Recommended Solutions in Identifying and Diagnosing Hearing Loss in Infants and Young Children," introduced by Alan Diefendorf, Ph.D. Dinner sponsored by Pediatrix Medical Group, Inc.
7:30 – 7:45	Break
7:45 – 9:30 Brent	Panel Presentation: "Post-identification and Diagnosis of Hearing Loss—What are the Gaps in the Delivery of Effective Educational and Healthcare Services for Infants and Young Children with Hearing Loss:" Moderator:Vanessa Winborne, Part C Coordinator for Michigan. Panelists: Barbara Raimondo, J.D., Conference of Educational Administrators of Schools and Programs for the Deaf; John Eichwald, M.A., Lead Public Health Advisor, CDC/NCBDDD; Nancy Roizen, MD, representative of the American Academy of Pediatrics and SUNY Upstate Medical University's Department of Pediatrics; and Charles "Sam" Woods, MD, representative of the American Academy of Otolaryngology—Head and Neck Surgery and SUNY Upstate Medical University's Department of Otolaryngology and Neurosurgery."
9:30 PM	Adjournment for the day.
9:30-10:15 Brent Room	Special Meeting with Small Group Discussion Leaders

Saturday, September 11, 2004:

7:30–8:30 AM	Continental breakfast is served in Brent Foyer and dining is in Brent Room.
8:30–9:00 Brent	Welcome, Robert J. Weber, MD, Chair, Department of Physical Medicine and Rehabilitation, SUNY Upstate Medical University. Plenary Session: Presider, Dorothy K. Marge, Ph.D. Introduction of Topic #1: "Constructing an ideal model of educational and healthcare interventions for infants and young children with hearing loss:"
9:00 – 9:15	Break

9:15–11:45	Small group discussions: Topic #1. Conferees are assigned to Brent Room, Captain Piercy Room, Room 519 or Room 520
11:45–12 PM	Break
12 –1:00 PM Brent	Buffet Lunch Speaker: Christine Yoshinaga-Itano, Ph.D.—"Update on Effective Educational Interventions for Children with Hearing Loss," introduced by Teresa McMahan, M.S.
1:00-1:15	Break
1:15 – 2:45	Small group discussions of Topic #1 continue in same room assignments. Moderators prepare Summary.
2:45 – 3:30	Plenary session: Presider: Michael Marge, Ed.D.
Brent	Summary recommendations from Discussion Groups for Topic #1. Introduction of Topic #2: "A coordinated educational/medical system of services for infants and young children with hearing loss: Education, medicine and other professional services providers working together in a systematic manner at the community level with a single point of entry and direction for the maximum benefit to the young child with hearing loss and to his/her family."
3:30 – 3:45	Beverage break
Brent Foyer	
3:45 – 5:30	Small group discussion of Topic #2. Each group will be comprised of a mix of representatives from each of the major areas of services and programs addressing the same topic. They include parents, physicians, audiologists, speech-language pathologists, teachers of the deaf and hard of hearing, and other specialists). Conferees are assigned to Brent Room, Captain Piercy Room, Room 519 or Room 520.
5:30 PM	Adjournment for the day

Sunday, September 12, 2004

7:00–7:45 AM	Continental breakfast is served in Brent Foyer and dining is in the Brent Room.

7:45-8:00	Break
8:00-9:00	Small group discussions of Topic #2 continue in same room assignments as Saturday. Moderators prepare Summary.
9:00–10:00	Plenary session: Presider: Margaret Turk, MD Summary recommendations from Discussion Groups for Topic #2. Introduction of Topic #3: "Required Federal, state, community and personnel resources needed to fully implement the model programs of intervention."
10:00–11:30	Small Discussion Groups: Topic #3. Conferees are assigned to Brent Room, Captain Piercy Room, Room 519 or Room 520.
11:30-11:45	Break
11:45–12:45 Brent	Buffet Lunch Speaker: Betty Vohr, MD– "Update on Healthcare Advances for Infants and Young Children with Hearing Loss," introduced by Brenda Lonsbury-Martin, Ph.D.
12:45-1:00	Break
1:00–2:15 PM	Small group discussions of Topic #3 continue in same room assignments. Moderators prepare Summary.
2:15–3:00	Plenary Session: Presider: Albert Mehl, MD Summary recommendations from Discussion Groups for Topic #3.
3:00-3:15	Beverage break in Brent Foyer
3:15- 4:00 Brent	Final summary, conclusions, and adjournment conducted by Drs. Weber and Dorothy Marge (Collection of Evaluation Forms).

I. CONSENSUS REGARDING EDUCATIONAL INTERVENTIONS

A. What are the Elements of a Model Educational Program?

1. Effective Child Find efforts.

It is imperative that all infants and young children with hearing loss are identified and offered appropriate educational and health care services. The problem of "loss to follow-up" after newborn hearing screening must be more effectively addressed, otherwise many children who require essential services will not receive them in a timely manner.

2. Key Decision-making by the Family About Choice of Services Among All Options.

Both hearing and deaf parents face similar challenges as they learn that their newborn has a hearing loss. They need to make decisions for a newborn child whom they are just beginning to know. Many hearing parents may start from a position of no knowledge or experience with hearing loss. While a parent who is deaf has personal experience with hearing loss, the parent still needs to learn about language development for their child, programs that are available, and other resources and community options. The initial emotional response to a diagnosis of hearing loss for most hearing parents may cause increased stress, rendering them emotionally vulnerable and susceptible to bias that may be provided by “experts.” While it is clear that all decisions belong to the parents, it is imperative that the parents have relationships with professionals with whom they are comfortable discussing choices and paths that families may take. As a result, professionals who guide them have an ethical and moral obligation to be as honest, open and informative as possible in such guidance.

The specialist relies on the family’s extensive knowledge of their infant/young child and listens carefully to their questions and/or concerns. This professional offers his/her knowledge and experience toward mutual problem-solving, collaboration and discussions of ways the family might work toward their goals for the child. Parents and professionals each offer unique expertise as they work out puzzles together. Like the parent-infant relationship, the parent-professional relationship is a reciprocal one between equal partners who have gained each other’s trust. Throughout the process the specialist utilizes *coaching* strategies specifically tested in early intervention programs (Moeller, personal communication, August 2004). The family gains the competence and self-confidence to not only participate as a knowledgeable member of the team but to manage the learning process for their child throughout the school years. The consultative approach increases the independent functioning of families and other caregivers by helping them to identify needs and problems, develop workable strategies to address them, thereby increasing the family’s feelings of self-efficacy. (Coleman, Buysse, Scalise-Smith, & Schulte, 1991).

With these two principles underlying services (relationship-focused early intervention and the consultant role for specialists) family members can discover their natural strengths in facilitating their child's growth across all domains.

Because parental involvement is a key contributor to outcomes for children, it is vital that parents have input at the beginning and in the development and implementation of their child's program of intervention and have the opportunity to eventually lead the process.

a. Parents should be recognized as the decision makers and the primary facilitators of their child's cognitive-linguistic and social-emotional development.

b. Professionals need to focus on strengthening the parents' competence and confidence to positively effect their child's development by making decisions regarding a) early intervention services, b) communication and language modalities and approaches, and c) assistive hearing devices.

c. Parents need guidance in becoming effective advocates for their child. To achieve this goal, there should be focus on strengthening the parents' competence and confidence to positively effect their child's development by making decisions regarding a) early intervention services, b) communication and language modalities and approaches, c) assistive hearing devices, and d) effective ways to communicate with program administrators.

d. Parents and members of the family need guidance in becoming informed consumers of services and programs for their child with hearing loss and as effective communication partners for their child. An informed consumer is one who is knowledgeable about choices and their advantages and disadvantages, knows when to seek professional advice and counsel when questions arise, and has a healthy skepticism or will not be afraid to question the source of the advice and counsel.

e. Parents' decision about modes of communication and desired outcomes should be honored and supported. This involves the following actions:

  - Provide training in the family's chosen communication approach(es) to allow them to be proficient/fluent communication partners with the child.

  - Explain all options of communication mode to parents in an unbiased fashion. Parents should be encouraged to explore programs with those that implement the various options. This is not just "presentation of choice" but a *process* to help parents make appropriate and informed choices including: 1) systematic observation of the child's use of residual hearing, vision, gestures, and vocalizations; 2) ongoing audiological testing; 3) child assessment; and 4) assessment of family needs and desired outcomes. The family choice may be one methodology or a combination of methodologies, or components of methodologies. The most comfortable and effective options for communication for the child and family need to be provided and supported.

f. Parents should be provided with complete information regarding the various amplification options available so that they can make fully informed decisions about the most appropriate option for their child and family.

g. Parent education is needed concerning Part C and Part B of the IDEA as related to children with hearing loss. Transition planning from Part C to Part B and from Part B preschool age to Part B school age is a vital part of any early education program. Parents' involvement in planning for these important transitions should be encouraged and supported.

h. Families need to be offered education about the development of early non-verbal cognitive skills, language, literacy (See Note 1), social-emotional health, auditory skills, sign language skills, speech skills, and strategies for promoting these skills through daily routines and play.

Note 1: For purposes of clarity, a widely used definition of literacy is found in The Workforce Investment Act of 1998. The Act defines literacy as follows: literacy in its broadest terms refers to an individual's ability to read, write, speak in English, compute and solve problems at levels of proficiency necessary to function in age-appropriate ways in the family of the individual, at school, on the job, and in society. This definition is broader than the traditional concept of literacy which focused only on an individual's ability to read.

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i. "Family-centered" programming needs to be provided in home or center environments, including a focus on natural daily routines as the medium for communication interaction and language growth.

j. Parent and family adaptation, sense of well being and accommodation to the child’s hearing loss should be promoted by providing comprehensive information, support (physical and emotional), and skills that enable families to:

- understand the consequences of a delay in language acquisition,
- actively participate and advocate for their child and family,
- develop realistically high expectations for their child’s future,
- access information and resources about deafness and hearing loss;
- access services within their communities,
- understand their rights, and
- develop skills to effectively interact and communicate with their child with a hearing loss.

k. Families need to be supported in providing the child fully accessible language stimulation that optimizes language development, from the earliest days and months of the infant’s life through natural, meaningful and developmentally appropriate interactions. Encourage families to have a high level of involvement in their child’s language and communication development. The parents need to respond to their baby's physical state and cues to wants and needs and to participate in non-verbal, turn-taking with their infant.

l. Parents should be offered support, including grief counseling, through the ongoing relationships with specialists who are skilled in counseling/active listening strategies, parent support groups specifically for families of children with hearing loss, parent to parent support and individual/family counseling if indicated.

m. Parents must have opportunities to meet and interact with children and adults who are deaf or hard of hearing to help them deepen their understanding of the impact of hearing loss and envision the future possibilities for their child. The Individualized Family Services Plan (IFSP) should document strategies that encourage family involvement/communication, parent-to-parent contact and opportunities to meet with adults who are deaf or hard of hearing and have all degrees of childhood onset hearing loss and who use a variety of communication strategies including spoken language and sign language.

n. A statewide parent advocacy center should be available for families of children with hearing loss. Expand the focus of existing federally funded Parent Advocacy Centers (PAC). Secure funding for states to increase family advocacy and training activities (e.g., parent training in teaming, IFSP development, decision making, etc.).

A number of federally funded programs already exist to provide parent-to-parent support and parent training (such as Parent Training Centers (PTC), Protection & Advocacy systems (P & A), Maternal and Child Health Bureau Centers (MCHB centers). These programs need to be better coordinated and directed to specifically address the needs of children with hearing loss and their families.

o. Services must honor the culture and values of families. Culturally sensitive programming includes: a) culturally sensitive interpreters, b) culturally and linguistically appropriate assessment tools, c) early interventionists from culturally and linguistically diverse backgrounds, d) hearing health education in racial and ethnic minority communities.

p. There should be support services to assist families to reduce and cope with multiple stressors in family life (e.g., marital stress, job satisfaction, economic problems, developmental needs of their other children, respite and child care, transportation to and from provider services when required). Emphasize **pre-literacy** skills. Parents need to be coached to actively read to their infants and toddlers each day. Support families in learning about and facilitating literacy in the home.

3. Choices of services that are specific to the needs and capabilities of the child and family.

These services include (a) choice of a professional partner (advocate/advisor/specialist/ ombudsman) in the development and implementation of the child and family program; (b) home or center-based services or both; (c) intensity of intervention; (d) amplification options; (e) frequency of assessment, (f) mode of communication (such as, auditory-oral, auditory-verbal, cued speech, sign languages, simultaneous communication); (g) consultants—mental health, spoken language, sign language, parent, deaf/hard of hearing; and (h) deaf/hard of hearing community participation.

Currently, there is wide disparity in information and materials being provided for parents by numerous professionals with whom a parent has contact after the child's confirmation of a diagnosis. There is no specific entity or one professional designated to provide information in most states. Often, professionals designated with the role of informing families do not have backgrounds or requisite knowledge on hearing loss topics, or balanced resources on available communication strategies. There is need, therefore, for a single source of unbiased and reliable information to guide the parents.

Each community should have available high quality services for families (quality auditory/speech development, sign language instruction, counseling services, information about hearing loss, home-based, parent-centered/directed services). Quality indicators include: 1) highly skilled service providers for each service component (i.e. auditory therapist, sign language instructor, counselor, etc.); 2) knowledge about audiological principles, auditory skill development, assessment and intervention; 3) speech and/or sign language skill development assessment and intervention; 4) language skill development (spoken or sign), assessment and intervention; 5) social-emotional development; and 6) cognitive development.

Parents should be provided with group and individual emotional support and counseling throughout the process of diagnosis and early intervention. Providers need to possess support and counseling skills for diverse populations (cultural, socio-economic) and functional and dysfunctional family systems. It has long been recognized that some parents of children with disabilities often experience grief comparable to grief associated with any profound loss. Parents may experience grief that is manifested as shock, denial, depression, anger, fatigue, and a wide range of other unpleasant and sometimes debilitating emotional states. Parent support groups, parent-to-parent mentors, access to professional emotional support, and the supportive practices of allied professionals assist parents in adjusting to the reality of their children's diagnoses which enhances their ability to effectively address their children's needs. With the advent of newborn hearing screening, the specific needs of parents of neonates will require particular attention because the loss is identified soon after birth when the critical bonding process between parents and their baby occurs.

All children who are deaf or hard of hearing are entitled to an environment that presents the fewest language and communication barriers to their cognitive, social, and emotional development. Direct and uninhibited communication access to all facets of an educational intervention program is essential for a child who is deaf or hard of hearing to realize his or her full human potential. Their programs also should apply the tenets of relationship-focused early intervention (see Note 2). Finally, specialists should assume the roles of partner, advocate, educator and advisor.

Note 2: The central concept of relationship-focused early intervention is taken from relationship-based preventive intervention developed in the field of Infant Mental Health (Barnard, Morisset, & Spieker, 1993). This concept integrates the parent-child relationship and the intervener-family relationship as an effective approach to service delivery. (Weston, D. R., Ivins, B., Heffron, M. C. & Sweet, N. (1997). Family-centered refers to a continuum that begins with a focus on the child and the parents and expands to siblings and other relatives over time. With parents as the lead players, the specialist interacts with the family in ways that *support and strengthen the central relationship within the family*---that between parents and their baby/young child---at the same time increasing the family's confidence in the effectiveness of their intuitive parenting and communication skills. Rather than taking control in a domineering manner, the professional functions as a balanced partner who supports the family by recommending ways to enhance the nurturing and growing attachment and communication interaction between parent and child, noting their responsiveness to one another and their success as communication and "play" partners. The specialist comments on observed parenting/communication/play skills and notes how they promote child development and may recommend additional ways to encourage further development. Formation of collaborative relationships can help the family learn about their child's unique talents and abilities and promote their confidence and competence to make informed decisions regarding their child's and family's future. There is empirical evidence from the field of special education to support the effectiveness of relationship-focused intervention in comparison to child-directed therapies (McBride & Peterson, 1997, Guralnick, 1997).

Under Part C of the Individuals with Disabilities Education Act (IDEA), the definition of Natural Environments is offered as follows: "To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate. Natural environments mean settings that are natural or normal for the child's age peers who have no disabilities."

It was the consensus of the Conference Conferees that the concept of "natural environments" in part C of the IDEA requires careful interpretation when applied to infants who are deaf or hard of hearing and their families. An effective interpretation of a "natural environment" is one in which the intervention takes place in the context of and through the primary participation of family. Many families report they benefit greatly from services in a center-based setting where communication access issues are discussed, they can see other children who are deaf and hard of hearing, talk with other parents, and share with a wider group of experts and experienced others. Further research is needed to determine what environments best support child and family learning when such circumstances exist.

In some regions, natural environment has been misinterpreted to mean exclusively "home-based intervention." This interpretation is narrow and misguided if continued as practiced in some states. It is not necessarily "natural" to have specialists come to the home where the family feels pressure to present a positive (but possibly unnatural) scene. In some cases, the "natural" environment has been misinterpreted to allow services to take place with an infant to 3 year old without the participation of a family member as long as it is in an integrated community setting.

The home is often the ideal context of delivery of early intervention services. Many families and professionals report that the home can be an ideal place to develop communication and play skills in an environment familiar to the child and where strategies can be integrated into the family's unique setting and routines. In certain instances where families are disadvantaged by poverty, without a home visit program they would be deprived of early intervention services. In some other instances, however, when the service provider must travel long distances, home visitation may not practical or financially feasible. In many families financial needs necessitate the use of daycare. In some cases, a child's medical vulnerability may deter such participation. In other cases, the child's hearing loss may require expertly facilitated interactions. Ideally a child would be placed in settings after careful consideration of individual vulnerability in terms of health, readiness for group interaction, the readiness of the group setting to accept and meet the child's needs, and availability of continued support to the family.

These materials need to include an array of resources for use by early interventionists in partnership with the family. These materials shall address:

- "Being Deaf or Hard of Hearing,"
- Amplification,
- Cochlear implantation,
- Psycho-emotional support for families and Infant mental health,
- Child and family assessment
- Basic intervention issues, including (a) Individualized approaches to assessment and intervention, (b) Early family/infant communication interactions, (c) Natural environments and routines, (d) Matching communication options to children, (e) Early visual communication and strategies, (f) Early spoken language through audition, (g) Language development, (h) Early auditory learning, (i) Play and Cognitive development, (j) Early literacy development, (k) Language programming including signing English, Bilingual-Bicultural (Bi-Bi), American Sign Language (ASL), Aural-Oral, and Cued Speech, and (l) Providing Deaf and hard of hearing mentor/role models with all degrees of hearing loss and communication modes for children and families,
- Technology (including captioning; flashing lights for clocks, doorbells, phones; telecommunication devices for the deaf (TDD); videophones),

- Programming for children who are deaf or hard of hearing and who have other disabilities, and
- Adult communication strategies that promote language acquisition.
- Access to videos, interactive DVDs, CDs, print materials, and on-line access to information in English and in other languages.

4. Ongoing monitoring of outcomes serves as a basis for educational planning.

Team assessments are interdisciplinary, comprehensive, family-centered, and inclusive of all developmental domains and multiple elements of auditory, speech, language, sign language, and language acquisition.

- Assessment with procedures that are appropriate for young children with hearing loss, at regular intervals, e.g., every 3 to 6 months, is needed to monitor outcomes, adjust goals and strategies, and meet the unique needs of each child and family.

- Assessments should include formal and informal measures. Criteria shall be established to guide recommendations for changes in sensory aids, intervention strategies and intensity of service based on assessment data.

5. Certified and qualified service providers with expertise in working with infants and young children who are deaf or hard of hearing.

Personnel must be thoroughly knowledgeable about issues related to the unique language and communication abilities and needs of the population, including the sociolinguistic diversity of people who are deaf. Review of the literature indicates that personnel found to be most successful are specially trained, have years of experience, understand child development, know how to work with families who have a child with a hearing loss, and have knowledge of the community resources. If a Part C Coordinator is a generalist, he/she should be linked with an early interventionist who has special training in hearing loss.

Specific Recommendations for Establishing a Model Educational Intervention Program:

Recommendation 1:** **Family involvement has a significant impact on a child's progress and therefore a family-centered approach should be used for infants and young children with hearing loss.

Recommendation 2:** **The choice of communication approach and language system and educational setting is a process that requires collaboration between parents and specifically trained professionals (Moeller & Condon, 1994).

Only after gathering information about the child's developmental abilities, unique characteristics, and the parents' perspectives and desired outcomes can professionals facilitate the decision-making process. Professionals must recognize that decisions parents make about the future of their child are not always based on the degree of their child's hearing loss or data-collected through a series of assessments. Parents' decisions are often based upon their views of the world, their experiences and their goals for their children, their individual family's situation, and their observations about their child's responsiveness to specific educational strategies.

Recommendation 3: Provide proactive, comprehensive and ongoing audiologic management, both for the hearing loss and the applied technology.

Statewide loaner hearing aid banks should be created. This will ensure that the infant receives sound stimulation immediately and consistently during the lengthy and tedious process of fitting amplification. Also, provide other types of assistive technologies, such as flashing lights connected to fire alarms, door bells, and phones at no or low cost.

Recommendation 4: Develop guidelines for increasing or decreasing placement in mainstream education settings based on the child's communication and academic development.

1. All children shall be provided continual support and assessment to ensure they maintain their progress. The Individualized Family Services Plan (IFSP) should document strategies that encourage family involvement and communication, parent-to-parent contact, and opportunities to meet with adults who are deaf and hard of hearing, if the family desires.

2. Provide access to other services: vision, medical, O.T./P.T, developmental assessments, social-service, respite care is available in a seamless system by professionals and agencies that work collaboratively and in a cohesive manner.

3. Collaborate with medical, audiological, and other service agencies and personnel, and also early intervention state and local systems and parent/family organizations; Include a medical model that ensures the family's access to family-centered medical care, and a cultural model that provides access to Deaf mentor/role models for the child and family.

Recommendation 5: The specialized and technological needs of infants and children with hearing loss are unique and require a professional with specific training in providing services for these children.

Recommendation 6: Based on research evidence, continually update and improve curriculum and training resources and materials for serving infants and young children with hearing loss and their families.

Early interventionists need access to curricula and an array of other media and materials to be used in and supportive of their early intervention work. In-service training materials for early interventionists are needed including demonstration and case study videos and DVDs.

These materials need to include an array of resources for use by early interventionists in partnership with the family. These materials shall address:

- Amplification,
- Cochlear implantation,
- Psycho-emotional support for families,
- Infant mental health,
- Child and family assessment,
- "Being Deaf,"
- Providing Deaf and hard of hearing mentor/role models with all degrees of hearing loss and communication modes for children and families,
- Basic communication issues,
- Early family/infant communication interactions,
- Natural environments and routines,
- Technology (including captioning; flashing lights for clocks, doorbells, phones; TDD; videophones),
- Individualized approaches to assessment and intervention,
- Matching communication options to children,
- Early visual communication and strategies
- Early spoken language through audition,
- Programming for infants from birth to 12 months,
- Language development,
- Early auditory learning,
- Play and cognitive development,
- Language programming including signing English, Bilingual-Bicultural, American Sign Language, Aural-Oral, and Cued Speech,
- Early literacy development,
- Programming for children who are deaf or hard of hearing and who have other disabilities, and
- Adult communication strategies that promote language acquisition.

Include a curriculum/curricular material that is a menu of resources for use by the early interventionist in partnership with the family in natural environments. In addition to the principles of family-centered practice, a comprehensive curriculum must address: a) Programming *for infants 0-12 months.* This is especially important in light of state EDHI's and universal newborn hearing screening. Some parents of babies desire to combine methods (speech, signing, listening), as more definitive testing information is being obtained and as the baby is being carefully observed, in order to take advantage of the earliest possible "window of opportunity" for maximizing *all* possibilities for the child's language, listening, and speech development; b) *Programming in other critical areas* including amplification (that includes high tech/digital amplification), cochlear implantation, psycho-emotional support for families, infant mental health, child and family assessment, "Being Deaf" and basic communication issues, early communication interactions, natural environments and routines, matching communication options to children, early visual communication, early spoken language through audition, early auditory learning, play and cognitive development, language programming including signing English, Bi-Bi, ASL, Aural-Oral, and Cued Speech, and early literacy development. c) *Programming for children with special needs* including deafness with other disabilities, auditory neuropathy/dys-synchrony, mild, moderate, unilateral, and conductive losses, sensory integration, syndromes and other medical conditions, and behavioral needs.

There are several curriculum/curricula materials that can be highly beneficial for early interventionists and families including the new SKI-HI Curriculum (2004), Parent-Infant Communication (1987), Access for All (1992), Listening Games for Littles (2002), Learn to Talk Around the Clock (2003), and John Tracy Clinic Courses (JTC founded in 1942).

B. What are the Best Approaches for Implementing a Comprehensive Educational Intervention Program?

1. Reducing the Shortage of Qualified Service Providers.

It is crucial that services, programming and placements for children who are deaf or hard of hearing and their families be communication driven and also based on a thorough assessment of the child by qualified personnel who are knowledgeable in the assessment of young children who are deaf or hard of hearing. This means that the personnel must be thoroughly knowledgeable about issues related to the unique language and communication abilities and needs of this young population, including the sociolinguistic diversity of people who are deaf.

Review of the literature indicates that personnel found to be most successful are specially trained, have years of experience, understand child development, know how to work with families who have a child with a hearing loss, and have knowledge of the community resources. If a Part C Coordinator is a generalist, he/she should be linked with an early interventionist who has special training in hearing loss.

Consensus Conference Participants unanimously expressed concern for the critical shortage of trained personnel to work with families and their young children who are deaf and hard of hearing. The quality of early education services hinges on the educational background and experiences of the professionals providing services. This preparation must include knowledge and skills for working with children with a range of hearing abilities and with multiple disabilities. Training needs to cross both medical and educational arenas at both pre-service and in-service levels.

Incorporate into professional preparation and curricula (deaf education, speech-language pathology, audiology and other allied professions), a focus on infants and young children who are deaf or hard of hearing and their families, referring to the state of the art methods appropriate for today's children and technologies.

Substantially increase federal funding for University pre-service educational training programs that build a strong foundation in child development and early intervention for infants and young children with hearing loss. These include deaf education, speech-language pathology, audiology, and other allied professions. Given the critical shortage (state of emergency) of qualified professionals to serve infants and young children with hearing loss and their families, the Federal government needs to take a leadership role in funding professional preparation of teachers of the deaf and hard of hearing, audiologists, speech-language pathologists, and early interventionists. To accomplish this goal, there is also the need to provide adequate faculty and student support.

Substantially increase local, state, and federal funding to recruit and provide stipend support for students from culturally and linguistically diverse backgrounds, including individuals with disabilities, especially persons who are deaf or hard of hearing to enter careers in the education of children with hearing loss.

Federal funding agencies (Maternal and Child Health Bureau of HRSA, U.S. Department of Education, and Centers for Disease Control and Prevention) should consider dedicating funds for research and development of effective evidence-based in-service training models that may include sustained training, distance education and mentoring components.

Substantially increase local, state and federal funding for professional in-service training in early intervention with families and their infants and young children who are deaf and hard of hearing. Make in-service training in early intervention with families and their infants and young children with hearing loss a priority in the U.S. Department of Education, Division of Personnel Preparation, Low-Incidence Competitions.

A comprehensive in-service training system must include:

(a) A set of standards and competencies for training of early interventionists.
(b) A system that carefully selects, trains, and provides experienced and qualified trainers with training standards and materials to ensure high quality training for early interventionists working directly with young children who are deaf and hard of hearing and their families.
(c) Ongoing infant-family specialist access to training, such as Webcasts, training Web sites, and "learning communities."

Develop systematic in-service training programs for hearing screening and hospital personnel, health care providers, audiologists, speech-language pathologists, deaf mentors, parent mentors/advocates, pediatricians and nurses, otolaryngologists, and Part C providers. Also, include community service agency providers, teachers of deaf and hard of hearing children, special education and early childhood program providers.

Training should be interdisciplinary in nature. No one professional can possess all of the information and skills needed to address the complex needs and priorities of all families, and therefore, an essential component of all preparation must be rooted in collaboration and interdisciplinary practices.

2. Need for a comprehensive, coordinated and continuous program of services for infants and young children and their family in each community throughout the Nation.

This conforms with the Objectives of Healthy People 2010 (the U.S. Department of Health and Human Services National Plan for Improving the Health of the Nation) and will require that each state and territory identify the current and future needs of infants and young children with hearing loss, the existing services, the gaps in current services and those projected for the future, and develop an implementation plan that utilizes the current resources of the state systems and expands the resources as needed with the assistance of expanded or new Federal funding.

Establish within each state and territory a comprehensive, coordinated and continuous system of early intervention health care and educational services that is accessed by parents and their children through a single point of entry. Each parent and their child from birth to three years of age will be continuously assisted through the system of services by an assigned case manager.

State IDEA Part C and Part B Programs must coordinate child data systems. In addition, they should collaborate with their local education agencies to reach consensus on assessment protocols, beginning with infants and young children who are deaf or hard of hearing to monitor progress of psycho-social, language, and communication development. There should be a system established for reporting findings and outcomes of the progress in the program of services.

3. Increasing Public Awareness and Knowledge about Hearing Loss in Childhood.

Public awareness campaigns should focus on what deaf and hard of hearing children can do – become contributing, productive citizens - rather than simply what they cannot do - hear. The Federal and state governments should fund and conduct research to determine the most effective approaches for disseminating information to relevant public audiences and base resource creation on empirical findings. NIH has a funded project at Boys Town Institute which has an effective public awareness program about childhood hearing loss for parents and physicians. The void in information on websites is specific information related to follow-through habilitative and intervention strategies.

In recent years there has been a tremendous flood of all kinds of media – VHS, CD, DVD, video streaming on the Web, etc. – the vast majority of which is not captioned when produced and distributed. This occurs despite the fact that some of it is produced using, in part, federal financial assistance and therefore, under section 504, should be captioned. Most of the media that are in use in PreK-12 programs and in postsecondary education programs are developed by private producers. While ADA title III requires places of public accommodation to provide services (including information that they offer) on a nondiscriminatory basis, it appears that few producers understand that this law includes captioning of video, streaming video, VHS, DVD and the like. For all of these reasons, it is recommended that all messages supported by federal funds become captioned under the authority of Part D of the IDEA for Media Services.

4. Improving Education Systems at the State and Local Levels.

Coordination of programs and services for infants and young children at the state and local levels is essential in order to provide a comprehensive approach for these children. According to EHDI and NCHAM surveys, only a handful of states are organized in such a manner that their pertinent resources are coordinated. The demands of providing a comprehensive service program require the coordination of available resources. In cases where state and local governments have made a decided effort to combine their resources but still cannot provide the full range of services required for effective intervention, the Federal government needs to become a more generous partner and provide the necessary additional funds to close the gaps in services.

5. Providing Health Insurance to All Families.

Because of the high costs of cochlear implants and hearing aids, it is important that all families with children who are deaf or hard of hearing have health insurance that will cover these costs. In a recent survey of health insurance agencies completed by NCHAM, only 11% of the insurance carriers cover the costs of hearing aids. Although Medicaid will pay for hearing aids for infants and young children, the families of children who are not Medicaid-eligible must pay for hearing aids which may cost them as much as $6,000 for binaural aids. Parents of children with hearing loss should receive support from either the Federal government or state government or both in order to provide their child with the best amplification as soon as the hearing loss is diagnosed.

6. Identifying and Supporting a Research Agenda.

The members of the Consensus Conference identified specific directions and priorities for studying the long term effects of early intervention on the language and communication development of infants and young children with hearing loss. Also, longitudinal studies to determine the most effective approaches were identified as a priority that should be adopted by the pertinent Federal research agencies, including NIDCD and NIDRR.

Specific Recommendations for Implementing Effective Educational Interventions

Recommendation 1: The U.S. Department of Education should monitor the progress of children who are deaf or hard of hearing in Part C and Part B preschool programs to ensure that children are developing language at a rate commensurate with their age and cognitive abilities.

Recommendation 2: Implement educational accountability systems for children who are deaf or hard of hearing that focus on language and communication as the foundation for education.

Accountability systems will ensure that children have their language and communication assessed, that there will be appropriate opportunities for children to develop language and communication, and that there is appropriate language and communication access in the learning environment. Then accountability systems will measure educational outcomes, using universally designed instruments that do not discriminate against deaf and hard of hearing children.

Recommendation 3: State Advisory Boards should include representatives from the deaf and hard of hearing communities as well as professionals who are deaf and hard of hearing.

Recommendation 4: State systems and national certifying organizations should adopt a comprehensive list of knowledge and skill-based professional competencies required for relationship-focused early intervention with infants and young children with hearing loss.

Recommendation 5: Provide early interventionists with the opportunity of affiliating with professional organizations for continuing education and updates through newsletters, conferences, Webcasts, and other sponsored events.

Recommendation 6: Develop and implement a centralized online database of employment opportunities in parent-infant programs nationwide for graduating students and practicing professional personnel.

Recommendation 7: Each state should have complete, up-to-date listings of all state and national resources for providers of early intervention programs and services, professional and/or consumer based organizations serving deaf and hard of hearing communities, social service agencies, statewide educational programs, parent resources, speech and hearing personnel, and related networks for referral purposes.

Recommendation 8: Involve families in the design and evaluation of programs and services that support family involvement in all aspects of the early intervention program.

Recommendation 9: Funds should be available to professional and advocacy organizations to develop video and internet-based media to be distributed to the general

public AND to create video and print materials to attract high school students into careers serving children who are deaf and hard of hearing and their families.

Recommendation 10: Funding is needed to support a demonstration project that would create materials for parents, audiologists and medical practitioners and promote a protocol for screening, referral, assessment, and intervention.

Recommendation 11: States should require private insurers to include coverage for hearing aids and related audiological services.

Only seven states have such laws, leaving insurers in other states to exclude hearing aids and services. There are very few other sources for payment, leaving parents often unable to pay for the necessary devices and services.

Reimbursement regulations for sensory aids must recognize that infants and young children require continual follow-up of their response to amplification and may require changes of equipment to optimize sound reception.

Recommendation 12: Modifications to state health insurance laws, Medicaid and state children's health insurance programs must be made to provide coverage of all specific types of early intervention services delineated in Part C of IDEA.

Recommendation 13: As a Policy initiative, increase emphasis and funding for early intervention.

Recommendation 14: Funds should be available to prepare parents of deaf children to act as ombudsmen for other parents/caregivers in their communities.

Recommendation 15: Support (financial assistance/resources) should be provided for parents/caregivers to acquire communication and language skills to effectively communicate with their young children.

Recommendation 16: Develop certification standards to ensure that families with young children with hearing loss have access to professionals who are highly qualified to provide services.

No family or child should have to work with unqualified or under-qualified professionals.

Recommendation 17: "No Child Left Behind" should clearly state the guarantee that all infants and young children with hearing loss should promptly receive essential services so that the child does not become victimized by delays in timely interventions.
Clearly much valuable time is loss in the care of young children who are forced to wait for hearing aids, cochlear implants, and appropriate intervention, and further diagnostic testing. Insurance companies often will fund a medical or clinical component of management when the intervention requires an experienced educator to ensure efficacy.

C. What are the Specific Recommendations for Educational Interventional Research?

The Consensus Conference Participants proposed the following Research Agenda for the area of Educational Interventions:

Recommendation 1: Funds should be provided to establish a research agenda in the area of early intervention for infants and children with hearing loss that addresses all aspects of the process from screening through early intervention and transitions to preschool and beyond.

Specifically request that research on effective intervention for infants and young children with hearing loss, especially in the area of language and literacy development, is a priority for funding by the National Institute for Deafness and Other Communication Disorders/HHS, National Institute on Child Health and Human Development/HHS, National Institute on Disability and Rehabilitation Research/US Department of Education, Office of Special Education Programs/US Department of Education, Administration on Developmental Disabilities/HHS.

Recommendation 2: Support research that compares and identifies the developmental milestones in language acquisition of children who are deaf and hard of hearing with the milestones in language development in children who do not have hearing loss.

Recommendation 3: Research should involve highly controlled, manufacturer-independent and unbiased studies on the long-term outcomes of childhood implants on auditory and communicative development, academic and intellectual development and achievement, psychological, social and emotional adjustment, and interpersonal relationship functioning. Comparative research on children without implants receiving parallel support services should also be conducted, especially those for whom sign language is the primary form of communication.

Recommendation 4: Increase prospective research with the birth to three populations that incorporates multiple elements of identification and intervention procedures for infants and young children who are deaf and hard of hearing and their families.

Recommendation 5: Promote multi-center, collaborative research efforts involving University-based and other programs.

Foster training in and implementation of evidence based practice in the field.

Recommendation 6: Fund research and model demonstration projects that identify and implement effective ways of meeting the unique language and communication needs of

infants and children who are deaf, as well as those who have mild, moderate or unilateral hearing loss.

Such projects should: (a) address the need for direct communication with peers and care-givers, (b) provide intensive support, counseling, and education for families, and (c) include collaboration with universities, schools, and state agencies.

Recommendation 7: Other research topics that are of particular interest to the research community include:

Identification of early language and literacy skills most essential for child's later academic success.

Identification of factors impacting the development of mental health of the child with a hearing loss, and the most effective intervention strategies.

Factors contributing to the successful use of cochlear implantation with children using different communication methods.

Comparisons of different early intervention orientations and approaches (parent-, family-, child-centered, etc.), and efficacy studies on early intervention curricula.

Studies of factors needed to ensure a timely flow-through from screening to diagnosis to early intervention.

Identification of successful strategies for incorporating therapies such as Auditory-Verbal Therapy into family-centered early intervention programming.

More studies on the effects of role models who are deaf/hard of hearing on both child and family outcomes.

More studies on how babies learn sign language and effective strategies for teaching families sign language.

Studies on critical factors necessary for successful use of any communication method.

Studies on the development of bilingual-bicultural communication approaches (Bi-Bi) in infancy and successful strategies to promote family use of Bi-Bi.

Best practice research for children who are deaf with other disabilities.

Identification of the professional skills needed to promote collaboration with a diversity of families.

Empirical study of parental expectations of early intervention practices in relation to professional expectations.

Studies on factors influencing early auditory skills development in infants with varying levels of hearing loss.

Effect of sensory experience across modalities on the development of an auditory perceptual system.

Study the long-term effects of congenital hearing loss on literacy and academic performance when early diagnosis and sensory and linguistic formulation have been measurably effective and then determine how the outcome compares with the literacy and academic performance of school age child with hearing loss who is educated with hearing peers.

Identify those aspects of family life and resources that contribute to the full development of a child who is deaf in a hearing family. What are the criteria for "full development?"

Recommendation 8: Design research studies to determine effective strategies for supporting families and promoting optimal growth in infants and young children with hearing loss who are at increased risk because of economic or social factors.

Study effective practices with the same groups, given limited and/or diminishing staffing and resources in public programs.

Recommendation 9: Study the content and methods of effective pre-service training that produces early interventionists with the requisite knowledge and skills to implement the ideal model[1] of early intervention set forth by the Consensus Conference.

II. CONSENSUS REGARDING HEALTH CARE INTERVENTIONS

A. What are the Elements of a Model Health Care Program?

Aside from any acute or chronic medical condition that a child with a significant hearing loss possesses (that, of course, needs timely and appropriate medical attention), communication is still the paramount issue even when the child's medical needs are considered. The best clinical care is one that focuses on the child's health needs as well as the child's communication within her or his immediate environment: parents, siblings, extended family, caregivers, clinicians, and teachers.

As it was stipulated for Topic 1 – Educational Interventions, and the role of parents in making informed decisions, parents must be offered all necessary information about the health needs of their child. The parents' desired outcome for their child needs to be identified and respected.

Parents are often made to feel that they must make definitive choices in critical matters such as devices or communication modality, which are often categorized as distinct and divergent approaches. Decisions prompted by significant biomedical and technological advances do not yet have the accompanying evidence base regarding predictive factors to guide parental and professional decisions.

How parents navigate the diagnostic crisis depends on a multiplicity of factors, among them the quality and degree of professional assistance, and the availability of information and resources. The information provided them should not be primarily influenced by the opinions, beliefs, and attitudes of health professionals, early intervention, outreach providers, or childhood educators.

Audiologists, early interventionists, and other hearing professionals should provide technical expertise and access to factual information to the families and to the primary care physicians as necessary. Excellent two-way communications between audiologists and primary care physicians should be the goal, in order to ensure a coordinated approach to the care provided at well child and other primary care visits with that provided at audiology visits.

The ideal model of healthcare interventions for infants and young children with hearing loss should consist of a seamless system of service delivery initiated at the time of the child’s failure of the neonatal hearing screening or the identification of high-risk indicators for late onset or progressive hearing loss, or the identification of hearing loss in childhood.

The child’s health care provider should be the child’s advocate for the exploration of etiology, and the final repository of all consultative reports. Information about the health care provider and the team of professional consultants should be included in a tracking or surveillance system and updated regularly. Mechanisms should be in place to provide all results of any follow-up evaluations or interventions to the health care professional.

The concept of the "medical home" is predicated on the assumption that a primary care physician (such as the pediatrician or family physician) will assume the leadership and management of the (a) the development of a comprehensive program of health care assessment, referral, and treatment of the child with a hearing loss, and (b) the collaboration with members of a team of specialists to include pediatric audiologists, speech-language pathologists, early interventionists, teachers of deaf and hard of hearing, geneticists and pediatric otolaryngologists. There are concerns related to the feasibility, cost-effectiveness, and efficiency of the concept of a "medical home." Ideally, if the primary care physician had the time and special knowledge about hearing loss and its many aspects, the primary care physician could be the coordinator of all health care services. But primary care physicians typically are engaged in a very active practice and may have to defer a number of decisions to his or her staff personnel who may or may not be trained sufficiently to carry out even basic responsibility for the health care management for special populations. Furthermore, certain geographic locations have few primary care physicians and lack referral services to essential specialists of the team. The efficacy of the "medical home" needs to be further researched, especially in view of the current evidence from State reports that few children with hearing loss are under the care of a pediatrician who is assuming the role of a manager and comprehensive coordinator.

Specific Recommendations for Developing a Model Program for Health Care Interventions

Recommendation 1: Approaches to protect the hearing health of the child should be accessible, family centered, comprehensive, continuous, coordinated, compassionate, and culturally sensitive.

Each child identified with a hearing loss in the newborn period should have a comprehensive, coordinated, and timely medical and audiological work-up. In addition, children who fail to meet language milestones in early childhood should be tested for the possibility of a hearing loss.

With regard to the health of the child, the implementation of a hearing healthcare pathway or treatment approaches, such as the American Academy of Pediatrics treatment algorithm, is recommended. The Core Team for this pathway should be the Primary Care Physician, Otolaryngologist, Early Interventionist, Speech-language Pathologist, and Audiologist. The Core Team will evaluate, assess, and determine the need for further referrals to other specialists, such as geneticists and ophthalmologist. A representative of the Core Team will coordinate closely with those responsible for the educational services and programs for the child, including early interventionists, educators, and other specialists. This coordination should include interfacing with Part C agencies and other relevant therapeutic interventions programs. These other programs include schools for the deaf and community agencies serving children who are deaf and hard of hearing.

Recommendation 2: Approaches to maintaining hearing health include limiting risks, ongoing surveillance and vigilance, and encouraging parental empowerment.

Ongoing monitoring of hearing and language development, and management of hearing health throughout childhood is recommended since hearing loss can have profound implications for the child's development. Children with known childhood hearing loss, including those with unilateral or mild hearing loss, should have their hearing retested on a regular basis to assure early diagnosis of progression. It is recommended that ongoing hearing evaluations of children with hearing loss should be conducted by an audiologist experienced in testing children. The evaluation should use both behavioral and electrophysiological test methods as needed.

Monitoring the psychological and emotional well-being of children with hearing loss is recommended. Risk assessment for abuse and neglect is also recommended, as these children are at high risk for such abuse. The parent-child relationship is critical to all aspects of development of the child with a hearing loss and family counseling by professionals and parent peers should be considered.

Ototoxic medications should be avoided if equally effective and safer alternatives are available. Appropriate dosing and blood level monitoring is necessary when ototoxic medications are used. Also, children below age 3 years are at increased risk for otitis media with effusion (OME). Infants and young children with permanent hearing loss (PHL) should be monitored closely for OME because of the decrease in threshold sensitivity that can accompany OME. Children with persistent or recurrent OME and PHL should be referred promptly to, and followed by, an otolaryngologist experienced with children.

Components of the medical workup of the child with a hearing loss should be reviewed in the context of the rapid evolution of diagnostic testing methods. Diagnostic approaches that are currently compelling include an ophthalmologic referral, EKG, laboratory testing for neonatal infections (*e.g.*, CMV), and radiologic imaging. To maintain their hearing health, children with Down syndrome should have periodic medical examinations to identify possible middle ear fluid. And, as needed, their treatment should include removal of cerumen, medications and/or PE tubes. Audiological evaluations should also accompany this regimen to determine the hearing status of children with Down syndrome.

Genetic consultation is important for the effective management of children with identified hearing loss and other risk factors, even in the absence of family history. A genetic consultation needs to be offered to parents for every child with an unexplained hearing loss. In the majority of cases the etiology is likely to be genetic, and the geneticist and genetic counselor have the expertise to conduct comprehensive evaluation and testing of the child and provide risk counseling to family members. It is important to remember that a genetic diagnosis has implications for both the immediate and extended family.

Geneticists may identify subtle dysmorphic features or obtain family history information suggesting a particular syndrome (e.g., Waardenburg); such features are likely to be missed by other health care professionals. Connexin 26 testing is now becoming routine, but genetic tests for other nonsyndromic and syndromic hearing loss will soon be available (e.g., Usher, Pendred, Jervell Lange-Nielsen, Alport syndromes). Without genetic testing the congenital hearing loss may appear to be nonsyndromic until much later when other anomalies such as vision loss begin. It will also enable relatives to determine if they are carriers. In the future, newborn genetic testing may provide an answer to the concern that children with onset of hearing loss after birth are missed.

In summary, while genetic testing is not yet available for all causes of hearing loss, it is important to inform parents of diagnostic testing opportunities as they become available in order to enhance management of the educational and social futures of their children. It is also critical that parents and non-genetic healthcare members of the team understand that (1) a negative test for connexin 26 does not mean that the hearing loss is not genetic, and (2) interpreting the results of a connexin 26 test is not necessarily straightforward. Both pre- and post-test genetic counseling must be provided. (Guidelines for the etiologic diagnosis of congenital hearing loss have been published by the American College of Medical Genetics in Genetics in Medicine 4:162-171 (2002).

The development of educational tools for parents and providers, to manage and minimize hazards to the hearing health of all infants and children is recommended. These include (1) avoid high noise levels such as T.V., portable music listening devices, and loud machinery; (2) avoid head trauma by use of proper restraints in motorized vehicles, helmet use, and avoid shaken baby syndrome; and (3) vaccination to prevent H influenzae type b (HIB), pneumococcal disease, rubella, and mumps (Level of evidence: A). Parent education should include language developmental milestones, including auditory perception. Parents need to know that such milestones are subject to critical periods of development, and lags in development may require proactive intervention if they are not met.

Recommendation 3: The most appropriate amplification technology (hearing aids, cochlear implants) should be selected after evaluation and verification of hearing instruments, including FM systems, using a prescriptive procedure specifically designed for infants and young children.

Throughout the process of evaluation and selection of hearing instruments, family preference must be honored at all times. Intervention choices must be offered without bias. At the same time, potential advantages or risks associated with choices should be made abundantly clear to families, and atypical choices should be discussed with accurate data and research.

It is recommended that the Core Team for diagnosis and treatment of hearing loss must inform the parents of the amplification technology options available to the family, and the availability of third party reimbursement. There should be communication among health professionals. The ideal workup and treatment algorithm, such as the one recommended by the American Academy of Pediatrics (AAP), will be updated as new testing and treatments become available.

Because of the growth of the child's ear, sound measurements of the hearing instrument at the eardrum should be verified routinely. In general, the preferred technology for bilateral hearing loss is hearing aids that significantly improve audition. If there is a bilateral hearing loss of severe or profound degree, which does not respond to hearing aids, then cochlear implants should be considered. Factors that influence the timing of cochlear implantation must be quantifiable in order to determine optimal timing of implantation. These factors include outcome-based monitoring of aided versus unaided benefit, advances/changes in auditory development, and family readiness.

Cochlear implant candidacy should be considered for infants and children with sensorineural hearing loss, who fail to make progress in early communication patterns and milestones with well-fit hearing aids including FM-systems, if the family preference is for the use of spoken language. The needed rehabilitative support of the cochlear implant program should require regular visits to the otolaryngologist for at least two years following implantation. Also, school options for intensive training of spoken language skills and full immersion in classroom activities with normal hearing peers, should be available. It is recommend that parents consult with a multi-disciplinary team familiar with communication development in infants and young children with hearing loss, to aid in this decision-making process. Pre-operative assessment is essential to guiding the post-implant intervention.

Children with cochlear implants are at increased risk for meningitis. This requires on-going surveillance and up-to-date immunizations.

The impact of unilateral hearing loss in some children can be significant. Children with unilateral hearing loss may benefit from a hearing aid in the impaired ear.

Recommendation 4: Family violence, child maltreatment, and behavior management issues are worthy of specific and sustained attention as well as monitoring by healthcare teams serving infants and young children with hearing loss.

Violence is a public health issue identified in Healthy People 2010. There is Level A research evidence that children who are deaf or hard of hearing are at increased risk to be victims of neglect and physical abuse by family members, both immediate and extended, and sexual abuse by extra-familial perpetrators. The majority of this maltreatment occurs in children 5 years of age and younger. Children who are deaf or hard of hearing with records of child maltreatment in the home miss more school days and score lower in reading and math than non-abused peers. This gap is exacerbated by the presence of domestic violence in the home. Thus, healthcare professionals need to be vigilant for signs of maltreatment and domestic violence in the homes of infants and young children with hearing loss. Hearing parents of deaf and hard of hearing children with and without cochlear implants are more likely to use physical punishment and increase its intensity after subsequent transgressions than mothers of hearing children.

__Recommendation 5: Referral to family counseling or family grief management should be coordinated with the primary care physician for the infant and young child.__

Audiologists, early interventionists, and other hearing professionals should provide technical expertise, factual information, and counseling within the recognized scope of practice for the respective discipline. Whenever there is a consideration for more specialized mental health involvement and referral, these concerns should be shared with the primary health care provider.

B. What are the Most Effective Ways to Implement Comprehensive Health Care Service Programs?

1. Reducing the Shortage of Qualified Service Providers.

Pre-service and in-service programs (licensing and credentialing programs) in audiology, including the AuD (Doctor of Audiology) programs throughout the Nation, should consider the skill-shortage in the assessment and management of infants and young children with hearing loss and provide a focus on this population. This approach could help to ensure that timely, comprehensive audiologic services are available for follow-through after newborn hearing screening.

Innovative ways of attracting trainees to this field need to be explored and developed through effective recruitment programs.

The elements of newborn hearing screening, medical work up, and effective intervention should be included in training—during residencies in pediatrics, family practice, IM/Peds, OB/GYN, and otolaryngology. Specialty boards for pediatrics, family practice, IM/Peds, OB/GYN, and otolaryngology should consider this entire curriculum and knowledge base when crafting specialty board certification examinations.

Due to the rapid changes in this field, continuing medical education is critical, and should include grand rounds, national medical meetings, web-based training modules, and educational initiatives that address topics related to the comprehensive management of infants and young children with hearing loss and educational/health care interventions.

Health care providers must be informed about the evaluation, options for intervention, and linkage with existing resources ***__immediately following audiologic diagnosis__***.

It is recommended that professions who address early intervention issues employ a model of communication with experts in their respective fields comparable to the state/chapter "Champions" network established through AAP (www.infanthearing.org)).

2. Increasing Public Awareness and Knowledge About Childhood Hearing Loss.

A consortium of interested parties should consider retaining a sophisticated marketing and research entity to enhance a public relations campaign for infants and young children with hearing loss.

Examples of models of implementation include:

(a) Continue efforts by the professional organizations and Joint Commission on Infant Hearing. The American Academy of Pediatrics' (AAP) Task Force on Early Hearing Detection and Intervention is working with physicians and state AAP Chapters and other organizations to educate physicians in the care of infants and young children with hearing loss.

(b) Increase public awareness about hearing loss in children through scheduled educational activities for the general population. Media spots to highlight the problem and issues would add to the public visibility of these issues. Note the efforts by the American Speech-Language-Hearing Association which celebrated May as "Better Hearing Month" for more than 40 years.

(c) Endeavor to have articles published in magazines read by the general public, such *Reader's Digest, Good Housekeeping, Time and Newsweek* and in magazines devoted to parents, like *Parenting (similar information in Spanish, targeting the Hispanic population in the U.S. should be published).* They could be written as interviews or experiences of families with both early and late identified children. If families were more aware of the process of language development, they would assert some pressure on healthcare providers to stay current, and encourage other family members who may have a child with hearing loss or speech delays to follow up in a timely manner.

3. Improving Health Care Systems at the State and Local Levels for Better Services to Young Children with Hearing Loss.

Federal and state agencies should strive for a cohesive plan of action that includes: a. trained and experienced pediatric audiologists, b. trained and experienced early interventionists, c. geneticists and genetic counselors, and d. pre-service and in-service training of primary care physicians and health care providers regarding the recommended protocols for health care of children with hearing loss.

The responsibility for providing interpreter services is that of the health and mental health service providers, at the time such services are rendered.

State reporting systems must evolve from simple statistical counting instruments to systems capable of assuring timely identification of infants and young children who have not completed their evaluations. Potential legal barriers concerning confidentiality should be anticipated, and mechanisms installed to overcome these barriers. Recall efforts should be directed both at the parents and at the identified primary care physician of record. Attempts to assure follow up should be rigorous and timely, and directed at both the parents and the identified primary care physician of record before the child reaches 6 months of age. Rapid infant brain growth requires prompt intervention typically including amplification, the use of an effective approach, a program to promote auditory skill development, language development, and other language skills. Further, this model of follow-up efforts must be conducted on a consistent basis.

Rapid infant brain growth requires prompt intervention, typically including: amplification; the use of an effective communication approach; and a program to promote auditory skill development, language development, and social-emotional skills. Identification of newborn hearing loss should be considered a neurodevelopmental emergency. Programs should be advanced for the immediate acquisition/use of personal hearing aids to include, if necessary, a loaner hearing aid system and health insurance coverage for, at a minimum, the cost of the first hearing aid in infancy and early childhood.

Networks of expertise within each state should be established and coordinated for early intervention. At the state level, various health and educational agencies have expertise in providing services for infants and young children with hearing loss. These agencies must coordinate their endeavors so that so that their collective expertise and cooperation are made available to parents, health providers and intervention programs. This cohesive model will improve accessibility to appropriate services for the child.

4. Providing Health Insurance for All Families of Children with Hearing Loss.

Health care services for hearing loss in infants and young children demand costs that most families cannot afford. These costs are related to specialized diagnostic services to determine amplification needs, the fitting of hearing aids, medical care for middle ear disease as needed, surgery for cochlear implants if appropriate, and the follow-up care of all procedures. Most health provider insurers do not cover all the costs needed for the unique health problems of these children. It is recommended, therefore, that the Federal and State health programs provide funding to fill in the gaps which private health insurance creates.

5. Program Recommendations for Congress.

Increase the awareness of infants and young children with hearing loss at the Federal and state levels through educational guides. Support the growth of the Congressional Hearing Health Caucus.

The Walsh Bill (H.R. 1193-- Newborn and Infant Hearing Screening and Intervention Act of 1999) should be reauthorized to provide appropriations for support of a national program that meets the education and health care intervention needs of infants and young children with hearing loss.

Specific Recommendations for Implementing Effective Health Care Interventions

Recommendation 1: Substantially increase the number of audiologists who have the training, experience and resource availability and are capable of providing quality audiologic services to infants and young children with hearing loss. Training should also include information about the deaf community.

Recommendation 2: Increase the number of speech-language pathologists and early interventionists who are comprehensively trained in assessment and interventions strategies for infants and young children with hearing loss. Training should include exposure to the spectrum of multi-lingual and various communication methods, including information about the deaf community.

Recommendation 3: All professionals involved in the health care of infants and children with hearing loss should be educated about the genetic and environmental causes of hearing loss, the types of hearing loss, the potential for progressive hearing loss, late onset hearing loss, and the impact of otitis media with effusion (OME) and permanent hearing losses.

Recommendation 4: Continue and coordinate national marketing and public relations campaigns to inform the Nation about issues related to infants and young children with hearing loss, including deaf community issues.

Recommendation 5: All professional specialty organizations addressing the topic of infants and young children with hearing loss, including deaf community issues, are encouraged to establish special study or interest groups that are advisory to all culturally and linguistically diverse populations in the U.S.

Recommendation 6: Federal and state funding should be appropriated to meet essential health care professional personnel needs.

Recommendation 7: Federal support is needed and should be expanded beyond screening to include services and devices for infants and young children identified with congenital hearing loss, at birth to age three.

Recommendation 8: In order to provide children with hearing loss with coordinated and appropriate services in a timely manner, all states must have longitudinal tracking and surveillance systems containing population based, unduplicated, identifiable, individual data on this population. All states need collaborative agreements for sharing information.

Recommendation 9: We recommend innovative models to serve rural and other under-served populations. Such models include the Department of Health and Human Services Model for Children with Special Needs, Rural Outreach, and models in genetics clinics connected to state public health departments.

Recommendation 10: The provision of health insurance for all families of children with hearing loss is integral to the success of a coordinated program of health care and hearing care options for the infant and young child with hearing loss. All families should have easy access to health insurance. The infant or young child with a hearing loss does face risks to his or her health, development, and well-being, including additional medical problems associated with hearing loss. Coverage for health care services is consistent with a wellness model for infants and young children with hearing loss.

Recommendation 11: Institute laws requiring insurance companies to cover all technologies and services available for children with hearing loss. It is recommended that the level of coverage be adequate to sustain the viability and continuity of health and hearing care services for the infant and young child with hearing loss. Furthermore, studies should be conducted on the cost and benefits of models of public/private insurance partnerships for providing services and technology to infants and young children with hearing loss.

Recommendation 12: Equity in insurance coverage and equal access to mental health services for children with hearing loss should be a priority.

Recommendation 13: Technologies and services for infants and young children with hearing loss should be covered by funded Federal mandates.

C. What are the Specific Recommendations for Health Care Interventional Research?

The Consensus Conference Participants proposed the following Research Agenda for the area of health care interventions:

Recommendation 1: Research is needed to further identify causes of progressive and late onset hearing loss, most appropriate interventions, optimal amplification, and gene-environment interactions associated with hearing loss.

Recommendation 2: Support research that measures the effectiveness of early identification and intervention.

Longitudinal studies should be conducted to determine the efficacy of early intervention models in developing cognitive, language and communication skills in young children with hearing loss. The current demand for evidence-based models of intervention requires such studies in order to support requests for Federal and state funding of early intervention programs for infants and young children with hearing loss. The purpose of the research is to identify, describe and test reliable and valid models that are (1) transportable to a diverse number of geographic locations and situations and (2) produce the same degree of successful outcomes as those realized in the experimental studies.

Outcomes should include not only positive measures such as improved academic and social functioning, and parent satisfaction but also potential harms, such as dropout rates, family disruption, and other potential drawbacks of the intervention. Once the models have been tested and evaluated to be effective and free as possible from the variability of those using the model, they are ready to be transported.

The successful studies that have developed transportable models include a training component for use by those who intend to apply the model and a recommended monitoring program to continuously assess the successful application of the model. All those who intend to use the model, therefore, need to be trained by an informed instructor in its application and assessment.

Recommendation 3: Develop a vaccine for cytomegolovirus infection (CMV).

Recommendation 4: If feasible and safe, study individual determinants of sensitivity to ototoxic drugs.

Recommendation 5: Develop programs to train facilitators who are capable of translating laboratory findings about hearing loss to practical applications more rapidly. It is recommended that federal agencies employ models of collaboration that enable evidence-based research findings to guide funding decisions.

Recommendation 6: Investigate prognostic and predictive factors in cochlear implant outcomes, particularly for children with developmental language disorders, autism spectrum disorders, and other co-morbid conditions.

Attention should also be focused on the differential outcomes of children with hearing loss. The diversity of this population should be explicated with genotype-phenotype correlations as well as prospective longitudinal clinical studies with direct relevance to educational and vocational interventions.

III. CONSENSUS REGARDING THE COORDINATION OF EDUCATIONAL AND HEALTH CARE SERVICES AND PROGRAMS

FOR INFANTS AND YOUNG CHILDREN WITH HEARING LOSS

This Section describes the intersection of educational and health care services combined into a coordinated and comprehensive program of services. Whereas the current situation within communities reveals a division of services, it is essential for the health and development of the child with hearing loss and his or her family to receive both educational and health care services in a systematic and cooperative manner.

A coordinated educational/healthcare system of services for infants and young children with hearing loss starts with general education and awareness of the community at large about

- Hearing health
- Prevention of hearing loss
- Hearing loss and the importance of early identification of hearing loss in order to maximize a childes potential for developing communication skills and literacy/academic skills.
- This might also include cost information for early identification vs. late identification.

A family-centered perspective should provide the framework for newborn hearing screening, evaluation and early intervention programming. A systematic and coordinated system for the provision of services to families with young children who are deaf and hard of hearing is essential. All professionals or organizations that come into contact with early identified infants and young children with hearing loss need to be fully informed about the range of services and educational/habilitation/healthcare options that are appropriate for the child.

A comprehensive system needs to have a single point of entry and family access to key individuals at the beginning to ensure uniform information provision and easy transition from diagnostic audiology to intervention. The system of Colorado Hearing Resource (CO-Hear) Coordinators, or something similar, is needed to provide diagnostic facilities with an uncomplicated and simple point of entry to ensure ease of access and accountability to further testing and treatment services. State-wide systems that are specific to hearing loss are the most likely to provide accountability for families and children. These systems can work cooperatively with current Part C systems, but will have central data management as opposed to local educational agency data management alone.

Specific Recommendations for Combining Educational and Health Care Services

Recommendation 1: A single point of entry into a comprehensive, coordinated and continuous system of services should be provided to include an advocate/ coordinator for the family.

Recommendation 2: The advocate/coordinator for the family should be a professional within an agency or organization that has been authorized and identified by local and/or state government to be responsible for oversight and coordination of the child and family program.

Specifically, the advocate/coordinator should be

- knowledgeable about childhood deafness and the expertise needed to provide quality services;
- aware of resources in their area and whom they can contact if they do not have the experience and/or expertise to provide service; and
- aware of the social and political issues that surround management of deafness in early childhood and maintain an unbiased and balanced position in providing choices and services to families.

This professional should provide the following to parents:

- a description of all options concerning language, communication and programming/educational services (Part C and Part B services under IDEA);
- videotapes or DVDs that explain procedures, communication options, educational program options, importance of language development, visual strategies, and maintenance of good health;
- expert consultation regarding the impact of hearing loss on a child's development;
- types of services available for a family within their community;
- information about community, state, and national resources/organizations concerning hearing loss;
- contacts with other parents of children who are deaf and hard of hearing and with parent support groups;
- coordination of visits to various early intervention program options;
- emotional and technical support;
- information regarding the family's rights under the law and parental rights under IDEA;
- contact with adults who are deaf and hard of hearing;
- on-going contacts with health care providers when the child's health becomes an issue;
- monitoring the family's involvement in early intervention services, including ensuring medical and audiological follow-up visits and assisting the family with informational counseling (i.e. guiding the family to become advocates for their child);
- extending the number of people and hours of service to the infant and young child with hearing loss.

Recommendation 3: Once the infant/child is identified to have hearing loss and the details of the hearing loss are understood, the primary care provider should coordinate the child's medical care with the child's case manager. The infant will require:

- ***referral to Part C services***
- ***ongoing audiological care***
- ***medical work-up***

The primary care provider should work with a team of the professionals who typically deal with children with hearing loss. The team includes the primary care physician, the audiologist, the early interventionist, speech language pathologist, and the otolaryngologist. When the child is diagnosed with hearing loss, the parents and the physician need to have the support and guidance of this team. The team needs the ability to refer the child in a timely manner for an evaluation, fitting of hearing aids and referral to other professionals specializing in genetics, neurology, and developmental pediatrics and who have experience in working with children with hearing loss. Communication between the members of the team must be clear, frequent, and timely. The skills of each professional involved in the care of the child should complement and augment the skills of other professionals. The knowledge of each professional must be transferred to other professionals involved in the care of the child with a hearing loss. This may occur through informal discussion, family care conferences, multidisciplinary team meetings, etc. All professionals involved in care for children with special needs must commit to a renewed energy in negotiating with their colleagues, and providing tireless teaching for their fellow professionals of various training backgrounds. Timelines, planning, and management are very important.

Recommendation 4: Each state should identify or establish Centers of Excellence and/or Networks of Expertise to facilitate collaboration and coordination of optimal care for infants and young children with hearing loss and their families and to provide professional training, technical assistance and dissemination of information.

Center of Excellence refers to a single location within a university or hospital where an interdisciplinary team of experts specializing in hearing loss in children work together to effectively manage the health and educational needs of each referral. Networks of Expertise refers to services provided via an interdisciplinary team specializing in hearing loss in children where members of the team may be located in different geographic locations but together manage the health and educational needs of each referral. The goal of both approaches is to provide each child with a comprehensive program of essential services. Comprehensiveness of service requires that collaboration with and communication among these disciplines becomes well-established. The low-incidence nature of hearing loss would not require that the team gather often. When the team does gather, there is an opportunity for professionals to learn from each other and value the specialty area of expertise of each team member. That is one reason why teams of medical/audiological/educational collaborators were required in early cochlear implant investigations and why they were so successful.

Recommendation 5: Candidacy for educational and health care programs should not be solely based on auditory brainstem response (ABR) results or audiograms. Children with all types of hearing loss or any dysfunction or abnormality along the auditory pathway that impedes the process of development, should be eligible for services.

Recommendation 6: Professional guidelines for multidisciplinary teams for medical evaluation should be developed with the input of parents and distributed by state and national organizations. The guidelines should include the use of existing evidence-based professional practices in specific areas related to children with hearing loss, such as history, physical findings, nature of hearing loss, and the potential impact of etiology.

Recommendation 7: Parents should have the option of requesting a pedigree. Families with hearing loss will benefit from determining whether the health condition of their child is the result of a syndromic or non-syndromic loss.

For example, it is common for individuals with Usher Syndrome to meet and marry. But they may be unaware of the genetic nature of their problems and lack genetic and social counseling with respect to their offspring. Mitochondrial disorders, especially connected to Aminoglycoside sensitivity, should be identified and family members warned of the auditory consequences of using these antibiotics.

Each child with an unexplained hearing loss should be evaluated by a pediatric ophthalmologist to assess visual acuity and to evaluate for syndromic forms of hearing loss involving the eye, such as that found in Usher Syndrome, NF1, NF2, viral inclusions, etc. Undiagnosed visual disturbance could be devastating for a child with hearing loss as he or she attempts to acquire oral or sign language. Knowing the genotype vis a vis Usher will prevent families from raising the child with ONLY sign language and no auditory options. If and when the child loses vision, exclusion from the sign language community is often the consequence (Miner, 1995). Contrastively, ignoring Auditory Neuropathy and insisting on aural auditory management without signs or cues is doomed to failure almost regardless of the audiogram. Similarly, ignoring Jervell Lange Neilson syndrome, Pendred, LVAS can lead to death in the former and considerable morbidity and progressive loss in the latter two. In summary, while it is too early to screen all children genetically for hearing loss, it is important to know their genotype once the hearing loss is identified to prevent death, as in J-L-N, and/or better manage their educational and social futures.

The pedigree drawing put together by the geneticist will be valuable for other team members. For example, if a mitochondrial pattern of inheritance is suggested, this may be critical information for another physician who may be thinking of prescribing aminoglycosides. Similarly an X-linked pattern of inheritance would be a warning to examine a CT scan before surgical intervention. Children with chromosomal disorders or multiple anomalies that include developmental delays need to have their hearing loss managed as early as possible; they must not be excluded from a coordinated system of hearing services. Also, the members of the healthcare team need to be aware of ethnic background, which may be informative in determining likely diagnosis and appropriate genetic testing. Members of the team must also be aware of and sensitive to issues that may be specific to particular ethnic groups.

Genetic advances and cochlear implants need to be available to those who choose to take advantage of them. On the other hand, much effort must be put into ensuring that they are not perceived as discounting the contributions of the Deaf Community.

Recommendation 8: The Case Coordinator must be most sensitive to the needs of parents who are deaf whose newborn or young child has a hearing loss.

Although, this is a minority within a minority and comprises only 4 to 6% of infants and children with hearing loss, it deserves special attention, care, and intervention by the education and healthcare teams. The Deaf Community has cultural and communication values that must be recognized and respected. Current and future technological advances in treating hearing loss in children raise the fear of the eventual extinction of the Deaf Community. Professionals on health care teams need extensive preservice and inservice exposure to these issues and to develop sensitivity to them. This is a community and family issue that raises ethical questions for intervention in healthcare settings.

Recommendation 9: Parents from minority cultures, particularly those whose primary language is not English, should be provided with resources that helps them overcome difficulties in coping with and successfully navigating through the necessary interventions for their child who is deaf or hard of hearing.

Early identification of hearing loss may accentuate decisional conflict and stress, and underscores the necessity of timely access to accurate and relevant information for parents and professionals. In serving diverse and underserved families, an understanding of the cultural, linguistic, and literacy needs of the parents, and relevant modifications of communications should be identified so that informational materials are assured to be accessible.

These parents must be given access to complete and accurate information in order to facilitate parental understanding and involvement. Even when parents and professionals speak the same language, the information presented may be misunderstood; but when there is a difference in the language spoken by professionals rendering care and the family receiving the information, the chances for misunderstanding, difficulty and stress increase exponentially. Interpreters may mitigate the communication barrier but only if properly trained. Parents who are deaf of children who are deaf are a particularly underserved group in need of a coordinated and accessible system of care.

All services should ensure that staff is trained to communicate effectively and with sensitivity, especially at pivotal times such as at the time of identification of the hearing loss, consideration of intervention options, etc. Cultural intermediaries and professionals known to and trusted by the family can provide necessary support and enhance engagement. Flexible scheduling to involve extended family members will ensure better participation and pave the way for a more relevant context in which to provide effective services.

Recommendation 10: The system of services should subscribe to the wellness model upon which the physical and psychosocial integrity of children and adults who are deaf or hard of hearing is based.

Families needs information about the lives of the vast majority of individuals who are deaf or hard of hearing and who have achieved optimal adjustments in all phases of life, have well-integrated and healthy personalities, and have attained self-actualizing levels of functioning, all with or without the benefits of hearing aids, cochlear implants, and other assistive devices.

Recommendation 11: Strengthen follow up systems to include:

A. Implementing improvements in data management systems of tracking and surveillance to minimize loss to follow up (perhaps merged with existing metabolic screening efforts).

B. Expanding efforts to identify infants with hearing loss who are birthed outside of hospitals.

C. Allocating additional resources for services to lower income and/or families of minority cultures, including those whose primary language is not English. This is necessary because these families may have challenges and barriers in navigating the system.

Recommendation 12: Early interventionists and health care providers must become knowledgeable about the two different models of the deaf experience: a. deafness as a medical condition; and b. deafness as a life experience and/or cultural community outside the medical condition and distinctively different from other special health care needs under which the medical home concept exists.

Recommendation 13: Provide appropriate support for families following diagnosis:

A. Ensure that all professionals who have early contacts with parents are well-informed about hearing loss and communicate effectively with families before screening, at screening, re-screening and throughout the hearing evaluations.

B. Develop specialized training for Part C Service Coordinators in issues related to hearing loss in infancy and its impact on the families.

C. Provide the resources to support families in carrying out the recommendations provided by specialists (i.e., financial support for evaluations, hearing aids, transportation, child care, etc.).

D. There should be a parent resource center, specific for parents of children with hearing loss, integrated with centers of excellence. This resource center should include parent-to-parent support as well as all the traditional supports (bibliographic, multimedia, community program information, etc.)

<u>Recommendation 14: Early intervention programs should recruit trained adults who are deaf or hard of hearing to serve on the coordinated service team.</u>

<u>Recommendation 15: State Early Intervention (EI) systems should attempt to find the optimal system of service delivery models (e.g. Centers of Excellence, Networks of Expertise, and regional centers), throughout the state to ensure service delivery to all who need it and to provide training among staff so that information bias is reduced.</u>

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APPENDIX 1

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We wish to sincerely thank each of the following Conference Sponsors for their generous contributions in time, advice and counsel, and financial support:

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