

# Chapter 26

## Bringing It All Together

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Efforts are being made by dedicated individuals who realize the tremendous advantages for D/HH children, their families, and society in general when EHDI program objectives are met successfully in a timely fashion.

**E**arly Hearing Detection and Intervention (EHDI) programs are celebrating almost 40 years of efforts to improve the accessibility, quality, and effectiveness of newborn hearing screening programs, pediatric diagnostic audiology services, and early intervention for deaf or hard-of-hearing (D/HH) children and their families. Efforts to impact newborn hearing screening programs have been successful, with the majority of states implementing legislation and/or rules and regulations through their state health department to guide state EHDI efforts. Currently, more than 98% of babies born in the U.S. are receiving hearing screening before hospital discharge. Much remains to be accomplished, however, before we can celebrate most children reaching their full potential because of EHDI program efforts.

While some state EHDI programs are meeting all the challenges of traversing the benchmarks for the components of their EHDI program, many states have substantial gaps in getting from screening to diagnosis and from diagnosis to intervention. In addition to these delays between EHDI components, one of the

most serious issues is the percentage of babies who are lost to the EHDI system (ASHA, 2008). The quality and quantity of pediatric audiology services need substantial improvement, since waiting lists for qualified pediatric audiologists are often extremely long. Once a diagnosis is made, referral to early interventionists who specialize and are knowledgeable about working with D/HH babies is difficult. In some areas of the country, appropriate early intervention services are simply not available. Finding programs that have staff qualified and sensitive to meeting the cultural needs of families is a challenge. These challenges for the state EHDI coordinator can be met by collaborative work with stakeholders at the local, state, regional, and national level. Efforts are being made by dedicated individuals who realize the tremendous advantages for D/HH children, their families, and society in general when EHDI program objectives are met successfully in a timely fashion.

### State EHDI Coordinator

In order to optimize services in a state EHDI program, the coordinator has

the tremendous task of pulling all the stakeholders in the service delivery system into a quality team effort through:

- Communication.
- Analysis of availability of services.
- Needs assessment.
- Establishing manuals of operating procedures.
- Specifying quality indicators.
- Inservice training.
- Documenting efforts through comprehensive information management.

State EHDI coordinators must have knowledge of grant writing, management of funding through federal, state, and local funding agencies, as well as reporting for accountability. When staffing is limited and the tasks are many, efficiency and teamwork can mean the difference in success, ease of operation, and accomplishing more tasks for a state EHDI program.

## Communication with Key Stakeholders

The efficiency of hospital-based newborn hearing screening programs is developed by one-on-one communication with the staff responsible for the EHDI program components. The state EHDI coordinator can develop a database of individuals responsible for hospital programs, qualified pediatric audiologists (with their geographic location), and early intervention providers with their areas of expertise and geographic location.

A database containing contact details, site variables, and performance data will quickly provide avenues for interaction between the EHDI coordinator and local programs—such a database will also be a valuable resource for consumers seeking information. Delineation of these key individuals and cultivation of professional relationships is critical. The EHDI coordinator can also communicate with these individuals through a monthly newsletter, conference calls, and regional conferences. Prior to scheduling a regional conference, it is wise to conduct a needs

assessment to determine relevant topics for expert presentations offered for continuing education credit, inservice training programs, and sharing of performance data. All of these efforts will help move programs forward. A performance review based on collected data, site visits for information gathering, and availability of prompt assistance will help cultivate professional relationships that will result in more children being identified, diagnosed, and in families receiving needed services.

Another important area of communication with stakeholders is communication with parents. Parents operate at so many different levels when it comes to information being discussed about their baby. The methods for communicating with parents vary, but usually it is helpful to have face-to-face verbal communication that is reinforced with written information that is succinct and presented without professional jargon at a level that is easily understood by the majority of readers. It is also helpful to have information presented in a sequential manner, so there is some repetition of the same information. This may occur on the same day, in sequential appointments, or in follow-up telephone conversations. Parents should always be given the opportunity to ask questions and given resources for obtaining additional information. Providing resources allows the interested parent the opportunity to seek out additional information—not trying to present all the information at once prevents information overload.

Having parents give their perceptions of situations is also helpful, as the professional can integrate those perceptions into their communication. When parents hear their own words spoken by the professional, they are reinforced in their involvement. For the professional who is inexperienced in discussing findings with parents, it may be helpful to have a script or list of talking points to ensure that all essential information is covered. This may also be helpful as a checklist for the experienced practitioner. Open-ended questions, such

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as, “How may I help you?” “What would you like to know about this?” “What do you think about your child’s hearing?” may provide an opportunity for parents to provide important information to help guide the counseling process. More information regarding parent counseling and family support may be found in the appropriate chapters of this publication.

- Early intervention association
- State pediatric association
- Otolaryngology association
- Family practice association
- State schools for the D/HH
- Early intervention program directors
- Interpreter associations
- Other relevant stakeholders in the EHDI program

## Interagency Collaboration

The need for interagency collaboration has been clearly established for EHDI programs. In many instances, EHDI program components are located in various departments of a state government. These may include the state health department and/or state education department. Within various state departments or agencies, there are different divisions that provide related services. When these entities operate independently, EHDI program effectiveness is impeded. Lack of communication interferes with data collection for the various components of the EHDI program. The EHDI coordinator needs to seek out collaboration and cooperation from all key stakeholders in the provision of service to D/HH children and their families. This may be a difficult task, as these agencies may not be accustomed to working together. Once they are provided with an avenue for discussion and sharing of objectives for the EHDI program, more cooperation can be expected to be forthcoming. Some agencies may see this as threatening, but when open communication is presented in a respectful manner, progress can be made. In addition to state agencies, relevant professional associations and service provider associations need to be identified and included in interagency meetings. These may include representatives from:

- State audiology association
- State speech and hearing association
- EHDI advisory board
- State licensure board for speech and hearing

## Needs Assessment

Needs assessment is an ongoing process—the complexity of which will vary depending on the particular needs of the state EHDI program. Numerous needs assessment tools with appropriate components are available on the National Center for Hearing Assessment and Management (NCHAM) website: [www.infanthearing.org](http://www.infanthearing.org). These components will relate to:

- Program performance
- Screening and diagnostic equipment
- Training
- Public relations
- Pediatric audiologists
- Early intervention personnel skilled in working with very young D/HH children
- Information management
- Funding
- Governance

Regardless of the performance status of the EHDI program, needs assessment studies may need to be strategically planned, developed, and conducted whenever there are:

- Staff changes
- Equipment issues
- Changes in technology
- Changes in protocols
- Changes in program location(s)
- Funding changes
- Regulatory changes

Results of needs assessment studies are needed to support budgetary requests and for long-range planning and implementation of program objectives.

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## Governance

EHDI programs are frequently located in state departments of health or education and are governed by the structure of those departments. The EHDI program usually has a coordinator who is responsible for day-to-day operation of the program but who reports to the director of the division within which the program is located. The EHDI program will usually have strong affiliations with the state speech and hearing organizations, state organizations for the D/HH, associations for early intervention, special education, and parent organizations. The EHDI coordinator must create an atmosphere of cooperation and collaboration by ensuring that all stakeholders are included in communications, meetings, and planning for program implementation.

## The State Advisory Committee

The EHDI program in most states has an advisory board whose members are either appointed by the governor, elected by professional organizations, or represent key stakeholders. The composition of a state advisory committee to EHDI is variable from state-to-state and may be defined by legislation, licensure board rules and regulations, or a manual of operating procedures. This composition usually includes representation from medicine that may be from pediatrics, otolaryngology, genetics, or other medical specialties when an individual physician has a particular interest in hearing loss. Audiology representation usually includes an individual who has expertise in diagnostic pediatric audiology as well as skill in facilitating family involvement in the EHDI process.

Early Intervention is frequently represented by an individual who has knowledge about specific services available and the broad spectrum of methodologies utilized by families in working with their child. A consumer representative on the advisory committee may be represented by a

knowledgeable parent of a D/HH child, deaf adult, politician, or other professional who is knowledgeable about the entire EHDI process from a recipient's perspective.

Higher education may be represented by researchers, instructors, or individuals knowledgeable about data management. The state program that houses the EHDI program may be education or public health and may have an administrative representative in addition to the state EHDI coordinator who can provide overview information about the components of the program. Other representatives may be required by the regulatory documents that govern the composition of the advisory committee to EHDI. The function of this committee varies from state-to-state and may include many purposes: regulatory, oversight, grant procurement, public relations, educational, and an interagency activity facilitator representative.

Advisory committees may meet monthly, quarterly, or one time per year. The impact of this committee is determined by many variables but can be substantial when it is composed of individuals who are interested in working together and are committed to improving services for D/HH children and their families. It is key that these committed individuals have comprehensive knowledge of the program, stay abreast of new developments, facilitate incorporation of new developments, and have a multifaceted plan of operation. Ground rules for sharing information and mutual respect for individual representatives and their knowledge bases advance interdisciplinary collaboration for constructive actions.

The program may be bound to follow guidelines developed through state legislative mandates. Standards of practice recommendations are also presented in position documents developed by national professional organizations or position statements developed by committees whose members are elected representatives of professional organizations (e.g., the [Joint Committee on Infant Hearing \[JCIH\]](#)).

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It behooves the EHDI coordinator to have available all guidelines from their division regarding any action steps taken. This affords the EHDI program staff some degree of protection in avoiding problematic issues by adhering to acceptable practices.

## Legislation

In the United States, 49 states have passed legislation governing the operation of their EHDI program. Most of these states have rules and regulations that broadly define the operating parameters for the EHDI program. These may be further supported by a more detailed manual of operating procedures (MOP) that outlines the specifics for all the components of the EHDI program. Legislation is an ongoing process that involves all the stakeholders and is frequently revisited to revise or amend. Recent activities in legislation have included mandated reporting, fee schedules for specific services, payment for hearing aids, and funding for the EHDI program.

## Manual of Operating Procedures

Key to success and efficiency for a state EHDI program is the establishment of a MOP developed with input from key stakeholders throughout the state. This manual is usually published in printed format and made available on a state EHDI website. Fortunately, many states have accomplished this task, and their products are available on the NCHAM website ([www.infanthearing.org](http://www.infanthearing.org)), the individual state website, or other websites. There are strengths and weaknesses for these individual websites, but there is something to be learned

from each one. Most states are willing to share information freely that can be incorporated into newly created material. The MOP should include legislation, established standards of care, public relations documents, as well as protocols for hospitals, audiologists, interventionists, and parents. These protocols should be developed, reviewed, and published for key stakeholders with multiple agency participation. Buy-in for the state EHDI program comes as a result of full participation of everyone involved.

The MOP should include comprehensive protocols for all components of the EHDI program, including screening, diagnostics, and intervention. There should also be protocols for procedures intended to reduce the loss to follow-up or loss to documentation. These protocols should include copies of forms to be used by EHDI program participants throughout the state. Whenever there are deviations from the protocols that have been developed and made available, there should be easy and accessible ways to report the discrepancy. The MOP should also include:

- Procedures for data sharing.
- Use of disposables and infection control.
- Equipment maintenance, calibration, and the documentation required.
- Training procedures and certification requirements for all program personnel.

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## Reporting

It is the responsibility of the state EHDI coordinator to have statistical information regarding overall performance of the components of the EHDI program,



Photo courtesy of NCHAM

as well as individual performance information from birthing, diagnostic, and intervention facilities. Integrated information management from the various facilities involved in the EHDI program facilitates access to this information. While states have worked to get their information management systems (IMSs) established, working, and accessible to service providers, information management is still an ongoing process. Some states have fully integrated IMSs, and others are still working with multiple sources of information and databases. Regardless of the status of the state IMS, it is the responsibility of the EHDI coordinator to learn as much as possible regarding the systems in place, work to improve the availability of information, and search for mechanisms to make this improvement possible.

## Training

Training personnel involved in the EHDI program may take many different directions. Whatever the direction, training is an essential component for the successful operation of an EHDI program. Many states hold an annual state or regional conference where EHDI personnel can obtain professional training with continuing education credit. Some states have conducted specialized training for practitioners serving D/HH children. When performance data indicates a specific problem, some state EHDI coordinators have done onsite training for individual hospitals. The EHDI programs across this country have encountered frequent turnover in the coordinator position. This has resulted in the need for extensive training from the top down and from the bottom up. In addition to the EHDI coordinator, screening program personnel, pediatric audiologists, parent support personnel, and early interventionists all need ongoing training. The population of D/HH babies identified before 3 months of age constitutes a new group of children needing services and is very different from the population of 1- to 3-year-old children most professionals in

this field were trained to serve. Numerous training programs have been developed and include national initiatives to provide comprehensive training. The NCHAM Technical Assistance Network—a group of experienced pediatric audiologists who provide services to 14 regions of the country—has helped to:

- Develop diagnostic and intervention courses offered online with follow-up, onsite presentations.
- Develop comprehensive training packages in electronic formats for cost efficiency and ease of utilization.
- Develop regional conferences for ready access for local participants.
- Encourage federal initiatives to provide additional funding for specific projects.
- Provide consulting and evaluation services to state EHDI programs.

The [Health Resources and Services Administration](#) (HRSA) has made substantial funding available to EHDI programs, including training efforts. The [Centers for Disease Control and Prevention](#) (CDC) EHDI program has provided funding for information management, as well as multiple research and training programs through the Center for University-Affiliated Programs. CDC has also provided financial support for conferences. This multiagency financial support has been instrumental in moving the EHDI program forward in ways that were not possible when the issues were first addressed by the National Consensus Development Conference sponsored by the National Institutes of Health in 1990.

## Family Involvement

Family involvement—from the first contact at the screening hospital to intervention program attendance—is the single most important aspect of any EHDI program. In spite of all the financial support the program has received, all the professional hours of involvement and collaboration, and all the legislative mandates, success in meeting the EHDI

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benchmarks will not occur if families are not involved, given respect, and given the opportunity to make choices in their child's program. Family involvement starts with prenatal training through the obstetric practice or public health clinic and continues into the pediatric office, Title V program, and Part C program. All of these offices offer the opportunity to provide information about the value of newborn hearing screening, diagnostic audiology, and very early intervention for D/HH children. Family involvement can be enhanced by participation in family-driven organizations, such as [Guide by Your Side or Hands & Voices](#). Further information regarding these organizations can be found in the "Family Support" chapter of this publication. Some states have hired parents of D/HH children to work in EHDI programs. These parents provide a number of services, including tracking and follow-up, information sharing, and service location. Informative videos, DVDs, or printed materials can give information to parents in multiple settings. This information can be reinforced with public service announcements, local newspaper stories, television programs, and professional publications that discuss the value of the EHDI program. When families are informed and given the

opportunity to participate, they will be more likely to follow-up on referrals and recommendations for their D/HH child. Participating families can be provided with a facilitator who can help them better understand the expectations for the family and for the professional. It is not unusual for a family and a professional to sign an agreement clearly stating what the next steps are and when these steps are to occur.

## Medical Home Involvement

The [American Academy of Pediatrics](#) (AAP) has been a strong advocate for early identification of hearing loss and has identified physicians in each state to serve as Chapter Champions for the EHDI program. These physicians may represent a number of specialties, but all have particular interests and insights into the EHDI program. The Chapter Champion can provide information for publication in state professional association newsletters, make presentations at professional meetings, serve on advisory committees, and offer numerous other invaluable services to help move the EHDI program forward. The involvement of the Chapter Champion can help primary care providers receive information about how to facilitate their patient's movement through the various components of the EHDI program. They can also provide information about ways primary care providers can serve as efficient case coordinators for D/HH babies who may have additional medical problems that require referral to other specialists.

The etiology of a hearing loss is frequently unknown, and the primary care provider is in a position to assist the family in trying to determine the cause of a baby's hearing loss. Hearing loss is frequently unstable, and the primary care provider can assist the family in monitoring the status of the hearing



Photo courtesy of Octicon A/S

Some children are born with normal hearing but have risk indicators for developing hearing loss later in life.

loss and making referrals for additional testing, when necessary. The primary care provider can serve as the case manager in consolidating diagnostic information for a D/HH child with additional medical problems. The primary care provider may be difficult to identify and often is not the physician of record during the newborn's hospital stay. It becomes the responsibility of the EHDI program staff to determine where the baby is receiving primary medical care in order to establish meaningful communication regarding screening results, diagnostic results, and intervention progress.

### Interdisciplinary Involvement

The EHDI coordinators from states that have very successful programs know that hearing loss seldom exists in isolation. Research from the Gallaudet program has consistently shown that approximately 40% of D/HH children have additional disabilities. These disabilities compound the problems associated with hearing loss. EHDI coordinators who give

appropriate attention to interdisciplinary assessment of hearing and related disabilities can expedite progress in early intervention. An interdisciplinary team can afford a child and his family an accurate diagnosis that will help in obtaining appropriate intervention services. Although these teams may not be available in every location where service is provided to D/HH children and their families, they can be made available in strategic locations across a state.

A statewide network of skilled professionals working in a collaborative manner can address the needs of a D/HH child with other disabilities. Many states have hired hearing resource coordinators who work in various sections of their state to facilitate interdisciplinary assessment. Some states have developed regional diagnostic centers throughout their state where more advanced diagnostic audiology services can be performed. This prevents families from having to travel long distances and avoids being placed on lengthy waiting lists. Service is expedited, and follow-up is more successful when it is available close to the child's home.

### Meeting the Needs of All D/HH Children through the State EHDI Program

While the majority of EHDI program efforts have addressed the needs of children with bilateral moderate-to-profound hearing loss, there is a substantial percentage of the population of children with auditory problems that are not included in this group. Those children who are not included are those with unilateral hearing loss, minimal/mild hearing loss, and auditory neuropathy/dys-synchrony. Research has shown that these children have substantial developmental, academic, and social difficulties associated with their hearing problem. In some states, children with these types of problems do not qualify for services, according to the guidelines established by many



Photo courtesy of Oticon A/S



One only needs to talk to one child with a unilateral hearing loss and their family to understand the extent of the difficulties they face as a result of their hearing loss.

state agencies. One only needs to talk to one child with a unilateral hearing loss and their family to understand the extent of the difficulties they face as a result of their hearing loss. It is the responsibility of the EHDI coordinator to ensure that efforts are made to screen, diagnose, and intervene for this group of children to optimize their developmental progress.

Some children are born with normal hearing but have risk indicators for developing hearing loss later in life. These risk indicators are often difficult to ascertain, because there are no specific screening programs in place to evaluate children with indicators for hereditary problems that are not evident in the newborn period; or for congenital infections, such as congenital cytomegalovirus infection (Dahle et al., 2000; Fowler et al., 1997). Hearing loss acquired early in childhood can have serious detrimental consequences, which often occur before speech and language are developed, and are therefore difficult to detect by parents. The EHDI coordinator should have knowledge of the indicators for delayed onset hearing loss, have mechanisms in place for monitoring these children, and provide education for primary care providers and audiologists regarding monitoring of risk indicators for progressive and delayed onset hearing loss in young children. The NCHAM website ([www.infanthearing.org](http://www.infanthearing.org)) has several state protocols for monitoring children with risk indicators for progressive and delayed onset hearing loss. Regardless of which protocols are employed, states that provide new parents with markers for normal auditory skill development have made efforts to educate parents about monitoring developmental milestones, so they can address any concerns with their primary care provider.

In addition to different types of auditory difficulties, children from a variety of cultures and ethnic backgrounds may require additional services, including interpreters and professionals with expertise in cultural perspectives. The Center on Cultural Competence has

extensive information and training materials available on their website ([georgetown.edu/research/gucchd/NCCC/foundations/frameworks.html](http://georgetown.edu/research/gucchd/NCCC/foundations/frameworks.html)). Understanding and knowledge regarding this information is essential for ensuring that EHDI program personnel are informed and adhere to all federal and state guidelines in providing services to individuals from all ethnic and cultural backgrounds.

## Intervention

Early intervention case managers for D/HH children and their families are charged with coordinating a very complex journey for the family. It is not unusual for families to see different professionals at each visit. They may see many different audiologists, early interventionists, vision experts, pediatricians, speech pathologists, and physical therapists throughout their intervention program. It is important that some familiar voice, with a familiar name, from a familiar location, maintain contact with the family as they go through the intervention process. This individual can serve as the early intervention coordinator and provide some unity to the objectives the family has helped to establish and to help the family as they transition through the levels of intervention. The success of intervention is based on a respectful relationship between parents and professionals. The parents are in a position to know their child best and be very aware of their child's specific needs. When careful interdisciplinary diagnostic assessments have been done initially, and the child is monitored by their family and professionals, intervention objectives can be addressed, progress can be monitored, and an optimum outcome can be anticipated.

## Research

The EHDI coordinator may or may not have experience with research, depending on his or her training and background. There is often considerable benefit to being involved with university researchers who are actively involved in studies related to

components of the EHDI process. Often these researchers have funding from some of the same federal agencies that fund the state EHDI program. Collaboration with these individuals will likely enhance the objectives of both entities. A bonus may be improved services for D/HH children and their families. Active participation in research assists the state EHDI coordinator to stay abreast of the latest information and may provide the opportunity to participate in service-related projects. Of course, this collaboration must adhere to all state departmental guidelines as well as HIPAA and FERPA mandates.

### Public Relations

The EHDI coordinator should take advantage of every opportunity to communicate the importance of normal development of speech and language through early identification and intervention. Sharing information about the EHDI program, available services, and important benchmarks for D/HH children should be a frequent occurrence. Human interest stories about the success of D/HH children are very appropriate for newspaper as well as television interviews. Public service announcements on radio and television reach a broad audience and can be used to inform the public about the objectives of the EHDI program. Information sharing enhances the opportunity for parents to obtain needed services for their children and may help to attract financial support for the EHDI program. Further, this enhances interagency collaboration, which results in

D/HH children receiving better services. The EHDI program coordinator should make every effort to serve on interagency taskforces, advisory boards, training programs, and plan to interact with professionals who provide services to D/HH children. The EHDI coordinator who knows about diagnostic audiology and early intervention programs available in the state is more likely to find ways to help families receive the services they need.

### Creativity

The new EHDI coordinator will face many challenges while administering a state EHDI program. Most of these challenges can be successfully addressed by engaging dedicated program constituents. These individuals can suggest many traditional and nontraditional methods for addressing challenges. As long as the methods are consistent with the department policy and guidelines, cleared through appropriate channels, have appropriate financial support, are documented, and meet the needs of the program as defined through needs assessment, they can be effective. The EHDI coordinator has support available through other local, state, regional, and national EHDI programs. Supportive efforts to optimize the opportunities available for D/HH children and their families have a long history. The success achieved in the last 10 years has far exceeded any reasonable expectations. Evidence shows that local, state, and federal initiatives are improving EHDI program effectiveness and, more importantly, outcomes for D/HH children.

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