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The Status of State-Wide Policies for Neonatal Hearing Screening

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Abstract

During the process of establishing follow-up procedures for our neonatal hearing program, we became interested in the current status of screening programs nationwide. Fifty states and the District of Columbia were surveyed to determine the extent and content of legislatively mandated neonatal hearing screening programs. Fourteen states have legislative mandates for screening and, at this point, approximately 50 percent of the states have no state-wide policy regarding neonatal hearing screening. Among the various state-wide protocols two basic approaches emerged: (1) the high-risk register and (2) in-hospital screening. In addition, information was obtained on screening methods, the level of program implementation, and some of the pros and cons for mandating neonatal hearing screening.

Key Words: Neonatal hearing screening, high-risk register, in-hospital screening, legislation, hearing tests, infant

Early identification of hearing loss is universally recognized as a necessary component to successful management of hearing-impaired children. Children who have prelingual hearing impairments suffer delays in communication, education, and psychosocial development (Bess and McConnell, 1981; Downs, 1986; Levitt and McGarr, 1988; Schum, 1987). In recognition of the potential liability of hearing impairments, the Joint Committee on Infant Hearing (1982) recommended that hearing loss be identified by the age of 3 to 6 months. To further encourage the early identification and habilitation of all types of handicaps, including hearing loss, Public Law 99-457 (the Education of the Handicapped Amendment of 1986) was passed. This law is, in part, a discretionary program that addresses the needs of 0 to 2-year-old handicapped children (ASHA, 1989; National Association of State Directors of Special Education, 1986).

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To meet the need for early identification of hearing impairment, neonatal screening programs are being examined and, in some cases, established across the country by state health departments, private hospitals, and audiologists. Our own experiences in establishing a neonatal screening program led to an interest in the current status of neonatal screening programs nationwide. The primary question of this study was how many states had legislative mandates for neonatal screening. Other information of interest included the types of screening programs that have been implemented, screening methods used, and why mandates were or were not wanted by hearing professionals and state agencies.

METHOD

A questionnaire requesting information on the existence of a state mandate or recommendation for neonatal hearing screening was sent to the state director of public health for each state plus the District of Columbia. Responses were received in writing from 39 states and by follow-up telephone surveys from the remaining 12 states. States responding nega-

tively or sending incomplete information about existing programs were contacted by telephone for clarification. An attempt was always made to talk to someone involved with speech and hearing services in the public health department, although this was not always possible. The information obtained through this survey is accurate as of November, 1988. The main emphasis in the questionnaire and the telephone survey was state run and/or mandated programs. Virtually every state has hospital-based screening programs, but the aim of this survey was to identify those states with comprehensive state-wide screening policies. This survey simply reflects the status of mandated neonatal screening programs at one point in time. As program development is an ongoing process, an exhaustive review of all the aspects of each neonatal screening program is beyond the scope of this paper.

RESULTS

State-Wide Screening Policies

The responses received were divided into three primary categories as illustrated in Figure 1. The states in Category 1 have a legislative mandate for neonatal hearing screening. Category 2 states have no legislative mandate, but have addressed the issue in some way at the state level. Category 3 states have no mandate and indicated that the issue has not been addressed at the state level.

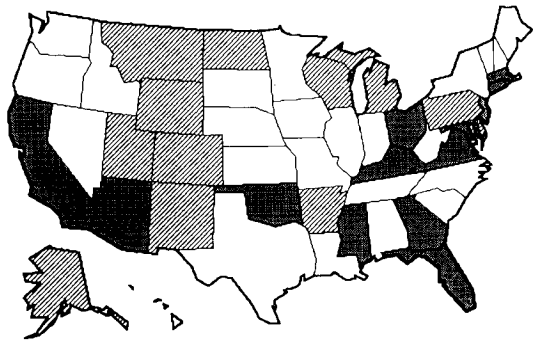

Figure 1 State-wide neonatal screening programs.

■■■ Category 1: States with mandates for neonatal screening programs.
▨▨▨ Category 2: No mandate, but neonatal screening is addressed at the state level.
□□□ Category 3: No mandate, no state-wide screening programs or policies.

The 14 states with legislative mandates addressing neonatal screening (Category 1) are listed in Table 1. The extent of program implementation varies widely among these 14 states. Some states have well-established programs, while other more recently established programs are in various stages of development ranging from those only in designated hospitals across the state to programs in the majority of hospitals in the state with newborn units. Two states have no state-wide implementation but do have privately run screening programs that cover a large number of their newborn population. Two states are in the process of developing the rules and regulations needed to implement their mandates and one state has a pilot program in one region of the state but has not received the funding for state-wide implementation. The screening approaches and testing techniques used in these programs are discussed below.

All 14 states with mandates for neonatal screening sent copies of their legislation. The wording in eight of the mandates was very broad, specifying no particular screening ap-

Table 1 States with Legislative Mandates for Neonatal Hearing Screening (Category 1)

	Date of Mandate	*Date/Status of Implementation*
Arizona	1987	Currently developing protocol
California	1983	Implemented in 1984
Connecticut	1981	Implementation limited to the development of brochures in 1981
Florida	1982	Implemented in 1984
Georgia	1978	Pilot program only—1982
Kentucky	1986	Implemented in 1986
Maryland	1985	Implemented in 1988
Massachusetts	1971	Implemented in 1971—revised 1985
Mississippi	1974	No state-sponsored implementation, but privately run programs cover a large percentage of the newborn population
New Jersey	1977	Implemented in 1980—revised 1985
Ohio	1988	Currently developing rules and regulations
Oklahoma	1982	Implemented in 1983
Rhode Island	unkn	No state-sponsored implementation, but privately run programs cover a large percentage of the newborn population
Virginia	1986	Implemented in 1987

proach and offering no program guidelines. The remaining six mandates were more specific, and included such items as the high-risk factors, the type of screening approach to be used, funding policy, and the age infants are to be tested.

Table 2 lists 12 states that have no legislative mandate, but have addressed the issue in some way at the state level (Category 2). Six of these states reported the majority of their high-risk infants receive a hearing screening. No specific numbers were provided by these states and the extent of state involvement in the screening programs varied. States with smaller newborn populations, such as Delaware and Wyoming, felt they have achieved good coverage just by encouraging the development of screening programs by private hospitals. Colorado reported they have achieved good coverage by actively promoting the development of local and regional programs and paying for hearing tests for any child age 5 months to 2 years with a suspected hearing loss. Utah provides comprehensive coverage through a high-risk register, follow-up diagnostic testing, and a state-wide parent-infant program. North Dakota maintains a high-risk register but has established no follow-up program.

The remaining six states in Category 2 (Table 2) recommend neonatal screening at the state level but provided no information on the extent to which the high-risk newborn population is covered. Through conversations with program personnel in this second group of states in Category 2, we found that recommendations may involve advice for starting up a screening program, educating medical personnel, and/or developing a brochure for distribution to parents of all newborns. Other states offer additional assistance. For example, Wisconsin, in conjunction with the initiation of their program, is providing inservice programs on infant and child testing for audiologists in the state so that they may update their skills.

Table 3 lists the 25 states with no mandate or recommendation for neonatal screening at the state level (Category 3). Eight of these states indicated that implementation of a screening program was under discussion or in the planning phase. Six of the state health departments stated that the seven high risk factors for hearing impairment recommended by the Joint Committee on Infant Hearing (Appendix 1) were used to refer infants in their perinatal follow-up programs for hearing testing. Attempts were made to confirm this information and to obtain copies of procedural guidelines, but it became apparent quite quickly that no single person or agency had taken a leadership role. Even though personal communication with audiologists in some of these states has indicated that steps are currently being taken to identify high-risk infants, we were unable to obtain, through our questionnaires or phone calls, any consistent in-

Table 2 Current State Policies in Those States that Address the Issue of Neonatal Hearing Screening with No Legislative Mandate (Category 2)

State	*State Policy*
Alaska	Screening programs have been implemented across the state
Arkansas	Recommended screening*
Colorado	Screening programs have been implemented across the state
Delaware	Screening programs have been implemented across the state
Michigan	Recommended screening*
Montana	Recommended screening*
New Mexico	Recommended screening*
North Dakota	State-wide high-risk register, but no follow-up program
Pennsylvania	Recommended screening*
Utah	Screening programs have been implemented across the state
Wisconsin	Recommended screening*
Wyoming	Informal program, but the majority of newborns covered

*Involves consultations to help start up a screening program, educating medical personnel, and developing a brochure.

Table 3 States with No Official Mandated or Non-mandated Neonatal Hearing Screening Program or Policy Implemented as of November, 1989 (Category 3)

Alabama	Maine†	South Carolina
District of Columbia	Minnesota*	South Dakota*
Hawaii*	Missouri	Tennessee†
Idaho*	Nebraska†	Texas
Illinois†	Nevada†	Vermont†
Indiana	New Hampshire	Washington†
Iowa	New York*	West Virginia
Kansas*	North Carolina	
Louisiana*	Oregon	

*State-wide screening programs and/or mandates under discussion.

†States that reportedly use high-risk factors for hearing impairment in their perinatal follow-up programs.

formation on the existence of any state-wide neonatal hearing screening programs. The lack of a central agency for coordination of efforts and the dispensing of information made it very difficult to ascertain the status of neonatal screening for states in both Category 2 and 3.

In summary, 14 states mandate neonatal hearing screening, 10 have implemented state run programs, two have privately run programs, and two are planning programs. Of the 27 states (including the District of Columbia) without a mandate, six have hearing screening services available for the majority of the at-risk newborn population.

Types of Screening Programs

Varying amounts of information on program protocol was provided by 17 states with screening programs (with and without mandates). Review of this information revealed two basic approaches: (1) a high-risk registry approach in which parents of infants at risk for hearing loss are notified and provided information on where to go for testing and (2) an in-hospital approach in which high-risk infants are identified and screened before discharge from the hospital. Table 4 lists the states with screening programs and the approaches used. States with mandates use the same approach across the entire state. In most of the states without mandates, the screening approach varied from hospital to hospital and region to region in order to meet local needs and resources. States using the risk-registry approach do not prevent private hospitals and audiologists from implementing the in-hospital approach on a local level.

Table 4 Type of Screening Programs Used in States with and without Mandates

States with legislative mandates	
California	In-hospital screening—NICU infants only
Florida	In-hospital screening
Georgia	High-risk registry approach
Kentucky	High-risk registry approach
Maryland	High-risk registry approach
Massachusetts	High-risk registry approach
Mississippi	In-hospital screening—non-mandated program
New Jersey	High-risk registry approach
Oklahoma	High-risk registry approach
Rhode Island	In-hospital screening—NICU infants only—non-mandated program
Virginia	High-risk registry approach for well-babies; in-hospital screening for NICU infants
States without legislative mandates	
Alaska	In-hospital screening—NICU infants only
Colorado	High-risk registry approach and in-hospital screening locally determined and managed
Delaware	High-risk registry approach and in-hospital screening—locally determined and managed
North Dakota	High-risk registry approach—no follow-up program established
Utah	High-risk registry approach
Wyoming	High-risk registry approach and in-hospital screening—locally determined and managed

(1) The Risk-Registry Approach

The risk-registry approach has been implemented both at the hospital and the state level. Using this approach at-risk infants are identified through birth certificate information or, more often, by in-hospital chart reviews completed by hospital personnel. Some states maintain a central office that manages the risk register and the follow-up program; in other states individual hospitals keep track of, and follow up, their high-risk infants. Generally, within about 4 months following discharge, the central office or hospital personnel notify parents of the infant's risk status. At this time, the parents are provided with information on developmental milestones, where to go for testing, and what funding is available to cover testing fees. A response from the parents is requested indicating whether the baby was tested and if he or she was found to have a hearing loss. If no response is received from the parents in another 2 to 4 months, a follow-up letter is sent. At this point programs vary. If no response is received to the second letter some drop the child's name from the list, some send another letter, and some notify local health department personnel so that they may follow up.

Policies among states with high-risk registers vary widely. Some programs aggressively follow up children in an attempt to meet the recommendation by the Joint Committee on Infant Hearing (1982) that diagnosis be com-

pleted and rehabilitation begun by age 6 months. Other states have no hard time line. In establishing a high-risk register the goals of the program must be clearly established. If the aim is to begin habilitation as early as possible, careful consideration must be given to the follow-up program.

(2) The In-Hospital Screening Approach

In-hospital screening programs also generally provide parents of all babies with information on developmental milestones and identify those infants at risk for hearing loss. Those infants identified as at-risk then receive an audiologic screen before they are discharged from the hospital. Some programs screen all newborns for risk factors while others only look at those infants in the neonatal intensive care nurseries (NICN). There are a few hospitals that have chosen to provide audiologic screening for all newborns, but this approach is not mandated in any state. Infants who fail the hearing screening or who are found to be at risk for progressive hearing loss are then contacted for follow-up testing 3 to 6 months after the baby is discharged from the hospital. Again, parents are contacted two or three times if no appointment for follow-up testing is kept. When a child is identified as hearing-impaired, referrals are then made to the appropriate agency or program for management and habilitation.

Those who advocate in-hospital screenings feel they are more effective at identifying hearing impairment before the infant is 6 months of age. Though the initial screen is done earlier, the follow-up program is still critical to meeting the goal of identification and habilitation by age 6 months.

Test Procedures

Test procedures used in screening programs include auditory brainstem response (ABR) testing, behavioral testing, and testing with a motion sensitive unit such as the Crib-O-Gram. Few states recommend or regulate the use of only one type of screening method. Table 5 lists the screening methods recommended by nine states with mandates for neonatal hearing screening. A procedure was considered to be recommended if the test name and/or test protocol were included in the program's rules and regulations. Four states and Virginia's well-baby program made no specific recommendations on test protocol. Two states and Virginia's NICU program included two or three different methods in their rules and two states recommended one method. Florida was the only state with a mandate that recommended only ABR in their screening protocol. No state specifically prohibited or discouraged the use of any particular method of screening. Limited information was available on screening methods used in states with no mandates. Utah (Mahoney and Eichwald, 1986) and Colorado provide guidelines for behavioral testing, and a portable VRA unit is used in outlying areas. Mississippi's nonmandated program utilizes the Crib-O-Gram in about 20 hospitals across the state, the majority of which have no audiologist on staff. Alaska and Delaware indicated their NICU populations receive ABR screens before discharge. Respondents in the other states indicated all three screening methods were in use in their states or were not sure of which methods were used.

Table 5 Screening Procedures Recommended by States with Mandates for Neonatal Screening

State	*ABR*	*Behavioral*	*Crib-O-Gram*	*No Recommendation*
California	X	X	X	
Florida	X			
Georgia	X	X		
Kentucky				X
Maryland				X
Massachusetts			X	
New Jersey		X		
Oklahoma				X
Virginia	NICU		NICU	well-baby

Habilitation Programs

As one objective of this survey we attempted to discover what type of habilitation programs infants in legislatively mandated programs were being referred to. The rules and regulations of the 14 mandated programs were examined for reference to available habilitation programs, or a central contacting agency for further information on available programs.

Table 6 displays the content of follow-up recommendations included in the mandated programs. For two states no specific information on follow-up programs was available, and one state had no screening program. Three states in-

cluded only a reference to medical and audiologic follow-up in their screening guidelines. Four states made a nonspecific referral for educational follow-up and four states made a specific reference to one of the following referral goals:

1. Coordinating the activities of the screening and intervention programs (Florida and Ohio).
2. Contacting local Parent Infant Programs (Maryland).
3. Developing an individual educational plan (IEP) for infants identified as hearing impaired (Florida and Georgia).

Only Florida specifically indicated that one of the main purposes of their screening program was to "facilitate referrals of these infants into medical and educational management systems" (Ryan and Ausbon, 1988, p 8). This information does not reflect what early intervention programs are available in each of these states. Many early intervention programs are run by the Department of Education, not the Department of Health. Description of early intervention programs and whether mandated screening programs have facilitated educational referrals could be the basis for another study. However, this information would be very beneficial in helping to determine the impact and/or need for mandated screening programs.

DISCUSSION

Currently, the status of neonatal hearing screening varies widely from state to state. With or without mandates, programming ranges from comprehensive state-wide coverage to screening just those infants admitted to the only state hospital with a NICU. We noted, however, that the majority of states (64 percent) with mandates have or are planning comprehensive programs that follow the infant from identification to habilitation. In contrast only 11 percent of the states without mandates have comprehensive programs. This would appear to support the need for a legislative mandate if a comprehensive state-wide program is to be developed. Representatives of states with and without mandates offered a number of arguments for and against legislating neonatal hearing screening, as listed in Table 7. The cost of current screening techniques and the need for, and lack of, trained personnel to implement these methods was cited by many as reasons for not mandating screening. When diverse intrastate geographies and populations are added to cost and personnel problems, then a state-wide screening program may not always appear feasible or appropriate for legislative mandate. To some professionals outside the field of communication disorders, the current state of the art does not seem to warrant legislation. They cite the lack of consensus among hearing professionals regarding the best way to screen. They also point out there is little data showing that cur-

Table 6 The Content of Follow-Up Recommendations Included in Legislation or Rules and Regulations for Mandated Neonatal Hearing Screening Programs

Referral made for medical and audiologic follow-up only: California, Arizona, Massachusetts
Non-specific referral made for educational follow-up: Kentucky, New Jersey, Oklahoma, Virginia
Specified the development of an IEP, referral to a parent-infant program, or the incorporation of screening procedures into early intervention programs: Florida, Georgia, Ohio, Maryland
No information available: Connecticut, Mississippi, Rhode Island

Table 7 Reasons for and against Legislative Mandates for Neonatal Hearing Screening

Reasons against legislative mandates
1. Current screening techniques are too costly.
2. State geography and populations are too diverse to implement one program for the whole state.
3. No consensus among hearing professionals on the best way to screen.
4. Efficacy of current screening programs not proven.
5. Screening is done without a mandate.
6. Follow-up testing and habilitation programs are not available throughout the state.
7. Lack of adequate personnel or equipment for screening and follow-up.
Reasons for legislative mandates
1. Insuring compliance of all hospitals in the state.
2. Consistent follow-up.
3. Earlier initiation of habilitation for hearing-impaired infants.
4. Coordination of existing screening and habilitation programs.
5. Instrumentation is now available.
6. Central referring/information agency.

rent screening programs are, in fact, resulting in significantly earlier identification. This observation suggests that more research is needed before programs are legislated. Some respondents reported that current programs in their state were adequate and legislation was not needed. Others felt that screening programs should not be implemented until follow-up testing and habilitation programs were available in their state. This is a valid concern. The cost of a screening program cannot be justified unless it results in effective treatment and reduces the consequences of the disorder (Sackett et al, 1985).

Respondents in favor of legislative mandates for neonatal hearing screening felt that legislation was the only way to insure the compliance of all hospitals or that only with a mandate would existing screening and follow-up programs coordinate their activities. From both points of view, legislatively mandating neonatal screening was considered necessary in order to provide consistent follow-up and earlier initiation of habilitation for hearing-impaired infants. Our experiences in trying to obtain consistent information on available programs in states without mandates (Categories 2 and 3) support the need for a central agency for coordination of efforts and the dispensing of information. The lack of a central coordinating agency impedes the establishment of consistent and comprehensive state-wide programming. In contrast to the arguments against a mandate, some cited the improvement in instrumentation for neonatal hearing screening as one of the reasons they were now seeking a legislative mandate.

The Education of the Handicapped Amendment of 1986 (PL 99-457) is also increasing state interest in neonatal screening programs in general, and hearing screening programs are a part of their focus. States that want to continue to receive federal financial assistance for birth to 2 year programs must establish early intervention services for all handicapped infants and toddlers by 1990–91. Section 676 states that the services provided must include a child-find system and a system for referring to service providers. This could help to provide the impetus to coordinate existing screening and follow-up programs in some states and develop programs in others. Early intervention programs are currently available in many states, but a system for identification and referral is lacking. Other components addressed by PL 99-457 are a public awareness program focusing on early identification of handicaps, training of public and private service providers, and research and demonstration projects (Asha, 1989; National Association of State Directors of Special Education, 1986). If implemented, these components could help to educate legislators and the general public on the impact of communication disorders and the need for early identification. Indifference to the effect that communication disorders have on life in general has been viewed as one of the obstacles to obtaining legislative mandates for neonatal screening.

States considering implementation of statewide screening programs, with or without mandates, need information on the costs/benefits of current programs. It may be possible to determine the costs by calculating the monies needed for equipment and personnel and examining false-positive and false-negative rates of the procedures used. It is a little more difficult to measure the benefits. Little information is available on whether current screening programs actually result in earlier identification. Currently the average age of identification is approximately 2 years or older (Stein et al, 1983; Eissmann et al, 1987). The ultimate test of the effectiveness of a neonatal screening program will be the age hearing-impaired infants are identified and the age habilitation begins.

Our contacts with state personnel revealed that efforts to develop and promote neonatal hearing screening are being made by professionals in audiology, public health, and education. To support these efforts we recommend that states with screening programs publish data and distribute it to public health, hearing, and education publications and that cooperation within states between hearing, health, and education agencies increases. This cooperation will probably be essential if the age that hearing impaired infants begin to receive habilitation is to be significantly reduced.

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Appendix 1 High Risk Factors for Hearing Impairment Recommended by the Joint Committee on Infant Hearing

1. A family history of childhood hearing impairment.
2. Congenital perinatal infection (e.g., cytomegalovirus, rubella, herpes, toxoplasmosis, syphilis).
3. Anatomic malformations involving the head or neck (e.g., dysmorphic appearance including syndromal and nonsyndromal abnormalities of the pinna).
4. Birthweight less than 1500 grams.
5. Hyperbilirubinemia at levels exceeding indications for exchange transfusion.
6. Bacterial meningitis, especially *H. influenzae.*
7. Severe asphyxia, which may include infants with Apgar scores of 0-3 or who fail to institute spontaneous respiration by 10 minutes and those with hypotonia persisting to 2 hours of age.