

A SOUND BEGINNING

OHIO'S INFANT HEARING SCREENING *and* ASSESSMENT PROGRAM



An evaluation conducted by



Submitted to

OHIO DEPARTMENT OF HEALTH
NOVEMBER 15, 1998

EXECUTIVE SUMMARY

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Evaluation Report

Abstract

Ohio's Infant Hearing Screening and Assessment Program (IHSAP) was initiated in 1990 to ensure that newborns with hearing loss were identified as early as possible. IHSAP requires all birthing and children's hospitals in Ohio to complete a Risk Indicator Questionnaire for all births or neonatal admissions and to complete or make a referral for a Hearing Assessment for all babies who have a risk indicator.

This report contains an executive summary of the results and recommendations of a 2-year evaluation of IHSAP conducted by the National Center for Hearing Assessment and Management (NCHAM) at Utah State University.

Results of the evaluation showed that IHSAP forms are completed accurately and that the Ohio Department of Health does a good job in training hospital staff and coordinating the process. Parents are very positive about the state's early intervention and preschool programs for infants, toddlers, and young children with hearing loss.

Although IHSAP has established a good foundation for identifying congenital hearing loss at an early age, several weaknesses need to be addressed. First, the current system is probably only identifying about one-third of the infants and toddlers with congenital hearing loss. Most of this is because risk-based systems have an inherent weakness—only about half the babies with congenital hearing loss exhibit any risk indicators. However, some of it is because a significant number of babies are lost to follow-up before a diagnostic evaluation is completed. Better procedures for tracking and reporting should be implemented to reduce the number of babies who fail the screening but do not complete a diagnostic evaluation. A second area of concern relates to how information about newborn hearing screening and identification is communicated to parents. Although many parents do not recall participating in IHSAP, many of those that do remember the process reported that they experienced significant levels of confusion, worry, anxiety, and anger. More attention needs to be given to ensuring that communication with parents is timely, sensitive, informative, and helpful.

The title of this report, "A Sound Beginning," summarizes the status of newborn hearing screening in Ohio. Clearly, IHSAP has been valuable. However, a lot of work remains to be done. At the time it was implemented, a risk-based approach to identifying newborn hearing loss was the best available approach. Since then, technological developments have made universal newborn hearing screening a feasible alternative that should be considered. Whatever newborn hearing screening procedure is used, the Department of Health should focus on (a) reducing the number of babies who are not screened or do not complete the assessment process, (b) strengthening the tracking and reporting mechanisms associated with the program, and (c) improving the way in which information is communicated with families.

A Sound Beginning: Ohio's Infant Hearing Screening & Assessment Program

Many people are unaware of the harmful effects of childhood hearing loss because it is largely an invisible condition. Most infants with hearing loss are healthy looking and appear to be developing normally. But if a hearing loss remains undetected during their first year, it will interfere tragically with young children's ability to learn language, to do well in school, and to contribute productively to society.

Because language develops so rapidly during the first few months of life, the longer a child's hearing loss remains undetected, the worse the probable outcome. For example, by 6 weeks of age, an infant with normal hearing is more attracted to human speech than any other sound. A 6-month-old baby already has the ability to understand language, and by 18 months, most children are producing simple sentences.

The good news is that appropriate early intervention prevents or substantially reduces the negative effects associated with hearing loss among babies. Such early intervention should include amplification, educational intervention, and medical care. Research studies have repeatedly shown that such early intervention results in dramatically improved language development and increased academic success for children with hearing loss.¹

OHIO'S INFANT HEARING SCREENING & ASSESSMENT PROGRAM

In March 1988, Ohio Governor Celeste signed an act to "require, under certain circumstances, hearing screening and assessment of newborn children." Enacting Sections 3701.503 through 3701.507 of the Ohio Revised Code, the bill took effect on February 1, 1990. On that date, Ohio's Bureau of Maternal and Child Health (BMCH) instituted the Infant Hearing Screening and Assessment Program (IHSAP) as a way of identifying infants and toddlers with hearing loss. In 1993, administrative responsibility for IHSAP was moved to the Bureau of Early Intervention Services (BEIS) within the Ohio Department of Health.

IHSAP comprises a two-tiered process to determine whether an infant needs a complete hearing evaluation. In Stage 1, all hospitals in Ohio that care for newborns are required to screen each infant to determine whether the infant is at risk for a hearing loss. To screen infants, the Infant Hearing Risk Questionnaire, developed by the Ohio Department of Health, is completed for each infant. The questionnaire is used to collect information about a number of factors which are associated with hearing loss. These factors include family history of permanent childhood hearing loss, depressed Apgar scores at 1 and 5 minutes, low birth weight, presence of syndromes associated with hearing loss, high bilirubin level, prenatal medical illness in the mother, defects of the head and neck, administration of ototoxic drugs, mechanical ventilation, and other risk factors defined by the health care manage-

Some babies are born listeners.



Others need your help.

ment team. For those infants who exhibit one or more of these risk indicators, the hospital must “promptly notify” (defined in the law as being within 42 calendar days) the infant’s primary care physician and the Ohio Department of Health of the infant’s name and the name and address of the infant’s parent or guardian. Furthermore, the hospital must provide to the infant’s parents or guardians information describing the risk factor and the impact a hearing loss has on the language development of infants and children.

All infants who exhibit one or more of these risk indicators are supposed to receive a hearing assessment as a second stage of the screening process. Hospitals may choose whether or not to administer this hearing assessments themselves. If a hospital elects to provide hearing assessments, it must provide an assessment for each infant it has identified as being at risk. If a hospital elects not to provide hearing assessments, it must provide the parent or guardian with a list of facilities within a reasonable distance that provide hearing assessments.

In Stage 2, objective hearing assessment is done to determine whether infants who have a risk indicator require a complete hearing evaluation. If hearing assessment results show that the infant needs a follow-up evaluation, the birthing hospital or facility that conducted the hearing assessment must “promptly notify” (defined in the law as being within 42 calendar days) the infant’s primary care physician and the Ohio Department of Health of the infant’s name and the name address of the infant’s parent or guardian.

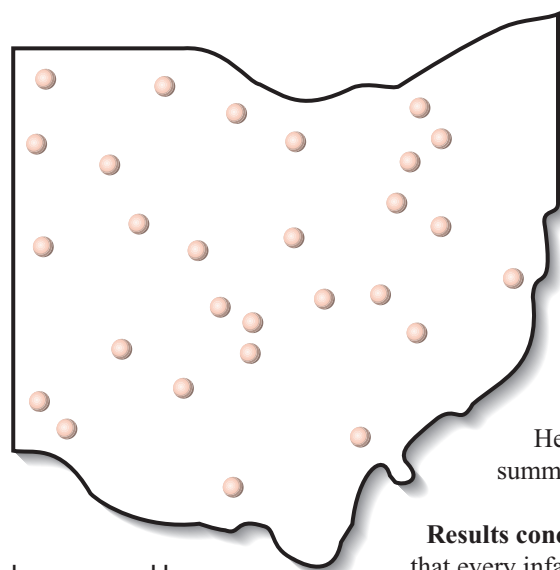
Since its inception in February 1990, the IHSAP program has been operating for 8 years. Approximately 139 hospitals currently participate in the program, and risk indicator questionnaires are supposed to be collected for approximately 150,000 babies born in Ohio each year.

IHSAP EVALUATION DESIGN

In an effort to continually improve the services provided to young children with hearing loss and their families, the Ohio Department of Health contracted with the National Center for Hearing Assessment and Management (NCHAM) at Utah State University to conduct a 2-year evaluation of IHSAP. The first year of the evaluation (1996-97) focused on the accuracy with which risk indicator questionnaires and hearing assessments were completed, the degree to which hospitals were complying with procedures for IHSAP outlined by the Department of Health, and the quality of IHSAP-related training and support activities provided by the Ohio Department of Health to hospitals. The second year of the evaluation (1997-98) focused on the way in which children with hearing loss are enrolled and served in early intervention programs and how well those programs link with existing preschool programs. Finally, estimated costs of identifying infants and toddlers with hearing loss using the current IHSAP were compared to the costs of implementing a statewide universal newborn hearing screening program.

YEAR 1 EVALUATION SUMMARY

Evaluation activities during 1996-97 included a prospective and a retrospective study of Infant Hearing Risk Questionnaires and Hearing Assessments, and a survey of hospital staff and administrators.



LOCATION OF HOSPITALS
PARTICIPATING IN 1996-97
EVALUATION ACTIVITIES

Procedures. A stratified random sample of 29 of the 139 birthing and children's hospitals in the state of Ohio were selected to participate in the first year evaluation. These hospitals were stratified by the size of the hospital, the geographic location (rural versus nonrural), the level of care provided, and whether the hospital staff conducted hearing assessments for infants referred with risk indicators or whether those infants were referred to other providers for the hearing assessment (assessment versus nonassessment hospitals). Infant Hearing Risk Questionnaires and Hearing Assessments submitted by those hospitals to the Ohio Department of Health during 1995 were analyzed. In addition, even though hospital staff are normally required to only submit information to the Ohio Department of Health for infants who do not pass the risk screening, each of these 29 hospitals were asked to submit all Risk Indicator and Hearing Assessment Questionnaires to the Ohio Department of Health for a 13-week period during early 1997. Finally, a sample of people at each of the 29 hospitals were given a questionnaire to rate the various training and support activities provided by the Ohio Department of Health. The most important results for each of these components are summarized below.

Results concerning the Infant Hearing Risk Questionnaire. The law requires that every infant born in Ohio be assessed for the presence of hearing loss risk indicators. For infants who have one or more of the risk indicators, a copy of the Infant Hearing Risk Questionnaire must be submitted to the Ohio Department of Health.

Hospital staff were generally very accurate in completing the Risk Indicator Questionnaire.

More than 20% of all infants are referred (which means) fewer babies with hearing loss will be missed, but . . . it may be causing parents unnecessary concern.

- For both the 1995 and 1997 samples, hospital staff completed the Infant Hearing Risk Questionnaire very accurately. The lack of differences between 1995 and 1997 suggests that the high degree of accuracy in 1997 was not a function of the fact that hospitals knew an evaluation was being conducted.
- Keeping in mind that most items on the Infant Hearing Risk Questionnaire were completed accurately, the items with the most frequent mistakes were related to the mailing address for the infant's doctor or clinic and highest bilirubin level measured for the infants. The errors in these items were probably of little consequence in terms of how effectively IHSAP functions, given that the doctor information was usually available from other sources and the mistakes on bilirubin level did not result in at-risk infants being missed.
- Although the overall accuracy is very good, there is a tendency for assessment hospitals to be slightly less accurate than nonassessment hospitals in completing the Infant Hearing Risk Questionnaires. This is probably because assessment hospitals know they will be doing the hearing assessment on all referred infants, and so tracking and follow-up is not a serious problem.
- More than 20% of all infants are referred as having a risk indicator. This is substantially higher than the 7-10% of infants found by most studies as having one of the risk indicators identified by the Joint Committee on Infant Hearing.^{2,3} With such a high referral rate, fewer babies with hearing loss are likely to be missed, but more hearing assessments are conducted and it may be causing parents unnecessary concern that their baby has a hearing loss.

The Risk Questionnaire was explained in a very haphazard way. It left my husband and I very worried, when there really was not much reason. The likelihood of hearing loss in our child was slim, and this was never explained to us.

—A Parent

Infant Hearing Risk Questionnaires are apparently not completed for 8% of all newborns (which) means that each year 12,000 babies in Ohio are not screened . . . we can estimate that 36 of these “missed babies” will have a hearing loss.

Finding out my child is hearing impaired was devastating! However, the professionals who helped diagnose our daughter were excellent, very knowledgeable and informative, and compassionate.

—A Parent

Hearing assessment report forms were missing for approximately 35% of the babies with risk indicators.

- Assessment hospitals and Level III hospitals identify a higher percentage of babies with risk indicators. This may be because those hospitals frequently have the capability to do hearing assessments themselves and, consequently, would rather refer the baby for hearing assessment if there is any question.
- Infant Hearing Risk Questionnaires are apparently not completed for approximately 8% of all newborns. Although 92% completion is good, it means that each year 12,000 babies in Ohio are not being screened for hearing loss before they leave the hospital. Because the prevalence of permanent congenital hearing loss is about 3 per 1,000, we can estimate that 36 of these “missed” babies will have a hearing loss that will most likely not be found until they are 3 to 5 years old.

Results concerning Hearing Assessments. By law, all infants who have one or more risk indicators must have a Hearing Assessment completed as the second stage of the screening process. Hospitals who have chosen to be “assessment hospitals” are required to submit the completed Hearing Assessment form to the Ohio Department of Health. Nonassessment hospitals are required to give parents a list of providers who can complete the Hearing Assessment.

- Hearing Assessment forms that are submitted are completed very accurately. There is a slight tendency for forms completed in 1997 to be less accurate than those completed in 1995.
- Hearing Assessment forms were not submitted to the Department of Health for approximately 35% of the babies with risk indicators who were born in assessment hospitals. This suggests that a substantial number of children who need hearing assessments are not having them completed.
- Because nonassessment hospitals are not required to submit the Hearing Assessment forms to the Ohio Department of Health, it is unknown how many babies from nonassessment hospitals, who should have had a Hearing Assessment completed, in fact did have one. We estimate, however, that the percentage of babies with missing Hearing Assessments from these hospitals is similar to what it is for the assessment hospitals.
- The fact that 8% of babies do not have an Infant Hearing Risk Questionnaire completed and that 35% of the babies who have risk indicators apparently do not have a Hearing Assessment form completed suggests that the current program is failing to identify dozens of infants with hearing loss each year.
- Hearing Assessment report forms are missing much more frequently for babies born in rural and Level I assessment hospitals than for babies born in nonrural and Level II or Level III assessment hospitals.
- A very small percentage of infants referred for Hearing Assessments actually require further audiological diagnosis (less than 5%). Thus, the first stage Infant Hearing Risk Questionnaire is not very efficient in determining which babies need a complete audiological evaluation.

Results concerning IHSAP training. The Ohio Department of Health is charged with the responsibility of making sure that hospital staff are informed about the purpose of IHSAP and have the necessary skills and knowledge to comply with the procedures.

I wonder how much further developmentally my child would be had his hearing loss been diagnosed at birth. That to me is really upsetting—that we are not testing at birth.

—A Parent

After her test, my daughter and I sat in a small room by ourselves for 4 hours. I held her close to me and cried the entire time. No one came to me for anything. There should be support people there to help. I was so scared, and I didn't know what to do.

—A Parent

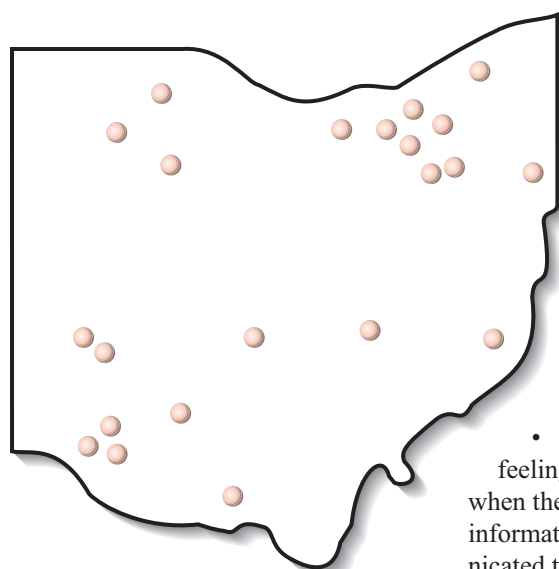
- Although most recipients view all aspects of the IHSAP training and support favorably, training about the parts of the program related to Hearing Assessment is viewed much more favorably than training about the parts of the program related to the Infant Hearing Risk Questionnaire. This is probably because fewer people are involved in activities related to the Hearing Assessments, and those people tend to be more aware of the need for early identification of hearing loss and have been involved with the program for a longer time.
- A substantial number of people believe that the forms used by IHSAP could be improved. There is little consistency, however, in the suggestions for improvement.
- Although there were no questions included in the evaluation instruments about universal newborn hearing screening, there was a moderate amount of spontaneous support for the concept of implementing a statewide universal newborn hearing screening program as an alternative to the IHSAP program.
- Hospital staff and administrators think that there should be better tracking and follow-up of infants referred from IHSAP.
- Very few administrators are substantially involved with or aware of details about IHSAP. This lack of awareness and knowledge, however, does not appear to have any negative consequences, because people actually operating the program are well informed about IHSAP's goals and objectives, are good at implementing the procedures, and are committed to the concept of early identification of hearing loss.

YEAR 2 EVALUATION SUMMARY

The second year of the evaluation included a survey of parents whose infants participated in the IHSAP program, a survey of parents of children with hearing loss who were enrolled in early intervention and preschool programs, and a survey of early intervention staff.

Procedures. The second year of the evaluation (1997-98) focused on how well children with hearing loss are enrolled and served in early intervention programs and how those programs link with existing preschool programs. The evaluative data were based on information collected from several groups. First, a stratified sample of parents/guardians of IHSAP babies (born during January through April 1997) who had risk indicators were asked to complete a survey about various aspects of the risk indicator screening, the hearing assessment, and further follow-up. Second, a sample of parents/guardians of children with hearing loss from each state-funded early intervention program and from some private early intervention programs were asked by survey how their child was identified and how well the early intervention program meets their child's needs. Third, a sample of parents/guardians of children with hearing loss in preschool programs were asked by survey about how their child was identified, about their child's previous early intervention program, and how well the preschool meets their child's needs. Finally, early intervention program providers were asked by survey about how children are enrolled and served in their programs.

Parents' perceptions of IHSAP. The law requires that infants with a risk indicator have a follow-up hearing assessment done to determine whether they needed a complete diagnostic audiological evaluation. Perceptions about how well this process functions were collected from parents of 146 infants with risk indicators born during January-April 1997 in assessment and nonassessment hospitals.



LOCATION OF EARLY INTERVENTION PROGRAMS PARTICIPATING IN 1997-98 EVALUATION ACTIVITIES

- About half of all parents were unaware of the existence of IHSAP or the results for their own baby. Because all of the babies included in this sample had a risk indicator, this suggests that results of the risk indicator screening are not being communicated well enough to parents. Because parents are the key to ensuring that appropriate follow-up is done, this weakness undoubtedly contributes to later deficiencies in IHSAP outcomes.
- Of parents who remember the Infant Hearing Risk Questionnaire, about 30% were confused by the explanations and what to do next (percentages were higher for those with less education and whose babies were born in nonassessment hospitals).
- Of parents who remember the screening, about two-thirds recall feeling worried, while about one-third recall feeling unsupported and angry when they were told the results. These problems were least evident when the information was communicated by an audiologist (but an audiologist communicated the information for only 15% of the parents).
- Parents of babies who received a Hearing Assessment following the Infant Hearing Risk Questionnaire have much more positive recollections of those tests and felt the assessment was valuable.
- Only two parents of a total of 146 “high-risk babies” reported that the child had a hearing loss. This is consistent with the conclusions from the Year 1 evaluation that many unnecessary Hearing Assessments are conducted, which may cause parents unnecessary concern.

The term ‘failed’ made us feel as if he had a serious imperfection . . . This added more stress to an already difficult period.

—A Parent

Parents’ perception of early intervention programs for children with hearing loss. A 0- to 3-year-old child with a hearing loss should be enrolled in an early intervention program. Once enrolled, Federal Law requires that the child (and its family) receive a number of services, and that an IFSP (Individualized Family Service Plan) be completed. Results in this section come from parents of 79 children with hearing loss enrolled in 16 different early intervention programs distributed around the state.

- Parents reported that their children were identified with hearing loss at an average of 10 months of age. Although this is relatively young compared to national averages,⁴⁻⁵ it means that almost a year of critical time for language development has been irretrievably lost.
- For children in this sample, the delay between positive identification of hearing loss and enrollment in an early intervention program was 2 months. On average, another 1 month elapsed before they were fitted with amplification. Although such delays are relatively short compared to national averages, valuable time is being lost.
- At the time their child was identified with hearing loss, most parents had little understanding of the impact it would have on medical needs, family finances, and the child’s success in school.
- For most, the diagnostic process worked very well, but a significant number of the parents (20% to 30%) were not satisfied and thought it was confusing and overly time consuming.

I feel the transition from the diagnostics to early intervention needs to evolve to a more precise procedure. There seems to be a breakdown in locating and ultimately receiving necessary early intervention services.

—A Parent

*The early intervention program staff is **excellent**—very caring and very concerned about my children. They are enthusiastic about working with and teaching my children, not to mention teaching my husband and myself. They have taught us so much about how to best help our boys.*

—A Parent

- About half of the parents whose babies were born in Ohio do not remember the IHSAP process. Of those that do remember, 30% to 50% recall being somewhat confused, angry, frustrated, and/or worried by the process.
- Most of the children in this sample (all of whom have a hearing loss) wear hearing aids, and most of their parents think the aids are very valuable and appreciate the financial assistance they had to get them.
- The vast majority of parents think their child's early intervention program is wonderful! However, 26% don't know if their child has an IFSP.
- About 20% of parents don't know much about where their child will attend school when the child turns 3 and are worried that future educational services may not be appropriate or as good as what they are currently receiving.

Perceptions of parents of preschool-aged children with hearing loss. A 3- to 5-year-old child with hearing loss should be enrolled in an appropriate preschool program and have an IEP (Individualized Educational Plan) as soon as they turn 3 years of age. Results in this section are based on responses of 20 parents of 3- to 5-year-old children with hearing loss. Keep in mind that this sample is smaller and less representative of the entire state than the early intervention sample.

- Parents reported that these children were identified later (18 months on average) and had hearing losses ranging from mild to profound (including babies with unilateral as well as bilateral losses).
- At the time their child was identified with hearing loss, most of these parents did not understand the impact it would have on medical needs, family finances, and the child's success in school.
- Twenty-five to 50% felt that the diagnostic process was overly time consuming, confusing, and that their opinion about the child's needs was not respected.
- Twenty-five percent of the parents reported that their child does not currently have an IEP. Those that have an IEP were quite satisfied with it.
- Almost all of the parents are very satisfied with the preschool program their child attends.
- About half of the parents don't know much about where their child will attend school when he or she "graduates" from preschool and are worried that future educational services for their child may not be as good or as appropriate for their child's needs as what they are now receiving.

The preschool staff is very supportive. They are always there when I need them and are concerned about my child's well-being.

—A Parent

Early intervention program staff. Early intervention staff help a family develop an IFSP and provide a variety of services to infants with hearing loss and their families. Responses in this section come from coordinators of 11 early intervention programs distributed geographically throughout the entire state.

- Almost all early intervention program staff felt their program had appropriately trained staff and good facilities and was providing excellent services to children with hearing loss who do not have other disabilities. They are less positive about the services they are able to provide children who have other disabilities in addition to hearing loss.

A great challenge to our program lies with the multi-handicapped children when their hearing loss is not the primary disability.

—An E. I. Staffer

Early intervention needs to be funded like any other special education unit so the teacher has time for home visits, group lessons, meetings with families, et cetera.

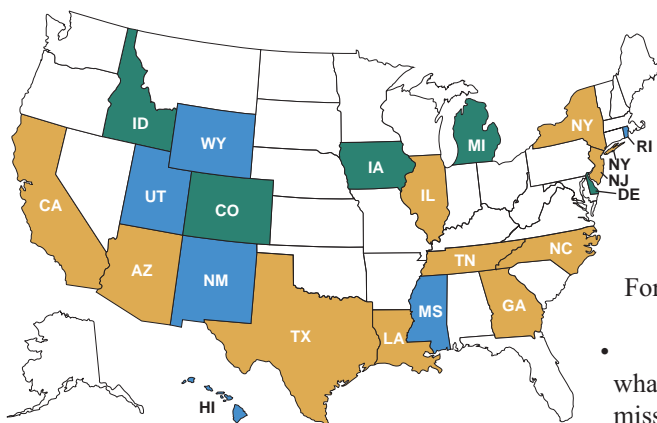
—An E. I. Staffer

- The biggest challenges to providing appropriate services are the large geographic areas they are required to serve and insufficient financial resources.
- Many early intervention staff do not have a clear idea of what IHSAP is or how it functions. Early intervention staff also report that they serve very few children with hearing loss who were identified as a result of IHSAP.
- Most early intervention staff believe they are well informed about the schools these children will attend when they “graduate” from early intervention, but they worry that the quality of services children and families receive will be much lower.

COSTS OF EARLY IDENTIFICATION OF HEARING LOSS

Ohio’s IHSAP was initiated at a time when there were no viable alternatives for identifying hearing loss during the neonatal period. Since that time, as a result of technological developments, many hospitals in other states have implemented universal newborn hearing screening programs in which all babies receive a physiologic screening prior to discharge. Although a comparison of universal newborn hearing screening with an at-risk-based screening approach like IHSAP was not a specified outcome of this evaluation, it is useful to briefly consider the costs and outcomes of the two approaches based on available data.

Numerous research studies have demonstrated that only about 50% of babies with congenital hearing loss exhibit one or more of the risk indicators recommended by the Joint Committee on Infant Hearing (which are essentially the same as those used by IHSAP).^{2,3,6-8} Therefore, if a risk-based newborn hearing screening program works perfectly (i.e., risk indicator information is collected accurately for all babies, and diagnostic assessments are completed for all babies with risk indicators), only about half of the babies with hearing loss will be identified. Given that about 3 infants per 1,000 have congenital hearing loss, comparative costs can be estimated for risk-based screening, such as is done in IHSAP (using information from the current evaluation) and universal newborn hearing screening (based on existing literature). Both estimates are based on 150,000 annual births.



For the current IHSAP model, assume the following:

- Risk indicators are collected for all babies (this is somewhat optimistic, since we know about 8% of births are currently missed).

STATES OPERATING SUCCESSFUL UNIVERSAL NEWBORN HEARING SCREENING PROGRAMS:

- STATEWIDE NEWBORN HEARING SCREENING PROGRAMS.
- STATES SCREENING MORE THAN HALF OF ALL BIRTHS, BUT NOT YET STATEWIDE.
- STATES SCREENING MORE THAN 20,000 BIRTHS EACH YEAR.

- There is \$10 per birth of personnel time required for paperwork and reporting of risk indicators. (This is only an estimate.)
- Twenty-one percent of births have a positive risk indicator and require a \$75 hearing assessment.
- There are 6.3% of the children referred for a complete diagnostic evaluation at \$250/child.
- Thirty-three percent of the needed diagnostics are not completed.

Assume further, based on data from the 1998 evaluation, that 150 of the 450 infants born annually in Ohio with hearing loss would be identified. The 300 infants who are not identified would be missed, because they did not have a risk indicator (n=225) or they do not complete the diagnostic assessment (n=75).

The total cost to identify 150 children with a hearing loss would be \$4,194,988—paperwork and \$150 for a hearing assessment), the cost to identify 150 children with a hearing loss would be a total of \$7,307,488—or a cost per child identified of \$48,717.

To estimate the cost of a universal newborn hearing screening program, the following assumptions were made:

- Hearing screening is completed for all babies (n = 150,000 births per year) at a cost of \$25 per birth.
- Complete diagnostic evaluation is required for 1% (n = 1500 children) at a cost of \$250 per evaluation.

Using these assumptions, which are based on numerous published reports of universal newborn hearing screening programs⁹⁻¹¹, the total cost of identifying 450 infants with hearing loss (3 per 1,000) would be \$4,125,000—or a cost per child of \$9,166.

Thus, the total cost of a statewide universal newborn hearing screening program would be about the same as the current IHSAP (if the cheapest assumptions about IHSAP costs are used), but three times as many babies with hearing loss would be identified.

CONCLUSIONS

Mark Twain once lamented the fact that even though everyone complains about the weather, nobody does anything about it. Dr. C. Everett Koop, when he was serving as the Surgeon General of the United States, noted that Twain's comment was uncomfortably reminiscent of our past efforts to reduce substantially the age at which hearing impairment is identified among young children in the United States.¹² According to the Commission on Education of the Deaf, the average age at which children in this country with severe or profound bilateral hearing losses are identified is 2-1/2 years of age—far too late. Children with milder but, nonetheless, significantly detrimental hearing losses are frequently not identified until 5 to 6 years of age.¹³

Recognizing the importance of identifying hearing loss as early as possible, Ohio was one of a handful of states to implement a statewide newborn hearing detection program as early as 1990. As a result of IHSAP, state law requires all babies born in Ohio to have a hearing loss risk assessment done before leaving the hospital. The law also stipulates procedure for all babies with a risk indicator to receive a follow-up hearing assessment and, as needed, a full audiological diagnostic assessment and be enrolled in an early intervention program.

The results of a comprehensive evaluation of IHSAP revealed significant accomplishments as well as areas where improvements are needed.

First, the accomplishments:

- IHSAP has made hospital personnel (doctors, nurses, and administrators) more aware and supportive of the need to identify hearing loss as early as possible.

- Almost all of the items on the IHSAP Infant Hearing Risk Questionnaire and Hearing Assessment reporting form are completed accurately. For those few items where mistakes are occasionally made, there are few negative consequences.
- Hospital personnel rate the training they received from the Ohio Department of Health as being comprehensive, well conceptualized, and competently delivered.
- Many babies in Ohio are being identified at relatively young ages and enrolled in early intervention programs. Almost all of these babies are fit very quickly with amplification (and parents appreciate the financial assistance often provided by the state).
- Parents of children with hearing loss are very positive and enthusiastic about the quality of early intervention and preschool education received by their children.

The accomplishments summarized above are good evidence that Ohio's Infant Hearing Screening and Assessment Program (IHSAP) is having a positive impact for babies and their families. There is still much that needs to be done, however, to improve upon the foundation which has been established during IHSAP's past 8 years. The three most important areas in which improvements are needed are summarized below.

Identifying all babies with hearing loss. Research studies provide convincing evidence that about half of all babies with hearing loss do not have any risk indicators.^{2,3,6-8} Thus, even if IHSAP were operating perfectly, at least half of all babies with hearing loss would be missed. However, results of the evaluation show that babies are “falling through the cracks.” For example, the Infant Hearing Risk Questionnaire is not completed for about 8% of all births, and there is no record that a follow-up hearing assessment (as required by IHSAP) is ever completed for at least 35% of the babies who have a risk indicator. This means that less than one-third of the babies with congenital hearing loss are found by IHSAP.

Improving communication with parents. About half the parents of 1-year-old babies do not remember participating in the IHSAP process, and about 30% of those who recall the process were confused, while about two-thirds were worried, and about one-third were angry. Many parents of children identified with hearing loss felt that their participation in the diagnostic process was not appropriately valued and that it was overly time-consuming and confusing. How and by whom information is communicated to parents appears to be particularly important.

Strengthening early intervention programs. Although parents are very grateful for the services they are receiving, the long distances program staff have to travel, and the relative infrequency with which services can be offered reduces the potential benefits of early intervention. Early intervention program staff also feel they are not prepared to serve the significant number of children with hearing loss who also have other disabilities.

RECOMMENDATIONS

IHSAP has provided a “sound beginning” for early identification of hearing loss in Ohio. As a result of IHSAP, dozens of children are identified and enrolled in early intervention programs. If it were not for IHSAP, these children would have been an average of 2-1/2 years old before their hearing loss was discovered. In spite of those accomplishments, it is only a beginning. In other words, many good things have been accomplished, but much remains to be done before all Ohio infants and toddlers with significant hearing loss are identified during the first few months of life.

Results of this evaluation point to three areas in which significant improvements can be made:

1. **Finding more children with hearing loss.** Even a perfectly operated risk-based newborn hearing screening program is inherently limited because approximately half the infants and toddlers with hearing loss do not exhibit any risk indicators. Because of technological improvements in the decade since IHSAP was first implemented, the Ohio Department of Health should seriously consider refocusing their efforts and resources to help hospitals implement universal newborn hearing screening instead of risk-based screening. Hundreds of hospitals across the country have already implemented successful and cost-efficient universal newborn hearing screening, and such programs should be considered in Ohio.¹²

As long as the current risk-based program is used, however, improvements are needed to ensure that Infant Hearing Risk Questionnaires are completed for all babies and Hearing Assessments are completed for all babies with risk indicators. This will require better tracking and follow-up. Several computer-based tracking programs are available for such purposes or such a system could be developed by the Department of Health.¹⁴

2. **Communicating with parents.** Finding out that your baby has or may have a hearing loss is often difficult, anxiety provoking, and confusing. The Department of Health should expand its training to give hospital staff more information and materials on how information can be given to parents most effectively. Pamphlets and other materials which explain to parents how IHSAP results are used, what resources are available to them, and how the process works should be developed and widely distributed. Efforts should also be made to help the medical community better understand the implications of newborn hearing loss and how they can effectively use parents' observations and experiences as a part of the diagnostic process. Wherever possible, efforts should be made to streamline the diagnostic process so it is completed as quickly as possible with minimum burden on the parents.
3. **Better tracking and reporting.** Additional procedure should be considered to ensure that an Infant Hearing Risk Indicator Questionnaire is completed for all babies. Currently, hospitals are only required to submit to the Ohio Department of Health a copy of the Infant Hearing Risk Questionnaire for babies who have one or more risk indicators. Thus, the Department of Health has no way of knowing whether questionnaires were completed for all births. Instead, hospitals could be required to submit a copy of the Infant Hearing Risk Questionnaire for all births to the Department of Health. However, that would require a massive increase in paperwork. A simple alternative would be to have hospitals submit a one-page form each month showing the number of births and admissions, number of Infant Hearing Risk Questionnaires completed, and number of newborns with a risk indicator present. Such a form could be included as a cover page to the copies hospitals are now submitting. Numbers from this page could be compared to reports from Vital Statistics or Metabolic Screening to check whether Infant Hearing Risk Questionnaires are completed for all newborns.

The Department of Health should also consider entering information from submitted questionnaires into a computer-based tracking program. By matching that information to data submitted to the Department of Health

about the Hearing Assessments, it would be possible to keep information about what happens to those babies for reporting purposes, to provide feedback to hospital administrators, and to reduce the chances of babies being lost during the process.

IHSAP has provided a sound beginning for the identification of babies with hearing loss in Ohio. The results of this evaluation suggest a number of ways in which the goals of IHSAP can be better achieved.

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