Effects of Universal Newborn Hearing Screening on an Early Intervention Program for Children with Hearing Loss, Birth to 3 Yr of Age

DOI: 10.3766/jaaa.21.3.5

Kathy S. Halpin*†
Kay Y. Smith*†
Judith E. Widen†
Mark E. Chertoff†

Abstract

Background: Universal Newborn Hearing Screening (UNHS) was introduced in Kansas in 1999. Prior to UNHS a small percentage of newborns were screened for and identified with hearing loss.

Purpose: The purpose of this study was to determine the effects of UNHS on a local early intervention (EI) program for young children with hearing loss.

Research Design: This was a retrospective study based on the chart review of children enrolled in the EI program during target years before and after the establishment of UNHS.

Study Sample: Charts for 145 children were reviewed.

Data Collection and Analysis: The chart review targeted the following aspects of the EI program: caseload size, percentage of caseload identified by UNHS, age of diagnosis, age of enrollment in EI, degree of hearing loss, etiology of hearing loss, late onset of hearing loss, percentage of children fit with hearing aids by 6 mo, percentage of children with profound hearing loss with cochlear implants, and percentage of children with additional disabilities.

Results: Changes in the EI program that occurred after UNHS were increases in caseload size, percentage of caseload identified by UNHS, percentage of children fit with hearing aids by 6 mo of age, and percentage of children with profound hearing loss with cochlear implants. There were decreases in age of diagnosis, age of enrollment in EI, and age of hearing aid fit. Before UNHS, the majority of children had severe and profound hearing loss; after UNHS there were more children with mild and moderate hearing loss. The percentage of known etiology and late-onset hearing loss was approximately the same before and after UNHS, as was the percentage of children with additional disabilities.

Conclusion: UNHS had a positive impact on caseload size, age of diagnosis, age of enrollment in EI, and age of hearing aid fit. The percentage of the caseload identified in the newborn period was about 25% before UNHS and over 80% after its implementation. After UNHS, the EI caseload included as many children with mild and moderate hearing loss as with severe and profound loss. By the last reporting year in the study (academic year 2005–2006) all children with profound hearing losses had cochlear implants.

Key Words: Birth to three, cochlear implants, early intervention, hearing aids, hearing loss, infants, Infant Toddler Services, toddlers, Universal Newborn Hearing Screening

Abbreviations: EI = early intervention; FDA = Food and Drug Administration; HFC = Hartley Family Center; HL = hearing loss; ITS = Infant Toddler Services; JCIH = Joint Committee on Infant Hearing; KUMC = Kansas University Medical Center; UNHS = Universal Newborn Hearing Screening

*Hartley Family Center, University of Kansas Medical Center, Kansas City; †Department of Hearing and Speech, University of Kansas Medical Center, Kansas City

Kathy S. Halpin, M.A., CCC-SLP, Department of Hearing and Speech, 3901 Rainbow Blvd., Kansas City, KS 66160; Phone: (913) 588-5750; Fax: (913) 588-8948; E-mail: khalpin@kumc.edu
For decades the people who have worked with children with hearing loss have claimed that early identification and intervention is a primary factor in a child’s success in learning language, in developing intelligible speech, and in ultimate reading ability and educational success. In the 1960s Marion Downs convened a small group of individuals, representing professions that were interested in infant hearing loss, to join forces for the purposes of advancing its early identification. This group became the Joint Committee on Infant Hearing (JCIH), which has gained stature and continues to promote the efforts to improve the outcomes of infants with hearing loss (JCIH, 1994, 2000, 2007).

On the educational front, in 1965 the Babidge Report recommended that a universally applied procedure be developed and implemented nationwide for early identification and evaluation of hearing impairment (Babidge, 1965). In 1967, the National Conference on Education of the Deaf recommended that a high-risk register be established to facilitate identification, a public information campaign be launched, and the testing of infants and children 5–12 mo of age be investigated. Despite this pronouncement, in 1988, the Commission on Education of the Deaf reported that the average age of identification of children with profound hearing loss was 2.5 yr old. Following the commission’s findings, an advisory group of national experts was formed by the U.S. Department of Education and Bureau of Maternal and Child Health for the purpose of advising the government about the feasibility of developing guidelines on early identification. It was recommended that the federal government fund demonstration projects to expand and document systematically the cost efficiency of proven techniques already in existence, but infrequently used, to screen infants’ hearing. In 1990, following the Commission on Education of the Deaf and the advisory group of national experts’ recommendations, the U.S. Department of Health and Human Services (1990), under the direction of Dr. C. Everett Koop, former surgeon general, recommended that by the year 2000, 90% of children with significant hearing loss be identified by 12 mo of age.

During the decade of the 1990s, several developments brought the possibility of Universal Newborn Hearing Screening to fruition. The work of Yoshinaga-Itano and colleagues (1998) in Colorado and Moeller (2000) and colleagues at the Boys Town National Research Hospital in Nebraska was convincing evidence that the sensitive age for language development was even younger than had earlier been thought. Development and testing of automated technologies for newborn hearing screenings suggested that screening of all newborns might be feasible. In 1993, the National Institutes of Health issued a Consensus Statement recommending that hospitals implement programs of universal hearing screening for all newborns within their first 3 mo of life. This statement included recommendations for comprehensive follow-up and intervention programs to support newly identified children and their families (National Institutes of Health, 1993). Likewise, the JCIH recommended that “all infants with hearing loss should be identified before 3 months of age and receive intervention by 6 months of age” in its 1994 Position Statement (p. 152). Federal funding promoted state departments of health to develop statewide systems for newborn hearing screening. By the year 2000, many states had passed legislation mandating newborn hearing screening, and many more had implemented without legislative mandate.

As newborns were screened and hearing loss was identified in very young infants, there were inevitable changes in the already existing early intervention programs. The purpose of this study was to determine the effects of Universal Newborn Hearing Screening (UNHS) on the early intervention (EI) program for children with hearing loss ages birth to 3 yr at the University of Kansas Medical Center (KUMC).

**METHOD**

**Early Intervention Program at KUMC**

The Department of Hearing and Speech at the University of Kansas Medical Center has a long history of providing early deaf education services in association with the audiology and speech-language pathology training program. The department’s Pre-school for the Deaf was founded in 1949 to provide early intervention services to deaf children 3–5 yr of age. At that time, the public school districts became responsible for these children when they reached age 5. In 1990, federal laws lowered this age to 3. Thus, the preschool redirected its attention to providing services to children from birth to 3 yr of age, which prepared them and their families for eventual entrance into the public schools. To accomplish this mission, the KUMC Hearing and Speech Department joined forces with school districts in the surrounding area and with the Kansas State School for the Deaf. The schools provide support in the form of state categorical aid, which helps pay staff salaries. In 1990 the W. C. Hartley Family became a major benefactor and has continued its support through the present day. Thus, the former preschool became the Hartley Family Center (HFC). Since its beginning in 1990, the HFC has served more than 300 families with deaf and hard-of-hearing children and hearing children whose parents are deaf/hard of hearing. These services are provided at no cost to the families.
The HFC views the infant/toddler as an active learner and the parents as the primary teachers of their child. The HFC assists families in this process by providing services and information in a variety of areas (e.g., audition, speech and language, motor skills, self-help, cognition, and social/emotional development). The amount and type of services provided to each family are determined by the family in a joint partnership with the HFC team. The family identifies specific needs and works with the team to develop an Individual Family Service Plan. Professional involvement in family service delivery is based on this plan. Most services are home based (i.e., provided by an HFC staff member or team in the child’s home).

Currently, the HFC staff includes two speech-language pathologists, one early interventionist, a deaf educator, and an academic liaison in the Department of Special Education. Administrative and clerical support is provided by the Hearing and Speech Department, KUMC. Although not technically an HFC staff member, an audiologist on the Hearing and Speech Department faculty plays an active role in the work of the HFC. Other faculty, staff, and students of the university have volunteered time with the HFC over the years.

Participants

The children and families enrolled in the HFC reside in Wyandotte and Johnson counties, Kansas, within suburban, urban, and rural communities. They range from low to high socioeconomic status levels. The children are referred from newborn hearing-screening programs and physician’s offices, usually by way of the counties’ Infant Toddler Services (ITS), the coordinating agencies for intervention services for children with special health care needs. Over the years the HFC caseload has consisted of children with all degrees and types of hearing loss, unilateral or bilateral, those who use air- or bone-conduction hearing aids or cochlear implants, and those with or without additional disabilities.

Aspects of the EI Program Noted to Change

Over the last two decades, HFC staff members learned to adjust to changes in the caseload and the nature of their work. Over time, they were seeing many more babies than they had in the past, many with mild hearing loss, and many children with profound hearing loss obtained cochlear implants while they were enrolled in the EI program. Program stability and continuity of records over time provided a prime opportunity to document their impressions of change, particularly as they might relate to the implementation of UNHS.

By reviewing the records of the children who had received intervention services over the years, we aimed to document some of the changes that had occurred. The chart review targeted the following aspects of the program: annual size of caseload, percentage of caseload identified by UNHS, age of diagnosis, age of enrollment in EI, degree of hearing loss, etiology of hearing loss, age of implantation, age of hearing aid fit, percentage of children fit with hearing aids by 6 mo, percentage of children with profound hearing loss with cochlear implants, and percentage with additional disabilities.

Reporting Years

This was a retrospective study based on chart reviews of children enrolled in HFC between the years of 1991 and 2008. Data were collected via chart review and compiled using the File Pro system. Specifically four academic years of data were analyzed: 1991–1992, 1998–1999, 2002–2003, and 2005–2006. The rationale for these particular years is as follows. Academic year 1991–1992 was the first year that HFC was fully staffed and operating, prior to UNHS and prior to the establishment of the state of Kansas ITS networks. KUMC was one of the few hospitals in Kansas that provided newborn hearing screening in its neonatal intensive care unit prior to state mandate. Newborn screening was also available to other families upon request. The year 1998–1999 was the last one prior to UNHS and after the Johnson and Wyandotte County ITS networks were established. The year was reviewed in order to document the impact of the establishment of the ITS networks on the primary and secondary variables. For the 2002–2003 year, UNHS had been in place for 3 yr. All children in the caseload were born after UNHS implementation and should have received a hearing screening at birth. The ITS networks remained the same. The 2005–2006 year was chosen in order to observe the trends over time. It was 3 yr after 2002–2003, preventing overlap of caseload.

RESULTS

Results are shown using figures with a similar format, with the years before screening in gray on the left and those after screening in black on the right. The second gray bar to the right represents the year following the establishment of the ITS.

Caseload and Percentage of Caseload Identified by UNHS

Implementation of UNHS had a clear impact on the number and age of the children who were enrolled in our intervention program. The number of children grew from 27 and 26 before UNHS to our largest enrollment
of 48 children in 2002–2003 (Fig. 1). Moreover, of the children enrolled, the percentage of children actually identified with hearing loss by newborn screening increased over the years. Figure 2 shows the change. Before UNHS, only newborns with risk factors (family history of hearing loss or infants who were in intensive care) were screened for hearing loss. Thus, less than one-third of the caseload was initially identified with hearing loss at birth. However, after UNHS was mandated over 80% of the children in our program were identified by UNHS. Regarding the impact of the ITS between Y91–92 and Y98–99, there was no apparent change in either caseload size or percentage identified in the newborn period.

**Demographics: Age of Diagnosis, Age of Enrollment, Severity of Hearing Loss, and Etiology**

The age at which the children enrolled in our program were diagnosed with hearing loss changed as a result of UNHS. Age of diagnosis was defined as the date of the first failure of the auditory brain stem response without a temporary conductive hearing loss due to middle ear fluid. The data reported do not include children who passed newborn hearing screening and/or follow-up and were later diagnosed with hearing loss. As shown in Figure 3, before UNHS, children in our program were diagnosed by about 1 yr of age. After UNHS was implemented, there was a clear decrease in age of diagnosis. The average age was only 3.7 mo in 2005–2006.

Children also enrolled in our EI program at an earlier age. As illustrated by Figure 4, after UNHS was implemented, most children were enrolled in the program by 5–7 mo of age, in contrast to children who were over a year old in the earlier years. The decrease in age from 17 to 13 mo suggests an effect of the ITS networks.

Implementation of UNHS modified the distribution of degree of hearing loss of the children in our program over the years. Degree of hearing loss was defined as the most severe level of loss for the better-hearing ear for bilateral losses. Early, before UNHS, about half of children enrolled in our early intervention program had profound hearing loss (Fig. 5), and few had mild hearing loss. However, after UNHS, the population became more evenly distributed. That is, we had approximately equal numbers of children with mild, moderate, severe, and profound hearing losses. Although not included in the figure, the percentage of children in the program with unilateral hearing loss increased over the time span. In 1991–1992, only 4% of the enrolled children had hearing loss in only one ear. This increased to 11% by the year 2005–2006.

UNHS did not have a strong impact on identifying the etiology of the hearing loss for the children in our program. Etiology was considered “known” if the hearing loss was associated with the following: meningitis, chemotherapy, syndromes with associated hearing loss, chromosomal anomaly, family history, or identified genetic link. Known etiologies remained constant at around 50% of the caseload before and soon after UNHS but dropped to 30% in the last reporting period (Fig. 6).

The term *late-onset hearing loss (HL)* was used to describe children with hearing loss who passed newborn hearing screening and/or follow-up evaluation and were later diagnosed with hearing loss. Figure 7 shows the percentage of the caseload with presumed late-onset HL. In 1991–1992, three cases of late onset were documented. These children were identified with late onset due to meningitis or family history of hearing loss. In 1998–1999, five children were diagnosed with late-onset HL. Three children had a family history of hearing loss in siblings or extended family; one child had meningitis; and one child’s etiology is unknown. In 2002–2003, six children were identified with late-onset HL: four children with family history of HL, one child possibly with enlarged vestibular aqueducts, and one child with an “unknown” origin. In 2005–2006, nine children were identified with late-onset HL: one child with family history, one child who received chemotherapy, one child with meningitis, and one child who
was diagnosed with cytomegalovirus. For the remaining five children, the etiology for the late-onset HL was unknown.

Hearing Aids and Cochlear Implants

Similar to the decrease in the age at which the children were identified with hearing loss, the age at which children received amplification (defined as the day the child received hearing aids) declined over the years. On average, before UNHS, children were about 18 mo old before receiving hearing aids. After UNHS, this dropped to an average age of 6–10 mo (Fig. 8). Moreover, by 2005–2006, over half of the children received hearing aids by 6 mo of age (Fig. 9).

The use of cochlear implants has also changed over the years. There were no children implanted in 1991–1992 because Food and Drug Administration (FDA) guidelines did not allow children under the age of 4 yr to be implanted. During 1998–1999, the first year that children could be implanted before 3 yr of age, slightly fewer than half of our children with profound hearing loss used cochlear implants. By 2005–2006, this changed dramatically, with all of the children with profound hearing loss in our program using cochlear implants (Fig. 10).

Additional Disabilities

Additional disabilities were defined as disabilities in “addition” to hearing loss/communication and included delays in cognitive development, fine motor, and gross motor skills. The percentage of the caseload with additional disabilities remained fairly consistent throughout the years, with a spike in percentage in 1998–1999 (Fig. 11).

DISCUSSION

Caseload and Percentage of Caseload Identified by UNHS

We have had our work cut out for us since UNHS. The caseload nearly doubled, and yet the HFC staff remained constant. In fact, the staff is smaller now than it was before. In the 1990s the HFC had a director who managed referrals, coordinated scheduling, and did some grant writing and fund-raising, all with the help of a secretary. One factor that has allowed the staff to remain small is that families now opt for a larger range in intensity of services. Direct intervention in the home may range from as often as twice a week to once every 3 mo. The figures show the average age of identification but not the range. In the Y91–92 reporting period, the children in the caseload ranged from 4 to 34 mo. In
2005–2006, the age range was two weeks to 20 mo. Because many of the children are younger now, the amount of delay in their development is often less than in the earlier years. In the 1990s when most children enrolled after a year of age, they were all delayed when they started the EI program.

Demographics: Age of Diagnosis, Age of Enrollment, Severity of Hearing Loss, and Etiology

We are encouraged to see the average age of diagnosis nearing the target of 3 mo of age as recommended by JCIH: Ours is 3.7 mo. By Y05–06, the average age of enrollment in EI was meeting the 6 mo target at 5.3 mo. We interpret the decrease in Y05–06 compared to Y02–03 as evidence that the process continues to improve. We think that this is evidence of the importance of not just the provision of the screening test per se but also the awareness and participation of hearing and health professionals who play a key part in lowering the age of diagnosis by encouraging families to seek follow-up and complete the diagnosis.

We are not surprised that our caseload now includes babies with mild hearing loss. This is consistent with reports from programs across the country. And, like many other programs, we often have difficulty convincing parents of the importance of full-time hearing aid use and adherence to the habilitation program. More than one child has been pulled out of EI in the first year only to reappear at 2 yr of age when speech delays became noticeable.

As to the etiology of hearing loss, we cannot explain the low 30% known etiology for Y05–06. It may be just a matter of time, that is, we may not learn the etiology until after several years have passed rather than at the time of diagnosis. For example, although genetic evaluation is recommended for all our families with an unknown etiology, many families do not follow through because insurance does not cover the cost. In some cases, it is only when a second child is found to have hearing loss that the family becomes curious about the etiology. We have found that physicians vary in their support of the genetics referral. The families that seek genetic counseling usually include children with major medical complications or with associated physical anomalies that suggest a syndrome.

Hearing Aids and Cochlear Implants

The continued improvement in the age at which hearing aids were fit probably reflects a concerted effort to
may choose. In association with research studies focusing on newborn hearing screening that may have increased awareness of early identification and diagnosis (Norton et al., 2000). Also, our history and reputation for specialized early intervention for hearing loss may have meant that in the early years KUMC received most all children with early diagnoses, whereas today there are several early intervention programs in the metropolitan area to which physicians may refer and families may choose.

We conclude that UNHS has had a positive impact on the number of children receiving early intervention services at the KUMC Hartley Family Center. The number of children with a timely diagnosis of hearing loss, fitting of amplification, and enrollment in early intervention services has increased substantially since UNHS was implemented in our community. The children with severe and profound hearing loss were able to begin candidacy for cochlear implants in a timely fashion to enable them to have surgery at younger ages as allowed by the FDA. This greatly increased the probability that these children with hearing loss will be more successful communicators and successful students in school.

Acknowledgments. We express our sincere appreciation to Alice Bergeron for special assistance and data collection, Erin Schuweiler for data collection, Sandy Keener for special audiology assistance, and Joan Gideon for her help obtaining and entering data into File Pro.

REFERENCES


