HOUSE AMENDED
PRIOR PRINTER'S NOS. 859, 1037, 1088, 1193, 1437 PRINTER'S NO. 1517

THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 100 Session of 2001

INTRODUCED BY LEMMOND, TOMLINSON, MELLOW, SCHWARTZ, MURPHY, RHOADES, HOLL, LOGAN, JUBELIRER, WAGNER, KUKOVICH, MADIGAN, MOWERY, HELFRICK, KITCHEN, ROBBINS, LAVALLE, MUSTO, THOMPSON, STACK, BOSCOLA AND O'PAKE, APRIL 4, 2001

AS RE-REPORTED FROM COMMITTEE ON APPROPRIATIONS, HOUSE OF REPRESENTATIVES, AS AMENDED, NOVEMBER 13, 2001

AN ACT

Establishing the Infant Hearing Education, Assessment, Reporting and Referral Program; and providing for powers and duties of the Department of Health.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Infant Hearing Education, Assessment, Reporting and Referral (IHEARR) Act.

Section 2. Legislative findings and purpose.

(a) Findings.--The General Assembly finds as follows:

(1) Hearing loss occurs in approximately three newborns and infants per 1,000 born in the United States.

(2) Hearing loss occurs more frequently than any other health condition for which newborn and infant screening is required.

(3) Reliance on either physician observation or parental recognition has not been successful in detecting significant hearing loss and over 50% of newborns and infants with hearing impairments go undetected until the age of two and a half.

(4) Infants with hearing loss do not develop normal language skills because 80% of a child's language ability is learned by 18 months of age.

(5) The lack of normal language development has a substantial negative effect on a child's cognitive and social development and will interfere with success in school and later in life.

(6) Technology is now available to cost-effectively screen for detection of hearing loss in newborns and infants.

(7) Screening for hearing loss, coupled with early medical, audiological, educational intervention and treatment, has been demonstrated to be highly effective in facilitating a child's normal development.

(8) Children with hearing loss who do not receive early intervention and treatment frequently require the expenditure of public funds for health care and for long-term specialized education services.

(9) An established Statewide system for the provision of early intervention services that can be utilized to further the purposes of this act already exists in this Commonwealth.

(10) Authoritative and respected government and professional groups, including the National Institutes of Health Consensus Development Panel, the Healthy People 2000 Report from the United States Department of Health and Human Services and the Joint Committee on Infant Hearing comprised

of representatives from the American Academy of Pediatrics, the American Academy of Audiology, the American Speech-Language-Hearing Association, the American Academy of Otolaryngology-Head and Neck Surgery and the Council for Education of the Deaf, have recommended that all newborns and infants be screened for hearing loss shortly after birth, with appropriate intervention and treatment begun before six months of age.

(11) Thirty-two states have passed legislation requiring newborn and infant hearing screening for all children born in the state.

(12) The Department of Health has sponsored a successful newborn and infant screening and tracking demonstration initiative since 1999. This initiative has enabled the department to identify the guidelines and protocol necessary for a Statewide universal screening program and reporting system.

(13) Even though more than 30 hospitals in this Commonwealth have demonstrated the feasibility and cost-effectiveness of operating newborn and infant hearing screening programs as part of the standard care of babies born in their facilities, less than 30% of all newborns born in this Commonwealth are currently screened for hearing loss before being released from hospitals.

(b) Purpose.--The purpose of this act is:

(1) to provide infant hearing screening for all newborns born in a hospital or within 30 days of the date of birth for those newborns born outside a hospital, to enable these infants and their families to obtain needed comprehensive, multidisciplinary evaluation, treatment and intervention

services at the earliest opportunity and to thus prevent or mitigate the developmental delays and excessive costs associated with late identification of hearing loss; and

(2) to provide the Department of Health with the information necessary to effectively plan, establish, administer and evaluate this comprehensive program of appropriate services for newborns, infants and children who have hearing loss.

Section 3. Definitions.

The following words and phrases when used in this act shall have the meanings given to them in this section unless the context clearly indicates otherwise:

"Advisory committee." The Department of Health's Infant Hearing Screening Advisory Committee.

"Birth admission." The time after birth that the newborn remains in the hospital or birth center prior to discharge.

"Birth center." A facility not part of a hospital which provides maternity care to childbearing families not requiring hospitalization. A birth center provides a home-like atmosphere for maternity care including prenatal, labor, delivery and postpartum care related to medically uncomplicated pregnancies.

"Child." A person up to 21 years of age.

"Department." The Department of Health of the Commonwealth.

"Early intervention." The existing Statewide system of coordinated, multidisciplinary, interagency programs maintained by the Department of Education, the Department of Health and the Department of Public Welfare to provide appropriate services to all eligible infants, children and their families under the act of December 19, 1990 (P.L.1372, No.212), known as the Early Intervention Services System Act.

"Health care facility." Any hospital providing clinically related health services for obstetrical and newborn care, or birth center, both profit and nonprofit and including those operated by an agency, State or local government. The term shall not include an office used primarily for private or group practice by health care practitioners where no reviewable clinically related health services are offered.

"Infant." A child 30 days of age up to 24 months of age.

"Newborn." A child up to and including 29 days of age.

"Parent." A natural parent, stepparent, adoptive parent, legal guardian or legal custodian of a child.

"Program." The Infant Hearing Education, Assessment, Reporting and Referral (IHEARR) Program.

"Secretary." The Secretary of Health of the Commonwealth.

Section 4. Infant Hearing Screening Advisory Committee.

The secretary shall appoint a six-member Infant Hearing Screening Advisory Committee within the department. The advisory committee shall advise and make recommendations on issues relating to, but not limited to, program regulation and administration, diagnostic testing, technical support and follow-up. Members of the advisory committee shall serve without compensation but may be reimbursed for necessary travel and other expenses in accordance with applicable law and regulations.

Section 5. Newborn and infant hearing education and assessment.

(a) General rule.--The department shall establish a program, a component of which shall be a system to screen all newborns in this Commonwealth for hearing loss before leaving a hospital, to screen all newborns who are not born in a hospital within the first 30 days of life and to provide information and instruction

to the parents of all newborns and infants on the merits of having the hearing screening performed and of receiving follow-up care.

(b) Program administration.--The department shall, in cooperation with the advisory committee, provide technical support, including, but not limited to, audiological and administrative technical support to the health care facilities and persons implementing the requirements of subsection (a).

~~(c) Refusal of test on religious grounds.--Screening is not required if the parents of the newborn or infant object on grounds that the test would conflict with their religious tenets or practices.~~ <—

(C) REFUSAL OF TEST.--SCREENING IS NOT REQUIRED IF A PARENT OF THE NEWBORN OR INFANT OBJECTS TO THE SCREENING FOR ANY REASON. Such refusal shall be documented in writing and made a part of the medical record of the newborn or infant and reported to the department in a manner prescribed by the department. <—

(d) Implementation.--The program shall be implemented as follows:

(1) By July 1, 2003, newborn and infant hearing screening is to be conducted on no fewer than 85% of the live births in health care facilities in this Commonwealth during birth admissions, using procedures recommended by the department's advisory committee. If a newborn is born in a location other than a hospital, the parents shall be instructed on the merits of having the hearing screening performed and shall be given information to assist them in having it performed within 30 days of the newborn's birth. The department shall determine the appropriate screening venue for a newborn born outside a hospital.

(2) If the number of newborns and infants receiving hearing screening does not equal or exceed 85% of the total number of live births in this Commonwealth on July 1, 2003, as shown in the most recent data collected by the ~~Department of Health~~ DEPARTMENT, or falls below 85% annually thereafter, the department, in consultation with the advisory committee, shall immediately promulgate regulations to implement a State-administered hearing screening program.

(3) By July 1, 2002, every health care facility in this Commonwealth shall provide information and instruct the parents of newborns and infants concerning the importance of screening the hearing of newborns and infants and of receiving follow-up care. An informational packet developed and supplied by the department shall explain in lay terms the importance and process of hearing screening, the likelihood of a newborn or infant having hearing loss, follow-up procedures and available early intervention services. The educational information shall also include a description of the normal auditory, speech and language developmental process in children. This information shall not preclude the health care facility from providing additional material nor shall it be considered a substitute for the hearing screening.

(4) By July 1, 2002, every hospital in this Commonwealth shall report to the department, in a manner prescribed by the department, the number of newborns and infants screened and the results of the screening. The department, based on this information, shall report to the General Assembly by January 1, 2003, and every January 1 thereafter, the following:

(i) The number of hospitals conducting hearing

screenings during birth admissions.

(ii) The number of live births in hospitals.

(iii) The number of newborns screened during birth admissions.

(iv) The number of live births in a location other than a hospital.

(v) The number of newborns born in a location other than a hospital screened within 30 days of the date of birth.

(vi) The number of newborns born in a hospital who passed and the number who did not pass the birth admission screening, if administered.

(vii) The number of newborns born in a location other than a hospital who passed and the number who did not pass a screening within 30 days of the date of birth, if administered.

(viii) The number of infants who returned for follow-up rescreening.

(ix) The number of infants who passed the follow-up rescreening.

(x) The number of infants recommended for monitoring, intervention and follow-up care.

(5) The department shall determine which hospitals in this Commonwealth are conducting newborn and infant hearing screening on a voluntary basis or as part of the department's demonstration initiative, the number of newborns and infants screened and the results of the screening. The department, based on this information, shall report to the General Assembly by January 1, 2002, the following:

(i) The number of hospitals conducting hearing

screenings during birth admissions.

(ii) The number of live births in hospitals.

(iii) The number of newborns screened during birth admissions.

(iv) The number of newborns who passed the birth admission screening, if administered.

(v) The number of newborns who did not pass the birth admission screening, if administered.

(vi) The number of infants who returned for follow-up rescreening.

(vii) The number of infants who passed the follow-up rescreening.

(viii) The number of infants recommended for monitoring, intervention and follow-up care.

Section 6. Reporting and early intervention referral.

(a) General rule.--The department, as a component of the program, shall implement a reporting and early intervention referral system that links hearing screening, if necessary, with expert diagnostic services and available early intervention services. It shall be the goal of the Commonwealth to identify 100% of newborns and infants with hearing loss within 30 days of the date of birth, to provide timely diagnostic testing, if indicated, and to provide appropriate referral for treatment and intervention before the age of six months.

(b) Program administration.--Recognizing the importance of tracking newborns, infants and children with hearing loss for a period of time in order to render appropriate early intervention services, the department shall, in consultation with the advisory committee, provide administrative technical support to the facilities implementing the reporting and early intervention

referral system pursuant to this section.

(c) Implementation.--The department, in consultation with the advisory committee, shall issue temporary guidelines by July 1, 2002, implementing a reporting and early intervention referral system for newborns, infants and children who have been recommended for further monitoring. The temporary guidelines shall expire on June 30, 2003, or upon promulgation of regulations pursuant to section 8, whichever occurs first.

Section 7. Confidentiality of records.

(a) Limitations on disclosure.--No person, employee or agent of such person who obtains information in the course of this act may disclose or be compelled to disclose the information except to the parent of the infant or child or to the department for statistical recordkeeping or for appropriate treatment referral and early intervention services.

(b) Confidentiality.--Data obtained directly from the medical records of a patient shall be considered confidential and shall be for the confidential use of the department in maintaining the tracking system and in providing appropriate services. The information shall be privileged and may not be divulged or made public in any manner that discloses the identity of the patient. Notwithstanding this subsection, anonymous statistical information collected under the tracking system shall be considered public information.

(c) Good faith.--Any person who acts in good faith in complying with the provisions of this section by reporting newborn and infant hearing screening results to the department shall not be held civilly or criminally liable for furnishing the information required by this act.

Section 8. Regulations.

The secretary shall promulgate regulations to implement the provisions of this act.

~~Section 9. Funding.~~ <—

~~(a) Appropriation.--The General Assembly shall make such appropriations as it deems appropriate to carry out the purposes of this act.~~

~~(b) Services and funding sources.--The department shall~~

SECTION 9. SERVICES AND FUNDING SOURCES. <—

THE DEPARTMENT SHALL utilize various services available through the National Center for Hearing Assessment and Management and the National Early Hearing Detection and Intervention Technical Assistance Program and shall submit grant proposals for public and private funding, including, but not limited to, the United States Health Resources and Services Administration, Maternal and Child Health Bureau programs and the Centers for Disease Control and Prevention programs.

Section 10. Effective date.

This act shall take effect in 90 days.