

Chapter 4

Utilizing Public Health Partners: Opportunities for Integrating & Improving State EHDI Programs

Nicole Brown, MSN, PHN, CPNP; Nicole Brys, MPH;
 & Kirsten R. Coverstone, AuD

Public health is the science of promoting health at the population level. The goal of public health is to prevent illness and other health-related problems.

Background: Early Hearing Detection & Intervention (EHDI) and Public Health

What is public health? Public health to many people means just vaccinations or sanitation laws. In reality, public health is much broader than that. It is the science of promoting health at the population level. While doctors and nurses have people as their patients, public health professionals view communities as their patients. The goal of public health is to prevent illness and other health-related problems. Among public health professionals, an analogy is

often made to a river into which people are being thrown. Health professionals, such as doctors and nurses, play an important role downstream in pulling the people out of the river to prevent them from drowning. Public health professionals, on the other hand, are upstream trying to figure out what is causing these people to be thrown into the river and how to stop it.

Public health professionals work to protect and improve the health of communities through a wide variety of strategies. Research on disease and injury prevention is used to formulate educational programs and other services to promote healthy lifestyles. Public health professionals work to influence policies that promote health on a broad scale. An example of this are

There is significant evidence that early intervention is key in promoting optimal language skills and communication in children with hearing loss.

the smoking bans in public places, which are the result of a concerted effort by public health professionals to change policies in a way that will promote the health of the public. Some of the main achievements of public health include vaccinations, safer workplaces, fluoridation of drinking water, family planning, a decline in deaths from coronary heart disease, and control of infectious diseases (Association of Schools of Public Health, n.d.).

Public health has an important role to play in the lives of children with hearing loss. The public health goal of preventing illness and other health-related problems is complicated in the case of hearing loss, because there are a variety of causes of hearing loss in children. In 50% to 60% of babies born with hearing loss, the cause is genetic. The cause is unknown in about 25% of babies born with hearing loss. In 25% or more of children with hearing loss, cause is attributed to environmental factors, such as maternal infections during pregnancy, complications after birth, and head trauma [Centers for Disease Control and Prevention (CDC), 2012b]. The CDC has used a three-stage public health cycle to guide their work with hearing loss in children (see *Figure 1*; CDC, 2010):

1. Tracking
2. Research
3. Intervention and prevention

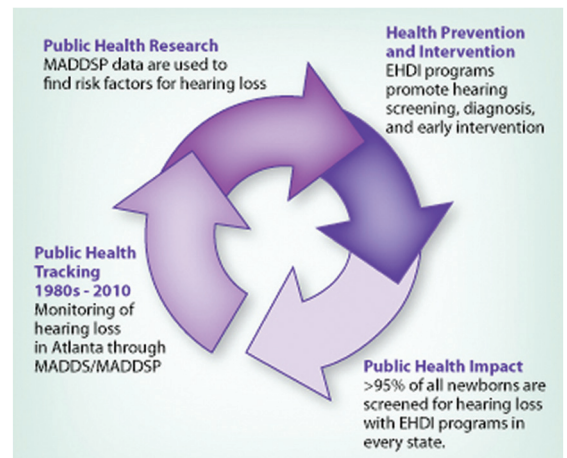
Tracking (or surveillance) of a condition or disability is an important public health strategy to determine the prevalence of the condition or disability among different groups and monitor changes in prevalence or incidence over time. CDC began tracking hearing loss in the early 1980s—giving public health professionals important information about the prevalence and age of first diagnosis of hearing loss in children. Data from 1991 through 1993 indicated the average age of initial diagnosis of congenital sensorineural hearing loss in children was 2.9 years. Only 8% of these children were diagnosed before 1 year of age. There is significant evidence that early intervention is key in promoting optimal language skills and communication

in children with hearing loss. For this reason, public health professionals used the CDC data to advocate for universal newborn hearing screening legislation.

The second stage of the public health cycle is research. The CDC uses tracking data to research potential risk factors for hearing loss and evaluate how these factors change over time. This information allows public health professionals to develop strategies to minimize risk factors for hearing loss. For example, CDC data shows that babies born at a lower birthweight are at increased risk for hearing loss. Public health professionals can use this data to justify prenatal care programs and educational campaigns to make parents and healthcare providers aware of the need to test for hearing problems among low birthweight children.

The last stage of the public health cycle is intervention and prevention. This is where Early Hearing Detection and Intervention (EHDI) programs come in. By promoting hearing screening, diagnosis, and early intervention, EHDI programs help maximize the communication and language development of children with hearing loss (CDC, 2010).

Figure 1 The Three-Stage Public Health Cycle and Hearing Loss



The Benefits of Program Collaboration and Service Integration

For years, public health professionals have called for better collaboration and integration of services provided by programs serving children and their families. Since there is no standard definition of collaboration, agencies and individuals within the field of public health have their own unique definitions. Common to most definitions are shared labor; a shared purpose or goal; and joint ownership of the work, risks, results, and rewards. Service integration is a distinct method of service delivery that provides persons with seamless services from multiple programs or areas within programs without repeated registration procedures, waiting periods, or other administrative barriers (Pindus et al., 2000).

Program collaboration and service integration is a mechanism for organizing

and blending interrelated health issues, activities, and prevention strategies to facilitate comprehensive delivery of services. Collaboration allows EHDI programs to accomplish jointly things they could not do alone. Many funding agencies have recognized the power collaboration can bring and call for interagency collaboration as part of the criteria for grantee selection (see *Table 1*).

Probably the most well known form of collaboration between EHDI and other public health programs are partnerships with state newborn genetic/metabolic screening programs. It makes sense that a program in charge of screening all babies for hidden, rare conditions that are serious but treatable would be a partner with a program charged with screening all babies for hearing before 1 month of age, ensuring audiologic evaluation by 3 months of age, and connectioning families to services before 6 months of age. The two programs are charged with screening the same population, providing tracking, and ensuring follow-up. Collecting

Table 1 Benefits of Public Health Program Collaboration

1	Better use of scarce resources.
2	Cost and effort are not duplicated. Fragmentation among services, programs, and initiatives is reduced.
3	Programs can create something in collaboration that they could not create on their own.
4	Higher-quality, more integrated outcomes for families.
5	Improved communication among programs.
6	Increased trust and understanding among individuals and organizations.
7	Potential for organizational and individual learning.
8	Better ability to achieve important outcomes.

Program collaboration and service integration is a mechanism for organizing and blending interrelated health issues, activities, and prevention strategies to facilitate comprehensive delivery of services.

hearing screening results via the newborn screening program specimen card is probably the most common example of collaboration among screening programs. EHDI programs, however, must consider additional opportunities to blend interrelated activities and strategies with other public health programs serving children and their families.

Important Related Public Health Programs

Title V. The Title V Maternal and Child Health (MCH, 2012) program is the longest-lasting public health legislation in the history of the United States. Title V of the Social Security Act was signed into law in 1935 by President Franklin Delano Roosevelt. It was intended to promote and improve maternal and child health nationwide. In 1981, Title V was converted into a block grant program consolidating various categorical child health programs into a single program of formula grants to states.

Each year, state MCH agencies (typically located within state health departments) apply for a Title V block grant. The amount of the grant is determined by a formula that considers the proportion of low-income children in a state to the total number of low-income children in the United States. States and jurisdictions must match every \$4 of Federal Title V money they receive with at least \$3 of state and/or local funds. Approximately \$6 billion of Title V and state/local match dollars are available annually for MCH health programs at the state and local levels. States and jurisdictions use their Title V funds to design and implement a wide range of activities to ensure the health of mothers, women, children, and youth (including children and youth with special healthcare needs) and their families. At least 30% of federal Title V funds are earmarked for services for children with special healthcare needs (MCH, 2000). States and jurisdictions report annually on their program activities and performance on outcome measures—

many of which are related to the EHDI program outcomes listed in *Table 2*.

Table 2 Title V Performance Measures Related to EDHI

Performance Measure #01

The percent of screen positive newborns who received timely follow follow-up to definitive diagnosis and clinical management for condition(s) mandated by their Statestate-sponsored newborn screening programs.

Performance Measure #02

The percent of children with special healthcare needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

Performance Measure #03

The percent of children with special healthcare needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

Performance Measure #04

The percent of children with special healthcare needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

The conceptual framework for services of the Title V MCH Block Grant (*Figure 2*) is envisioned as a pyramid with four tiers of services and levels of funding that provide comprehensive services for mothers and children. Unique to the MCH Block Grant, it is the only federal program that consistently provides services at all levels of the pyramid, including direct healthcare services. EHDI programs have utilized funding as the payer of last resort for direct services not covered by any other program. In 2011, six states, including Arkansas, Arizona, Hawaii, Louisiana, North Carolina, and Wyoming, reported

The Title V Maternal and Child Health program is the longest-lasting public health legislation in the history of the United States.

Much of Massachusetts' EHDl's strategic planning has been focused on supporting and connecting families to other families with similar life experiences. They have taken a "life course" approach to their work—recognizing that early life experiences impact lifetime health

in their Title V Block Grant Annual Report that they have utilized Title V funds to purchase hearing aids or hearing services for families lacking other funding sources (MCH Bureau, n.d)

intervention for those infants diagnosed with hearing loss. EHDl staff approves audiological diagnostic centers, works closely with the community, and provides three statewide trainings each year. Working in the context of Title V and the Children and Youth with Special Health Needs Program, they focus on cultural competency and identify and address health disparities. Much of MA EHDl's strategic planning has been focused on supporting and connecting families to other families with similar life experiences. They hold an annual family forum and support/facilitate community

Figure 2 MCH Pyramid of Health Services

(reprinted from MCH Bureau)

The Title V framework and priorities serve as a model for EHDl programs

to meet the needs of children and their families.

According to the Massachusetts Department of Public Health,

Population-Based Services

Infrastructure Building Services

Direct Healthcare Services

(Gap filling)

Examples: Basic Health Services and Health Services for CSHCN

Enabling Services

Examples: Transportation, Translation, Outreach, Respite Care, Health Education, Family Support Services, Purchase of Health Insurance, Case Management, Coordination with Medicaid, WIC, and Education

Examples: Newborn Screening, Lead Screening, Immunization, Sudden Infant Death Syndrome Counseling, Oral Health, and Injury Prevention

Examples: Needs Assessment, Evaluation, Planning, Policy Development, Coordination, Quality Assurance, Standards Development, Monitoring, Training, Applied Research, Systems of Care, and Information Systems

Universal Newborn Hearing Screening Program, being part of Title V gave Massachusetts the edge to rapidly establish policies and strengthen existing infrastructure when the state's comprehensive hearing screening law was passed. MA Title V involved families, consumers, stakeholders, and diverse communities in an advisory capacity and with their guidance quickly amended the hospital licensure regulations to require screening, effective communication of results to families, and scheduling follow-up appointments.

The Childhood Hearing Data System was established to track screening and follow-up. This system is integrated with the birth certificate and other childhood databases. Almost 100% of newborns are screened for hearing loss. The state is a leader in assuring access to follow-up appointments and

events for families. They have taken a "life course" approach to their work—recognizing that early life experiences impact lifetime health and include wellness activities whenever possible.

The program works in close collaboration and refers families to many other Title V programs and initiatives, including:

- Hearing Aid Program
- Family Initiatives
- Medical Home
- Care Coordination
- Public Benefits
- Catastrophic Illness in Children Relief Fund
- Community Support Line
- WIC
- Home Visiting
- Newborn Blood Screening
- Immunization
- And many others

Title V and Part C early intervention services are coordinated within the same Bureau of Family Health and Nutrition. This close working relationship enhances our ability to comprehensively serve families of infants and children with hearing loss in the state of Massachusetts (Farrell, 2012).

Women, Infants, and Children (WIC): The Special Supplemental Nutrition Program for Women, Infants, and Children. WIC was established as a pilot project in 1972 and became permanent shortly after in 1974. Administered by the United States Department of Agriculture (USDA) through state health departments, WIC is a federal grant program that provides funds for supplemental foods, healthcare referrals, and nutrition education for low-income women, as well as infants and children up to age 5 who are at nutritional risk. It has proven effective in improving the health of pregnant women, new mothers, and their infants. WIC serves approximately 53% of all infants in the United States through over 10,000 clinics in all 50 states, 34 tribal organizations, the District of Columbia, and five territories (Northern Mariana, American Samoa, Guam, Puerto Rico, and the Virgin Islands; USDA, 2012).

The WIC program's mission is to safeguard the health of its participants and be a partner with other services that are key to childhood and family well-being. It has set a precedent for public health program collaboration to improve the health of children. In 2000, WIC was directed by the White House Executive Memorandum to screen the immunization records of all infants and children under the age of 2 at their WIC certification visits. One of the direct benefits to WIC participants is screening and referrals to other health, welfare, and social services.

The idea of utilizing the well-established WIC program to improve follow-up for infants who do not pass their newborn hearing screen is not new for many state EHDI programs. In Wisconsin a "Hearing Screening Alert" is noted if an infant is

greater than 30 days of age and has not had hearing follow-up reported to the state EHDI program. One of two hearing screening alerts is placed, depending on WIC site status "A" or "B" (Stevens & Martin, 2012).

Table 3 WIC Screening Alert Examples

WIC A: Hearing Screening Alert

Baby did not pass newborn hearing screening and needs follow-up. Give family Hearing Screening Follow-Up Letter and review it when you interact with family.

WIC B: Hearing Screening Alert

Baby did not pass newborn hearing screening. Wisconsin Sound Beginnings can conduct a hearing screen with baby's next WIC appointment. Call xxx-xxx-xxxx to coordinate care.

The Wisconsin Sound Beginnings (EHDI) and WIC collaboration was implemented in 2011, resulting in a 63% success rate for cases that have a WIC alert (Martin, 2012). Additional collaborative opportunities are presently being explored, but overall this has been a very successful initial effort.

A similar project is beginning in Oregon (Oregon, 2011):

- EHDI follow-up messages will be integrated with the WIC system.
- Innovative methods to reduce loss to follow-up in regions with greatest economic and geographical barriers will be implemented through collaboration with WIC (text messages, etc.).

In 2011, the Association of University Centers on Disabilities sent out a Research Topic of Interest on "Improving Early Hearing Detection and Intervention (EHDI) Loss to Follow-Up/Loss to

The WIC program's mission is to safeguard the health of its participants and be a partner with other services that are key to childhood and family well-being.

Documentation through Screening at Women, Infants, and Children (WIC) Certification Visits.” The University of Colorado, Boulder, was awarded this 2-year grant with Dr. Christie Yoshinga-Itano as the principle investigator. It is expected that additional information on this EHDI/WIC partnership will be available in the near future (Association of University Centers on Disabilities, n.d.).

Home Visiting. The Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program is funded by the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA). This program provides funding to states and communities to implement evidence-based home visiting programs that improve the health and development outcomes of at-risk children. The program is offered on a voluntary basis to pregnant women or families with children up to age 5. The state and territorial grantees determine their priority populations. These populations could include low-income families, pregnant women under age 21, families with a history of child abuse or neglect, families with a history of drug or tobacco use, children with developmental delays or disabilities, children with low student achievement, or military families.

For MIECHV, nurses, social workers, or other trained home visitors meet with at-risk families in their homes. They evaluate the families’ circumstances and connect the families to assistance, such as healthcare, developmental services for children, early education, parenting skills training, child abuse prevention programs, and nutrition education or assistance. The legislation establishing MIECHV requires the home visiting programs to demonstrate quantifiable, measurable improvements in the populations they serve. Each program targets one or more of the following participant outcomes:

- Improved maternal and child health.
- Prevention of child injuries, child abuse, or maltreatment and reduction of emergency department visits.

- Improvement in school readiness and achievement.
- Reduction in crime or domestic violence.
- Improvements in family economic self-sufficiency.
- Improvements in the coordination and referrals for other community resources and supports.

The legislation authorizing MIECHV requires that 75% of grant funding be spent on home visiting service delivery models that have proven to be effective. There are currently 12 home visiting models that meet HHS criteria for evidenced-based models. These are home visiting service delivery models that have had at least one high- or moderate-quality impact study that found statistically significant impacts in two or more outcome domains. At least one of the impacts must be from a randomized control trial that has been published in a peer-reviewed journal, and at least one of the impacts must have been sustained for 1 year or more after program enrollment (U.S. Department of Health and Human Services, n.d.).

Rhode Island provides a great example of how EHDI programs can collaborate with MIECHV programs. In 2007, the Rhode Island EHDI program began working with the First Connections home visiting program to find children who would otherwise be lost to follow-up. The two programs share information about the children they serve through the Rhode Island Department of Health’s statewide children’s health data system. The EHDI program used the home visiting program’s information to find up-to-date addresses for families who had moved. Home visitors from First Connections would aid in getting newborns that did not pass their newborn hearing screening to a rescreening or diagnostic appointment. At the home visit, the home visitor would educate the family on the importance of follow-up and assist the family in scheduling the rescreening appointment.

Home visitors aid in getting newborns that did not pass their newborn hearing screening to a rescreening or diagnostic appointment. The home visitor would educate the family on the importance of follow-up and assist the family in scheduling the rescreening appointment.

Evidence is growing that enhanced models of primary care improve maternal and child health and well-being.

In August 2012, the Rhode Island EHDI program expanded its collaboration with the First Connections home visiting program. With HRSA funding, the EHDI program has purchased portable screening equipment and hired two screeners. These screeners accompany First Connections home visitors to perform rescreens for families who have not followed through on having their baby's hearing rescreened.

As part of this collaboration, the Rhode Island EHDI program provided extensive training to home visitors. This training included information on what the screener would do during the home visit, an actual screening demonstration, and instructions for communicating the results of the rescreening to the parent. The home visitors were also taught to provide parents the information they would require if the child needed further audiological examination.

Although the EHDI program still encounters difficulties reaching some families, this collaboration with home visiting has helped reduce loss to follow-up rates, particularly for home births.

Because of the success of this collaboration, the Rhode Island EHDI program plans to begin working with three other home visiting programs in Rhode Island in the future.

culturally effective (AAP, 2002). The medical home is responsible for the provision of primary care, including preventive services and appropriate screening (including newborn hearing screening). Within the medical home, primary care providers act in partnership with parents to identify and access appropriate audiological, intervention, and consultative services that are needed to develop a global plan of appropriate and necessary health and habilitative care for infants identified with hearing loss and infants with risk factors for hearing loss (Joint Committee on Infant Hearing, 2007)

Evidence is growing that enhanced models of primary care, such as integrated community-based systems and patient-centered medical homes, improve maternal and child health and well-being (Ockene et al, 2007). Most, if not all, opportunities to integrate public health services, such as EHDI, immunizations, and Early and Periodic Screening and Diagnosis and Treatment (EPSDT, 2012a) programs for children require involvement from primary care providers within the medical home.

The Utah Department of Health (UDOH) has made the integration of children's services and information about public health services much easier for primary care providers to track. The Child Health Advanced Records Management (CHARM) data integration system provides access to information stored in program-specific databases to track and monitor child health status. This includes hearing screening results, immunization status, referrals, assessment, treatment, and outcomes for children and their families. Several programs are available through CHARM, including [vital records \(birth and death certificates\)](#), Utah Statewide Immunization Information System ([USIIS; \(Utah's immunization registry\)](#)), Newborn Hearing Screening, Newborn Blood Spot (heel stick) Screening, and [Baby Watch/Early Intervention](#). Future developments will include the integration of Children with

Medical Home

The medical home concept was first introduced by the American Academy of Pediatrics (AAP) in 1967. This concept included the belief that healthcare should be provided to all children, including children with special healthcare needs that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and



Photo courtesy of NCHAM

Special Healthcare Needs (CSHCN) clinic visits (including neonatal follow-up) and the [Birth Defects Network](#). CHARM acts as an electronic broker (middle-ware). It does not replace existing UDOH databases. The participating programs are fitted with their own front-end “agent” that plugs into the CHARM infrastructure. CHARM is a modular approach to integrating systems—beginning with a core of programs and leveraging funding and incremental successes to achieve a long-term vision for a statewide integrated system (Harward, 2012).

Immunizations. The CDC declared vaccinations to be 1 of the 10 great public health achievements of the 20th century. In the first decade of the 21st century, an estimated 2.5 million deaths were prevented each year among children under 5 years of age through the use of measles, polio, and diphtheria-tetanus-pertussis vaccines (CDC, 1999).

Primary care providers, including pediatricians, nurse practitioners, and family doctors, have worked diligently to ensure that all children without a valid contraindication receive all childhood immunizations on time. Organizations such as the AAP and the National Association of Pediatric Nurse Practitioners—in conjunction with state and national health agencies—work closely together to improve immunization coverage. Immunizations provided through a medical home as part of a child’s comprehensive healthcare is the major reason there have continued to be improvements in immunization coverage—representing significant progress toward meeting the goals set forth through the Healthy People objectives (AAP, 2002).

The AAP policy statement, “Increasing Immunization Coverage,” has recommended interoperability of immunization information systems and electronic health records. It suggests the ability to accommodate the bidirectional flow of information will facilitate provider participation in immunization

information systems. With support from the HHS, interoperability of electronic health records and public health information is progressing at a rapid pace (AAP, 2010).

Partnerships with state and local immunization programs have been an effective strategy for engaging primary care providers in EHDI follow-up and integrated services for families.

In New Jersey, the EHDI program partnered with the state immunization program to create an EHDI interface in the New Jersey Immunization Information System (NJIIS). The NJIIS is populated with electronic birth record data. A 2004 law requires that all children be enrolled in the NJIIS, unless the parent refuses participation. In 2006, an EHDI module was added to the NJIIS to allow providers to view hearing evaluation data and electronically submit EHDI outpatient follow-up information. The NJIIS is a secure, authenticated, Web-based system with role-restricted access to the various modules. Primary care providers can view hearing screening data in addition to viewing and editing immunization data. Audiologists can access evaluation results and report outpatient testing results but cannot access the immunization section of the system. Over 100 audiologists and others who conduct outpatient screening or track follow-up have been trained by EHDI staff to use the NJIIS-EHDI module. Approximately 88% of outpatient hearing follow-up reports are currently submitted to the EHDI program through the NJIIS. The immunization program staff are enthusiastic about the inclusion of hearing information in their tracking system, since it can benefit them through increased provider participation (Aveni, 2012).

In Oregon, the Immunization Program drafted administrative rules so the EHDI program (through auspices of the Oregon Health Authority) can obtain information from the immunization tracking and recall registry (ALERT). Consent of the client or parent/guardian is not necessary if the information is used for

Partnerships with state and local immunization programs have been an effective strategy for engaging primary care providers in EHDI follow-up and integrated services for families.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) provides preventive healthcare and necessary treatment services to children.

the purposes of outreach, follow-up for missed hearing screenings, or other public health interventions designated by rule of authority. These changes to administrative rules allow data-sharing activities, which include importing the current primary care provider information from ALERT to the EHDI information system (EHDI-IS). These rules allow for the importing of screening and diagnostic results from EHDI-IS to ALERT in order to notify primary care providers that action is needed (Oregon, 2011).

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). EPSDT (2012b) is a mandatory set of services and benefits for all individuals under 21 years of age enrolled in Medicaid. Added to the Medicaid Act in 1967, it provides preventive healthcare and necessary treatment services to children. The overall goals of EPSDT are to identify health concerns, assure that treatment is provided before problems become complex, and to medically justify that services are provided to treat or correct identified problems.

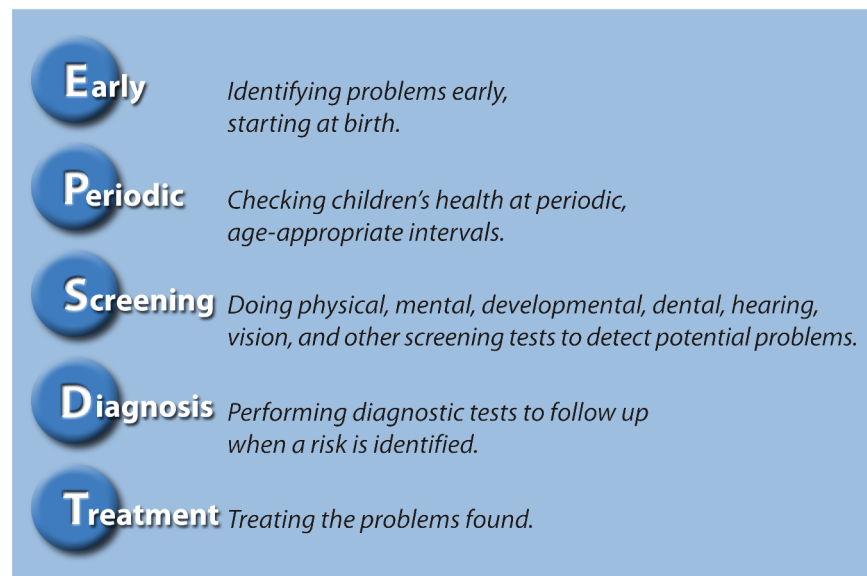
EPSDT, as stated by HHS, is the child health component of Medicaid. It's required in every state and is designed to improve the health of low-income children by financing appropriate and necessary pediatric services.

EPSDT is designed to help ensure access to needed services, including assistance scheduling appointments and transportation to keep appointments. As described in federal program rules: The EPSDT program consists of two mutually supportive, operational components:

1. Ensure the availability and accessibility of required healthcare resources.
2. Help Medicaid recipients and their parents or guardians effectively use these resources.

The second component involves the administrative obligations of informing parents, utilizing supportive services to ensure that care is secured (i.e.,

Figure 3 *Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)*



Increasing the efficacy of linkages between pediatric providers and other entities serving children is one key step toward improving care and services for families.

transportation, case management), and reporting. All services must be medically necessary, and states are required to cover a comprehensive set. Each state may have its own unique name for its EPSDT program—for example, in Minnesota, it is known as “Child and Teen Check-Up (C&TC),” and in Louisiana, the program is known as “KIDMED.”

The potential benefit of improved linkage between EPSDT and EHDI programs has long been surmised. In 2005, 10 state EHDI coordinators and EPSDT directors developed a written action plan focused on using EPSDT to improve EHDI services to children. States, including Iowa and Texas, provided EHDI education for EPSDT providers. In Massachusetts, the action plan included updating the EPSDT policy manual to include information on risk factors for hearing loss and follow-up.

Increasing the efficacy of linkages between pediatric providers and other entities serving children is one key step toward improving care and services for families. Managed care structures affect how public health agencies carry out their community-wide public health responsibilities.

Memorandums of Understanding (MOUs) are proven to be an effective tool for improving linkages between Medicaid managed care organizations and public health agencies serving children. With respect to EPSDT, MOUs might define interaction related to case management, data reporting, immunization billing, children with special healthcare needs, and so forth.

It is well known that EPSDT outreach workers play a critical role in follow-up and care coordination for hard-to-reach groups. The EHDI program ensures that hearing screening and follow-up is incorporated into EPSDT’s existing administrative outreach efforts.

Birth Defects Surveillance

Birth defects are an important public health issue, because babies born with

birth defects have a greater chance of illness and long-term disability than babies without. One in every 33 babies in the United States is born with a birth defect. Many children with hearing loss may also have a birth defect. For this reason, it is important that EHDI professionals be aware of birth defects surveillance efforts in their community and find ways to partner with these efforts.

Birth defects surveillance programs serve multiple purposes. The information gleaned from these tracking systems is used to monitor the prevalence and incidence of birth defects over time. This information helps policymakers allocate resources and services to families and provides a means to refer babies with birth defects to appropriate services. The data are also used to determine the causes of and risk factors for birth defects and to guide the development of programs aimed at prevention. Educating the public about birth defects and how to prevent them is a major purpose of birth defects surveillance programs.

Birth defects tracking systems vary in the strategies used to find babies with birth defects and confirm diagnoses. Some programs use active case finding, which involves dedicated staff members reviewing medical records from healthcare facilities. While this method often identifies most children with birth defects, it can be quite time-consuming and expensive. Passive case finding with confirmation is another method used by tracking systems. Rather than having dedicated staff members collect the data, tracking systems that use this method receive reports about birth defects cases from healthcare facilities. Program staff review these reports and use various methods to verify birth defects diagnoses. A final tracking strategy is passive case finding. Like passive case finding with confirmation, these tracking systems receive reports about birth defects from healthcare facilities. However, these programs do not follow up to confirm the diagnoses of birth defects (CDC, 2011).

The percentage of newborns in the United States screened for hearing has increased dramatically over the past decade.

Forty-one states currently have birth defects tracking programs. Fourteen of these programs, including the one in Minnesota, are currently funded by the CDC. The Minnesota Department of Health's (MDH) Birth Defects Information System, which is an active case-finding system that tracks babies born with a birth defect up to 1 year after delivery, was created in 2005 (CDC, 2011).

In 2010, Minnesota passed legislation that authorized the expansion of birth defects monitoring and analysis activities. As part of this expansion, MDH partnered with local public health (LPH) and tribal health agencies to facilitate birth defects service delivery in local communities. The birth defects partnership with LPH was inspired by the EHDI program at MDH. In 2010, MDH began implementation of a strategy that engages LPH/tribal health agencies in the facilitation of hearing rescreening, diagnosis of hearing loss, and connection to services/supports such as Part C early intervention for children diagnosed with permanent hearing loss. In the first 2 years of this partnership, with the help of LPH nurses, MDH was able to decrease lost to follow-up after screening by 50%. Building upon this success, the MDH birth defects program partnered with LPH as well. The birth defects and EHDI programs have made a conscious effort to collaborate with one another in this partnership. The programs use the same grant contract with LPH. Communications with LPH, including a monthly newsletter and quarterly teleconferences, are done in tandem. Often one person from the LPH agency does both EHDI and birth defects follow-up, which avoids duplication of services. LPH is asked to report data into the same database system for both programs. This collaboration reduces the burden on LPH agencies and allows the birth defects and EHDI programs to learn from one another, save money, and work more efficiently.

In addition to their collaboration on the LPH project, the Minnesota EHDI and birth defects programs are working on developing a process for sharing appropriate cases with each other for case-finding purposes. In the future, the birth defects program will be able to share case information about children in their database who have a hearing loss with the EHDI program. Likewise, the EHDI program will be able to share cases from its database, where the child also has a birth defect, with the birth defects program. Because children with hearing loss often also have a co-occurring birth defect, the programs expect to find cases that they would otherwise have not.

The Future of EHDI and Public Health Program Partnerships

The percentage of newborns in the United States screened for hearing has increased dramatically over the past decade. The numbers of children lost to follow-up continue to decrease, while the number of infants and young children identified with hearing loss who are connected to services continues to improve (CDC, 2012a). Many factors have influenced these positive trends. One that cannot be overlooked is the promising approach of public health and EHDI partnerships as a way to attain and effectively utilize resources, share knowledge, and improve population health outcomes. EHDI programs must seek ways to improve collaboration by creating new opportunities and building upon the accomplishments of states using innovative public health partnerships, such as those described above, in order to effectively improve the health and developmental outcomes of the children and families served.

Acknowledgements. We would like to express our sincere gratitude to the state EHDI program staff who found opportunities to integrate with related public health programs and were willing to share their successes with us; Janet Farrell, Massachusetts; Rebecca Martin, Wisconsin; Richard Harward, Utah; Kathryn Aveni, New Jersey. Thank you also to Irene Forsman for her expert guidance in the development and review of this chapter.

Reference List

- American Academy of Pediatrics. (2002). The medical home: Medical home initiatives for children with special needs project advisory committee. *Pediatrics*, 110, 184-186.
- American Academy of Pediatrics. (2010). Increasing immunization coverage: Committee on practice and ambulatory medicine and council on community pediatrics. *Pediatrics*, 125, 1295-1304.
- Association of Schools of Public Health. (n.d.). *The 20th century's ten great public health achievements in the United States*. Retrieved December 28, 2012, from whatispublichealth.org/impact/achievements.html
- Association of University Centers on Disabilities. (n.d.), Retrieved January 4, 2013, from <http://www.aucd.org/template/page.cfm?id=334>
- Aveni, K. (2012, December 17). *New Jersey Department of Health*. Personal communication.
- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT). (2012a). *Overview, U.S. Department of Health and Human Services*. Retrieved on December 7, 2012, from mchb.hrsa.gov/epsdt/overview.html
- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT). (2012b). *Services in Medicaid Knowledge Path*. Retrieved on December 7, 2012, from mchlibrary.info/KnowledgePaths/kp_EPSDT.html
- Farrell, J. (2012, December 11). *Massachusetts Department of Health*. Personal communication.
- Harward, R. (2012, December 17). *Utah Department of Health*. Personal communication.
- Iowa EPSDT Care for Kids Newsletter. (2011). Retrieved from iowaepsdt.org/EPSDTNews/2011/Fall2011/HearingLoss.htm
- Joint Committee on Infant Hearing. (2007). Position statement: Principles and guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics*, 120, 898-921.
- Martin, R. (2012, December 11.) *WI Sound Beginnings Outreach Specialist*. Personal email communication.
- Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. (2000). *Understanding Title V of the Social Security Act*. Retrieved from <http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf>
- Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. (2012). *Title V information system*. Referenced December 12, 2012, from mchdata.hrsa.gov/tvisreports
- McManus, White, Farrell. (2006). *Effective use of Medicaid to support EHDI programs presentation*. Retrieved from <http://www.infanthearing.org/meeting/ehdi2006/presentations/index.html>
- Ockene, J., Edgerton, E., Teutsch, S. M., et al. (2007). Integrating evidence-based clinical and community strategies to improve health. *American Journal of Preventive Medicine*, 32(3), 244-252.
- Oregon HRSA Universal Newborn Hearing Screening Project Abstract, FY 2011. (2012). Retrieved December 14, 2012, from <https://perf-data.hrsa.gov/mchb/DGISReports/Abstract/AbstractDetails.aspx?Source=TVIS&GrantNo=H61MC00057&FY=2011>
- Pindus, N., Koralek, R., Martinson, K., & Trutko, J. (2000). *Coordination and integration of welfare and workforce development systems*. Washington, DC: Urban Institute. Retrieved from www.urban.org/UploadedPDF/coordination_FR.pdf
- State Leadership Workshops on Improving EPSDT through Medicaid and Title V Collaboration (2011, June). *HRSA*. Retrieved from mchb.hrsa.gov/.../state_leadership_workshops_tool_kit.pdf
- Stevens, C., & Martin, R. (2012). *Reducing loss to follow-up through parent professional partnerships*. Retrieved from ehdimeeting.org/2012/schedule/griddetails.cfm?aid=568&day=TUESDAY

- The Centers for Disease Control and Prevention (CDC). (1999). Ten great public health achievements—United States, 1900–1999. *MMWR*, 48, 241.
- The Centers for Disease Control and Prevention (CDC). (2010). *Public health cycle*. Retrieved from <http://www.cdc.gov/ncbddd/hearingloss/publichealth.html>
- The Centers for Disease Control and Prevention. (CDC). (2011). *Birth defects state-based tracking systems*. Retrieved from <http://www.cdc.gov/ncbddd/birthdefects/states/index.html>
- The Centers for Disease Control and Prevention (CDC). (2012a). *Annual data Early Hearing Detection and Intervention (EHDI) program*. Retrieved from <http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>
- The Centers for Disease Control and Prevention (CDC). (2012b). *Hearing loss in children*. Retrieved from <http://www.cdc.gov/ncbddd/hearingloss/facts.html>
- U.S. Department of Agriculture. (2012). *About WIC—food & nutrition service*. Retrieved December 14, 2012, from <http://www.fns.usda.gov/wic/aboutwic/>
- U.S. Department of Health and Human Services. (n.d.). *Maternal, infant, and early childhood home visiting program*. Retrieved December 28, 2012, from <http://mchb.hrsa.gov/programs/homevisiting/>
- Watkins, C. (2008). *Finding lost EHDI babies utilizing partnerships*. Retrieved from <http://www.infanthearing.org/meeting/ehdi2008/Topical%205/Watkins%20session%205.pdf>