

Examining Early Hearing Detection and Intervention through the Essential Services of Public Health

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ABSTRACT

Early Hearing Detection and Intervention (EHDI) programs in the United States serve to support the screening, diagnostic evaluation, and eventual intervention to foster the development of children who are D/deaf and hard of hearing and their families. With this goal, EHDI is an inherently interdisciplinary system working to meet a diverse range of needs and individuals. This manuscript examines this system from the view point of public health. Public health as a discipline plays a crucial role in the EHDI system supporting the implementation of services in line with the legislation at the state and federal level. The ten essential services of public health provide a structure and vocabulary that can be used by clinical service providers, including educational and pediatric audiologists, to better conceptualize the EHDI system. This manuscript serves as an introduction for those in the realm of audiology to the ten essential services of public health and how this interdisciplinary perspective supports the various elements of family-centered care that are critical to clinical service provision.

INTRODUCTION to Early Hearing Detection and Intervention and the Role of Public Health

The overarching goal of Early Hearing Detection and Intervention (EHDI) is to ensure that all children receive hearing care services starting at birth (American Academy of Pediatrics, 2018; Joint Committee on Infant Hearing [JCIH], 2013; 2019). Since 2019, the EHDI program in the United States has ensured access to screening service for over 95% of infants, ideally by one month of age, to identify whether they require a diagnostic evaluation (CDC, 2021a). Of those who require diagnostic evaluations based on screening results (61,475), only 71.9% do before three months of age (CDC, 2021b). From there, children who are identified as D/deaf or hard of hearing (5,934) should access early intervention services before six months of age (CDC, 2021b; JCIH, 2019). Eligibility for this entitlement program supports the critical access to services early in life (JCIH, 2019; Muñoz, et al., 2011; Yoshinaga-Itano, 1999, 2003, 2013). At any point in this system of referrals and service providers, a child and family may not make it to the next clinically indicated step. These children, who are lost to follow-up/documentation (LFUD), will have delayed access to services.

Warren and Levy (2021) consider the EHDI system the most prominent example of the successful implementation of hearing assessment programs. EHDI is a public health service governed by the Public Health Service Act (Early Hearing Detection and Intervention Act of 2017). EHDI is a public health service, and it should be evaluated against public health principles. As shown in Figure 1, one way to approach EHDI is to use the Centers for Disease Control and Prevention's (CDC) (2014) ten essential services of public health to address system-level challenges (e.g., LFUD). A benefit of considering EHDI in this broader context is that it might provide a greater understanding of the systemic factors related to health, such as social determinants of health (SDOH), which impact how and why there are challenges with recommendation adherence in EHDI. Public health concepts provide a vocabulary and structure that lends itself to discussing the key points of EHDI service provision, as well as to address strengths and areas for growth. Throughout all the essential services, the connection between EHDI and public health reaffirm one another.

Figure 1. The ten essential services of public health and their broadened applications to the implementation of Early Hearing Detection and Intervention. Adapted from CDC (2014).



Monitor Health Status to Identify Community Health Problems

According to the CDC, to monitor health status, public health programs can use health-related data to make information-driven choices around what public health needs or concerns may be present in a community (CDC, 2014). In the same vein, health-related data on newborns can speak to current and future public health program needs regarding EI and public education. This type of data can be collected through newborn screening. The Secretary of the Department of Health and Human Services recommends including 35 diagnoses, including hearing differences, in the screening due to the long-term implications of delays in care (Boyle et al., 2014; Health Resources & Services Administration, 2019).

It is important to note that screenings are not able to determine specific diagnoses. The screening system helps detect lifelong and long-term diagnoses with the potential to impact individual and community health drastically (Boyle et al., 2014). However, screening is not a substitute for a diagnostic evaluation. Hearing screening is consistent with the goal of decreasing long-term disability/challenges associated with a diagnosis by identifying newborns who should eventually enter into EI to support development (JCIH, 2019; White, 2019). Screening provides those working in public health positions opportunities to monitor pediatric hearing at the population level by collecting baseline data on almost all newborns (Boyle et al., 2014).

Diagnose and investigate health problems and health hazards in the community

As implemented by the Early Hearing Detection and Intervention Act of 2017, newborn hearing screening is available to children born in the United States of America, regardless of risk factors related to hearing. To ensure accessibility and be consistent

with federal guidance, there is a need for services that are sensitive to race, ethnic identity, disability status, and religion (Early Hearing Detection and Intervention Act of 2017). This idea is echoed in qualitative assessments of satisfaction in families participating in various support services (Carpenter, 2003; Powell, 1990; Zionts, et al., 2003; Early Hearing Detection and Intervention Act of 2017). It is essential to remember that hearing screening is only the first component of the EHDI system and is designed to refer children who are at an increased chance of hearing differences to diagnostic services (JCIH, 2018; 2019). For those working in public health, the process of identification provides insight into potential etiologies and population-level changes in hearing thresholds. Data on the incidence of hearing differences can be combined with etiological data to identify underlying causes or co-occurring public health needs and future interventions to be developed to meet those needs.

For example, the current JCIH position statement (2019) notes that congenital cytomegalovirus (cCMV) can result in seizures, microcephaly, developmental delay, vision loss, and hearing differences. Given the connection between cCMV and pediatric hearing levels, data on newborns can provide insight into the incidence and prevalence of cCMV. Implementing cCMV screening in response to hearing screening results, while not universal, is a means of further investigating the etiology of childhood hearing levels and potentially determining the role that CMV plays at the community level with infant health.

Inform, educate, and empower people about health issues

The EHDI system is predicated on sharing information. For the system to function, stakeholders, including families, must be aware of diagnostic labels, further referrals, and available supports. This process is supported by coordination across governing bodies and mandated data reporting at the state, federal, and local levels. For families, data should be supported by education, accessibility, and family empowerment resources. Family members should be informed of their child's hearing levels through clear explanation by professionals, educated on intervention options, and empowered to make care and service provision decisions for themselves and the child (Early Hearing Detection and Intervention Act of 2017).

Federal regulations identify families as decision-makers, and states are required to support families so that they can "make important decisions for their child" (Early Hearing Detection and Intervention Act of 2017). This decision-making power goes beyond selecting intervention services. Families are gatekeepers for their children. They determine what professionals have the opportunity to engage and facilitate if there is to be any ongoing care. In addition, families are recognized explicitly as having their own needs, independent of the child. As such, states are also required to provide "family-to-family and deaf and hard-of-hearing consumer-to-family supports" (Early Hearing Detection and Intervention Act of 2017). Families and providers become partners in personalizing and improving services for the family as a whole (Wells, 2011).

Mobilize community partnerships to identify and solve health problems

To be successful, public health programs should reflect the specific needs of the communities they serve and should be developed through partnerships created in those communities (CDC, 2014). In implementing EHDI, the family, therapists, teachers, adults who are DHH, and families of children who are DHH should be included in those partnerships (Meadow-Orlans, et al. 1997; Mikkelsen et al., 2001).

Parent-to-parent support groups and dialogues are among the most effective support methods for families (Jackson, 2011; Matloff & Zimmerman, 1996; Mikkelsen et al., 2001). These groups and interactions foster emotional support to families (Matloff & Zimmerman, 1996; Moores et al., 2001). A group of stakeholders may also be organized into a medical home for children and families. In the medical home, care is centralized, and a teamed approach to healthcare is enacted in an environment that is accessible, continuous, family-centered, culturally effective, and compassionate (Asarnow, et al., 2017; Nageswaran & Farel, 2007; Nickel, et al., 2003).

Develop policies and rules that support individual and community health efforts

Social determinants of health are the components of the human experience, and the environments we exist within can impact health (SODH) must be considered when addressing barriers to communities meeting EHDI goals. The JCIH explicitly called upon public health researchers to identify and measure the impacts of SDOH in EHDI (2019). Assessing EHDI policy in the context of SDOH may help refine EHDI policies to better support individuals in their hearing healthcare efforts, and to identify innovative efforts to reshape community-level challenges.

Economic stability

Under the umbrella term of economic stability are employment, food insecurity, housing instability, and poverty (Healthy People 2020, 2019). Without the financial resources, securing food and housing may be difficult. Given the definition of poverty as implemented in support program eligibility requirements, these concerns may be further complicated with poverty. An example of this would be that eligibility for programs that provide support in these areas, such as the Supplemental Nutrition Assistance Program, the Housing Choice Voucher program, and Medicaid, are related to income. The yardstick used for qualification in programs varies and does not include all people who experience the impacts of economic instability (Connecticut Department of Social Services, 2019; Connecticut Department of Housing, 2019). Within EHDI, research has brought attention to the impact of socioeconomic status on adherence to screening and follow-up recommendations (Liu, et al., 2008). From the perspective of SDOH, it is required that policymakers look past the label ascribed to an individual based on income and consider the underlying implication of that label and the functional implications it has in terms of access to care and perception of care.

While research has highlighted a connection between maternal public insurance and increased risk of LFUD, it is inappropriate to conclude that the type of insurance their mother has is the driving factor behind why children are at a higher risk of being lost to follow-up (Lui et al., 2008; Scheepers, Swanepoel, & le Roux, 2014). Instead, considering the impact of economic stability as a whole is warranted. The type of coverage provided by insurance may not be the driving factor behind this connection. Instead, the relationship between insurance type and income may inform the correlation between insurance type and LFUD. Demographic variables around economic stability are proxies for root needs.

Neighborhood and built environment

Neighborhood and built environment refer to topics such as crime and violence, environmental conditions, quality of housing, and access to nutritious food (Healthy People 2020, 2019). The built environment is the physical context of a community. Examples that may be important for individuals who are DHH include the number of audiology clinics in the area or what locations are looped for telecoil usage. The built environment, or lack of specific built environment components, may play a part in care access. To illustrate, rurality, which is associated with lack of built environment, is associated with higher lost to follow-up rates in EHDI (JCIH, 2019; Liu et al., 2008). Living in a rural environment may limit access to providers who can perform follow-up services due to distance to providers, which providers are covered by insurance, or the hours of operation for a given provider. Characteristics specific to a state, municipality, or region must inform interventions to support access such as gas card or bus card programs for traveling to appointments, contact information for clinics with varying hours of operations or mobile service provision, and coordination of appointments to limit travel needs (Hunter et al., 2016). Since COVID-19, the utility and practical application of telehealth have also been at the forefront of clinical service provision and may serve to meet this accessibility need as well.

Education

Within SDOH, education refers to early childhood education and development, enrollment in higher education, high school graduation, language, and literacy (Healthy People 2020, 2019). For this discussion, these parameters should also be expanded to conceptual knowledge of EHDI and EI. Through these programs, early childhood education and development, language, and literacy can be targeted in a way conducive to education which removes barriers to health.

Higher levels of maternal education are associated with decreases in LFUD (Cunningham, et al., 2018; Liu et al., 2008). We must ask what about maternal education impacts EHDI. Is an increasing amount of education associated with more knowledge about EHDI? Alternatively, is maternal education serving as a proxy for income or other economic root needs? Few studies in this area successfully control for maternal income. Examples of this failure include not taking into account the impact of disposable

income or how different jobs, employment contracts, or benefits such as insurance and paid time off. One barrier is this type of information about maternal income is not included in the child's birth record, a common point for this type of data to be collected at the population level.

Of specific note here is the role of health literacy. Health literacy refers to the skill of taking in, processing, and understanding health-related information (American Speech-Language-Hearing Association, n.d.a). Many health providers, including audiologists, tend to speak at a level above what is accessible to an individual or family (Donald & Kelly-Campbell, 2016; Nair & Cienkowski, 2010). Changes to address this communication barrier include development of print materials consistent with American Speech-Language-Hearing Association (n.d.a) guidelines, which include use of short sentences, active voice, limited jargon, and bulleted lists.

Health and healthcare

The EHDI system is the combined effort of birth hospitals, primary care providers, and specialists such as audiologists, speech-language pathologists, and other necessary specialties (JCIH, 2019). Having access to all of these healthcare providers can be complicated by SDOH such as barriers to affording the cost of care, accessing transport to providers (when available), understanding the need to see providers, and overcoming discrimination or isolation. These may be further complicated when individuals do not have access to a primary care provider (PCP) and a medical home (Hing, et al., 2017). Guidelines that reinforce the role of the PCP and support the ability of families affected by all SDOH to access care is a needed area of further policy development.

Social and community context

Social and community context refers to community participation and social cohesion (Healthy People 2020, 2019). Community participation barriers for individuals who are DHH and their families have been noted across the continuum of communication approaches (Emond & Sutherland, 2015; Johnson, 2012; Steinberg, et al., 2002). Pre-existing strains on cohesion including discrimination due to ethnicity, or other demographic characteristics, may further complicate needs. It is crucial to also consider cultural identity as it relates to participation as well (Madell & Flexer, 2014; Padden & Humphreys 2006). Families may experience non-cyclical grief following identification (Kurtzer-White & Luterman, 2003). This emotional response can change how families interact with their community and impact social cohesion and participation. Alternatively, families connected to the Deaf community may feel an added level of cohesion and find new opportunities for participation.

Enforce laws and regulations that protect health and the environment, and ensure safety

Newborn hearing screening legislation was not implemented in one legislative session. The start of what would become EHDI

was in the 1990s with the development of usable technology for screening purposes and the implementation of some state-level universal screening programs, the first of which was Rhode Island in 1993 (National Center for Hearing Assessment and Management NCHAM, 2016; 2018; White, 2019). The current federal legislation reaffirms goals from the Early Hearing Detection Act of 2010 for universal screening. It provides the foundation for developing and monitoring state programs in meeting standards of care outlines such as referral to early intervention (EI) and the provision of services to all children, not only newborns, who are DHH. (Early Hearing Detection Act of 2017; NCHAM, 2018; n.d.b). States are charged with developing legislation around EHDI as well as designing and maintaining state-level programs to support the screening, evaluation, identification, and application of EI to children who are DHH. However, the NCHAM (n.d.a) notes that state legislation does not always mandate all components of a successful system. State guidelines tend to align with the recommendations published in the 2019 JCIH position statement and may go beyond what is mandated by federal and state laws.

Link people to needed medical and mental health services and assure the provision of healthcare when otherwise unavailable

Screening, identifying, and providing intervention requires that newborns be connected to screeners, referred by the screener (as appropriate) to a pediatric audiologist, and provided access to support services that are consistent with family goals.

The first point of contact between families and the EHDI system is the initial screening. In 2016, 94.8% of the 3,852,497 children reported to Vital Records as being born in the United States received a hearing screening by one month of age (CDC, 2018d). Another 2.7% of children were screened after one month, resulting in 97.5% of all newborns receiving a hearing screening in 2016 (CDC, 2018a; JCIH, 2019). The most commonly reported reason why the screening did not occur was "unknown" (CDC, 2018g). Following the screening, 65,156 children were referred for diagnostic evaluation (CDC, 2018c). Diagnostic results were reported for 40,835 of these children (about 63%; CDC, 2018c). However, only 47.5% of these children were seen and had their hearing levels documented by three months of age, as recommended by the JCIH (2007; CDC, 2018c).

In 2016, over half of the 6,337 children identified as DHH were enrolled in EI programs, consistent with EHDI targets (CDC, 2018b,c). However, over 30% of those children identified as DHH, are not reported as enrolling in early intervention services (CDC, 2018b). Reported data provide limited insight into why families were not enrolled in EI. Over one-third of those families reported "unknown" reasons for not enrolling, with another quarter of those families indicated that they had declined to enroll (CDC, 2018f).

Currently, there are breakdowns across the EHDI system in connecting families to care. The most common non-medical and non-logistical reason families did not progress through EHDI systems was that they declined services (CDC, 2018e; 2018f; 2018g). This breakdown is inconsistent with the evidence-based-foundation of EHDI in developmental, audiological, and

speech-language research that called for family-centered care and intervention services to mitigate communication challenges and the positive impact of EI on children and families (NCHAM, 2019a; Yoshinaga-Itano, 1999, 2003, 2013). While families have the right to decline services, the reasoning behind this decision has not been investigated. Instead the social determinates of health bring into question if this declination is true refusal of services or a declination of engagement with the current system.

Assure a competent public health and personal healthcare workforce

The critical stakeholders within EHDI are broad. Each individual within the system, including family members, has mandated education and/or lived experience associated with their job or role. The federal legislation directing states in their implementations calls on families as decision-makers (Early Hearing Detection and Intervention Act of 2017). This mandate goes further than supporting the family's participation in decision-making. The family's role in directing care is codified in federal law and thus, the family becomes part of the healthcare workforce (Early Hearing Detection and Intervention Act of 2017).

Yet, there is a large body of literature suggesting that families are still searching for or can benefit from more explicit instruction on EHDI topics, including information on screening (Krishnan, et al., 2019), EI (Haddad, et al., 2019; Khoza-Shangase, 2019; Larsen, et al., 2012; Pendersen & Olthoff, 2019), hearing aids and technology (Haddad et al., 2019; Van der Spuy & Pottas, 2008), financial supports (Haddad et al., 2019), family support services (Haddad et al., 2019; Van der Spuy & Pottas, 2008), and hearing levels in general (Donald & Kelly-Campbell, 2016; Sax et al., 2019). Family education on EHDI is consistent with the goal of ensuring those involved with public health programs are competent and can provide vital services.

Evaluate effectiveness, accessibility, and quality of personal and population-based health services

Family decisions determine whether health data can be collected through screening, what diagnostic appointments are attended, and whether EIs are pursued. With this in mind, interventions focused on families can support all of the essential services of public health within EHDI. It is vital to investigate current literature on how families are being educated around their role in EHDI. A small base in the research includes empirically evaluated family-based interventions around EHDI topics such as LFUD (Cockfield et al., 2012; Hunter et al., 2016; Yarbrough et al., 2018).

System-level intervention to support care coordination

Hunter et al. (2016) implemented a two-year LFUD reduction program based on the integration of EHDI with the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). The WIC program is federally funded and supports mothers and children accessing healthy and nutritious foods (Hunter et al., 2016). Families were offered hearing rescreening

services at their community WIC office if their child did not pass their initial screening and if the family was receiving or planned to receive WIC benefits. This study highlighted the power of service coordination with the families that enrolled in the intervention. The baseline LFUD rate of 33% was reduced to 9.6% across both years of the study. While this form of intervention excels at connecting individuals with non-hearing related supports in a way that is consistent with addressing economic stability and neighborhood as SDOH, integrating these two services is fiscally impossible as presented unless additional funding is procured (Hunter et al. 2016). Hunter et al. (2016) did not have an explicit mechanism for imparting hearing-based knowledge to families. There was no direct intervention with families, as is consistent with the essential services that have been presented above.

System-level intervention to integrate family-driven practices into EHDI

Yarbrough et al. (2018) reported on a system-navigational intervention called "Guide by your Side". Families of children who had already navigated the EHDI system, called Family Educators, were connected to hospitals and audiologists providing screening services as well as families who requested social and emotional support related to hearing screening results (Yarbrough et al., 2018). In the year that the Family Educators were connected with the staff at hospitals and families directly for emotional support, LFUD rates at these specific locations were reduced by 4.4%. The average age at rescreening following the intervention was lowered by one month. While hospitals and organizations received information and training on how to decrease LFUD that could be applied to all individuals, the educational component of Guide By Your Side was not universally applied or targeted to disengaged families. No statistical analysis was conducted. Individuals who participated in the direct family-level education and support services had to elect to enroll. This approach does not address families who are disengaged, are struggling to connect, or have not been engaged with the EHDI system as of yet.

Birth parent-level intervention to infuse education into the screening

Cockfield et al. (2012) implemented an intervention at two hospitals where, following the hearing screening results, the audiology assistant that performed the screening would alert a nurse practitioner. The nurse practitioner then obtained consent and provided the mother with a standardized lesson on EHDI. This lesson included a brochure on the Georgia Newborn Hearing Screening program and a guide to benchmarks that are important for timely follow-up on their results. The birthing parent was also provided with the information for the child's next audiology appointment. This is the only identified birth parent-level education study aimed at LFUD reduction, but it did not provide information on statistical impact.

Research summary

The next step in furthering family-based education

interventions for EHDI is to ensure adherence to the principles of public health, early intervention, and family education. Examples of this work include creating materials with family education in mind, service delivery consistent with public health programs, interventions implemented within a pre-existing structure of services to reduce the impact of SDOH, and data collected past three months of age/diagnostic assessment.

Research for new insights and innovative solutions to health problems: Family education

A family education approach to LFUD is different from other methods of engagement that have been implemented. Unlike the approaches reviewed above, family education for children identified through EHDI is based on the public health model of informing, educating, and empowering people about health. The behavior change associated with taking a child in for further testing, identifying hearing levels, or enrollment in EI is intrinsically linked to the National Extension Parent Education Model (Smith, et al., 1994).

Understand

By following through with EHDI services, families can access information they need to understand their child's specific development and how hearing may impact the child's environment and family relationships. Hearing levels, when left unaddressed, can diminish the quality of communicative experiences (Carrigan & Coppola, 2017; Lederberg & Everhart, 1998). Feelings of grief have been associated with families observing and experiencing their child struggling to communicate and the social ramifications and stress of communicative isolation if these results are not expected or hoped for by the family (Feher-Prout, 1996; Kurtzer-White & Luterman, 2003). Without awareness of hearing differences, these struggles may be seen as without cause and negatively impact parental anxiety (JCIH, 2007).

The literature on parenting and families also provides supporting data on why recommendations stress avoiding delays in care, starting with a poignant statement from Russell and Guite (2019) that asserts "parents are critical pragmatic facilitators of their children's care..." Families are gatekeepers to their child both formally, in terms of consent, and informally, in terms of deciding when to ask questions, seek providers, or sustain intervention services. Therefore, the emotional needs of families must be met in EHDI initiatives. The long-term impacts of stress stemming from the identification of a child with a disability can include depression, physical illness, and stress disorders in some families that need to be met with appropriate professional referral (Brehaut et al., 2011; Zajicek-Farber, 2013). For families that experience these feelings, isolation and grief will color how they contribute and shape the child's environment (Smith et al., 1994; Steinberg, 2001).

Guide and nurture

Individuals without access to language, spoken or visual, lack the means to support the goals of nurturing or the act of guiding through formal communication. With little communication,

Smith et al. (1994)'s goals of setting limits, allowing choice, and expressing emotion are challenged. Children who do not have access to language due to hearing levels, non-identification, or lack of intervention services to support language in any modality may experience reduced communication and understanding in the parent-child dyad. This may make it challenging for a nurturing family to share goals even with gesture systems in place (Carrigan & Coppola, 2017; Lederberg & Everhart, 1998). Not pursuing identification and intervention services or having an existing accessible language can risk the child's health and safety, given the essential nature of early language access for later language and cognitive development (Mayberry, 2010). Knowledge of hearing levels allows families to take steps to ensure language access and support growth and the family's goals to guide and nurture by ensuring communication through a shared language.

Advocate

Advocacy is part of the National Extension Parent Education Model and a goal for all family education programs. It is also integrated into the third essential service of public health, given that to advocate means to be empowered in the decision-making process. When a child is LFUD, the family and the child may not access the information necessary to advocate. While informal and communication-based services are still accessible, formal care environments with specific intervention goals are another component of EHDI that are designed to support the family as a whole. Undocumented hearing levels, or a lack of education on what hearing levels mean, strip the families of the knowledge they need to find appropriate resources and build relationships with and for their child in the community. Without this information, a family cannot develop advocacy skills. Being stripped of this knowledge precludes families from pursuing attitudinal and behavioral changes in their parenting to meet their child's needs better. Education in newborn hearing screening, specifically through family education, lays a foundation for parenting skills such as communication and advocacy.

Conclusion

Assessing EHDI through the ten essential services of public health highlights areas of strength and the potential for family involvement to improve this system. Now it is time for policies around EHDI to capitalize on the current body of work around risk factors for loss to follow up. Concurrently, SDOH should also be considered as a way to effect environmental change to support healthy living (Healthy People 2020, 2019). With policies built on these principles and sufficient flexibility to allow states to meet the needs of their families, the true goal of EHDI can be reached and more children can access services that will benefit them. Currently, the drop-off in EI enrollment is not being addressed in a manner consistent with SDOHs and family-centered care (CDC, 2018b). One way to meet this need is to restructure how families are perceived within EHDI and embrace the Early Hearing Detection and Intervention Act of 2017, where families are a part of the public health workforce. Currently, families shape LFUD, are present in

every public health service as it functions with EHDI, and may contribute to one of the most common reasons for not accessing services (CDC, 2018b). These families must be educated on their new role to meet the essential service of assuring a competent workforce.

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