

# Early Hearing Detection and Intervention (EHDI) Within the Medical Home

## Implications for Policy and Practice

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The pediatric medical home is a model to provide quality health care to a child that is coordinated and overseen by a team of professionals who are grounded in family-centered practice (Cleveland Clinic, 2012; Munoz, Nelson, Bradham, Hoffman, & Houston, 2011). The medical home can be a centralized, consolidated, and comprehensive approach to address concerns for a child and can bolster the early intervention goals of Early Hearing Detection and Intervention ([EHDI]; Buchino et al., 2019; Munoz, Shisler, Moeller, & White, 2009; Munoz et al., 2011). With early access to screening information for children who are D/deaf or hard of hearing, the medical home plays a role in early diagnostic services and follow-up care that are critical to EHDI. This connection allows for discussion of how the medical home can exist and be supported within the context of existing service provision systems as a potential preemptive intervention to address the needs of children and families. By reviewing publicly accessible materials, the state of Connecticut can be used as a case study to look at various methods of medical home engagement with the outcome of supporting EHDI-based benchmarks (Connecticut Department of Public Health, 2014, 2018). At the same time, a novel means of data collection through the medical home is proposed. **Key words:** *deafness, Early Hearing Detection and Intervention, hearing, medical home, patient care team, patient-centered care*

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### WHAT IS A MEDICAL HOME?

The medical home is not a physical location. It is a method for the organization and provision of health care (Asarnow, Kolko, Miranda, & Kazak, 2017). The concept of the medical home combines medical professionalism with care coordination and is the foundation for family-centered care. In a prototypic pediatric medical home for a child who has been identified as D/deaf or hard

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of hearing, the primary care provider (PCP) is a pediatrician and there is an interdisciplinary team of related professionals, such as speech pathologists and developmental pediatricians, who follow a child and his or her family to provide managed, comprehensive, individualized care during all phases of diagnosis and treatment (Braddock, Snyder, Neubauer, & Fischer, 2012; Cleveland Clinic, 2012; Munoz, Nelson, Bradham, Hoffman, & Houston, 2011). However, it should be noted that in the reality of care provision, specifically for children with special health care needs living in rural environments, general practitioners, nurse practitioners, and physician assistants are more likely to be the individual providing care (Skinner & Slifkin, 2007).

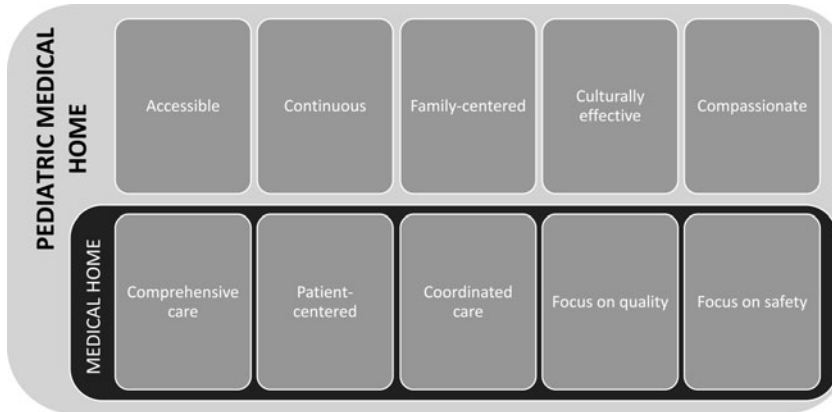
Team-based care is the model of service provision where services are developed and provided by a small workgroup with shared responsibility and collective identity related to the support of the child or family (Coufal & Woods, 2018). Within the team, various specialty areas, represented by members, utilize a collaborative process with each discipline providing context and referrals for the others. In the “Medical Home Portal” associated with a number of states, including Montana and the Rural Institute, information for providers includes directories for audiological referral, links to protocols for lost to follow-up reduction, and testimonials from providers in different professions (including a pediatrician and a social work student; Early Hearing Detection and Intervention Program, 2012; Medical Home Portal—Montana; 2020a, 2020b). For example, an audiologist working on proper left and right hearing aid insertion, according to color markers on the devices with a child who is D/deaf or hard of hearing and legally blind, can benefit from the knowledge that a pediatric ophthalmologist, another member of the team, has about that child’s access to color information.

Outside of professional medical knowledge and a team approach, the tenets of the medical home include comprehensive care, patient-centered services, coordinated care, and a fo-

cus on quality and safety (Hing, Kurtzman, Lau, Taplin, & Bindman, 2017). For example, in the population of older adults who use Medicare, access to a medical home, and therefore the continuity of care provided by the medical home, has been associated with a decrease in Medicare spending (Perry, McCall, Wensky, & Haber, 2016). Although the medical home presents as a cost-of-care initiative in adult populations, the concept itself has its early roots grounded in strategically supporting children with special health care needs and has now evolved to focus on comprehensive care for all children throughout the life course by adapting as individuals grow and develop (American Academy of Pediatrics [AAP], 2002; Asarnow et al., 2017). As such, the health care provided by the medical home not only is responsive to immediate medical needs but also has preventive and long-term applications (AAP, 2002; Asarnow et al., 2017).

When working with children with special health care needs, the interdisciplinary, team-based medical home model incorporates all aspects of the aforementioned service delivery model to provide accessible, continuous, family-centered, culturally effective, and compassionate health care (AAP, 2002; Asarnow et al., 2017; & Farel, 2007; Nickel, Cooley, McAllister, & Samson-Fang, 2003). The medical home for children with special health care needs goes beyond the basic tenets of the medical home by including uniquely family-oriented components. See Figure 1 for a graphical representation of this interconnectivity.

These additional four parameters are modifications to the standard in order to account for the unique needs of the family and the impact of entitlement services, such as early intervention and universal screening. Concerning pediatric hearing levels, it is also critical to ensure that decisions made around early intervention and language access are made proactively, based on potential need and access concerns, rather than in response to delay or deprivation (American Academy of Pediatrics EHDI Experts and Staff, 2019).



**Figure 1.** The interconnectivity between the medical home and the pediatric medical home (AAP, 2002; Asarnow et al., 2017; Nageswaran & Farel, 2007; Nickel et al., 2003).

**WHAT IS EARLY HEARING DETECTION AND INTERVENTION?**

At birth, all children in the United States have the opportunity to be screened for a number of diagnoses. At its core, newborn screenings (NBS) are a way for the health care community to identify newborns who may require additional testing or services. Boyle, Bocchini, and Kelly (2014) highlighted that this is not a test to see whether a child has a specific diagnosis; instead, it is “a complex system that includes the initial screen to identify infants with a high probability of having the condition, a follow-up diagnostic test to identify true cases, and the ongoing treatment of the condition” (p. 961).

For NBS, the Recommended Uniform Screening Panel (RUSP) consists of a core 35 diagnoses including metabolic, endocrine, hemoglobin, and other disorders that the Secretary of the Department of Health and Human Services recommends being screened for at birth across the United States (Boyle et al., 2014; Health Resources & Services Administration, 2019). From there, states can choose to expand on those to meet the needs of their population. Since the first iteration of the RUSP, hearing loss has been one of the core conditions that is screened for at birth through newborn hearing screening

([NBHS]; Grosse et al., 2017; Health Resources & Services Administration, 2019; National Institutes of Health, 2017). The incorporation of hearing loss as part of the RUSP demonstrates the importance of identifying children as D/deaf or hard of hearing early, as undiagnosed hearing levels can have a profound impact on development. Yet, as summarized by DesGeorges (2003), “deafness is different” and “[t]he journey a family goes through upon the discovery of a child with hearing loss very soon takes a departure from the typical ‘medical model’ . . .” (p. 90). With this, discussions around the impact of hearing need to consider there are multiple meanings behind hearing levels in addition to language development, such as culture and diversity (Bauman & Murray, 2009).

Birth through newborn hearing screening is a subsection of NBS that is conducted as part of the Early Hearing Detection and Intervention (EHDI), as described most recently at the federal level in the Early Hearing Detection and Intervention Act of 2017. This Act codifies the role of NBHS using broad statements of requirement for program implementation and goals where, embracing federalism, states can explicitly delineate how these requirements will be implemented in the form of guidelines and protocols. In accordance with the Act, state funding opportunities were created

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to support states to develop and monitor screening, diagnosis, and intervention services for children who are D/deaf or hard of hearing while also expanding the evidence base for recommended practices for effective models of these systems. The Act emphasizes training personnel and the importance of family-centered decision-making. With this emphasis on family-centered decision-making, state-level implementations of EHDI must take into account the unique elements of hearing levels referenced by DesGeorges (2003) and meet a wide range of needs related to the cultural implications of hearing levels.

States are required to collect EDHI data (Early Hearing Detection and Intervention Act of 2017). These data are reported to the Centers for Disease Control and Prevention (CDC) in order to improve data collection, conduct applied research on child outcomes, ensure the quality of programs, support systems in implementation, and take an aggregate look at screening, diagnosis, and intervention utilization (CDC, 2019c; Early Hearing Detection and Intervention Act of 2017). Based on state-reported data, the national prevalence for hearing levels outside of the typical range in children during 2016 was consistent with past years at 1.7 per 1,000 at the national level (CDC, 2013, 2014, 2016a, 2016b, 2019c, 2019d, 2019e). At the state and territory level, incidences ranging from 0.0 per 1,000 in Palau to 11.1 per 1,000 in the Marshall Islands were reported (CDC, 2019c, 2019d). In the state of Connecticut, the incidence was 2.2 per 1,000 children screened (CDC, 2019d). Yet broadly, hearing changes and differences, including adult-onset hearing loss, are termed “a hidden disability” and people tend to not be aware or fully informed of newborn hearing screening services (Cohen, Labadie, & Haynes, 2005; Krishnan, Lawler, & Van Hyfte, 2017; Mackenzie & Smith, 2009; Ravi, Gunjawate, Yerraguntla, Rajashekar, & Lewis, 2016).

With the wide range of perspectives, cultures, labels used, and education on EHDI, a brief discussion of these terms is warranted. Hearing loss is a common descriptor used to

define hearing sensitivity that is outside of the typical range and is the term that is used explicitly by the RUSP (American Speech-Language-Hearing Association, 2020; Health Resources & Services Administration, 2019). The use of the term “hearing levels” comes from the Joint Committee on Infant Hearing (2019) acknowledgment that this terminology may be more culturally sensitive and in the case of congenital hearing levels, there has been no hearing “loss.” The phrase “D/deaf or hard of hearing” throughout this document is implemented with the same goal for cultural sensitivity and inclusion as the Joint Committee on Infant Hearing (2019). Utilizing this phrase and the combination of capitalization and terms “deaf” and “hard of hearing” addresses the wide range of labels and cultural identities that may be encompassed by the population that is being discussed (National Association of the Deaf, 2020).

Encapsulated in the first three goals of the National Center for Hearing Assessment and Management’s (2019a), national goals for EHDI is a three-pronged approach to services that is in line with expectations in the Early Hearing Detection and Intervention Act of 2017 and recommendations from the Joint Committee on Infant Hearing (2007), consisting of hearing screening, diagnosis of hearing levels, and interventions services where appropriate (American Academy of Pediatrics, 2018). These milestones are tied to the timeline for delivering services: All newborns should receive a hearing screening by 1 month of age; for those who are referred on the basis of the results of their screening, hearing levels should be diagnosed by 3 months of age; those who are identified as D/deaf or hard of hearing should have early intervention services initiated by 6 months of age.

The first milestone is the screening of all newborns, regardless of hearing-related indicators or risk factors, by 1 month of age (White, 2019). Of the 3,852,497 births reported to Vital Records in 2016, 97.5% were screened through a state-level implementation of EHDI and 94.8% were screened by 1 month of age (CDC, 2018b, 2018d). In

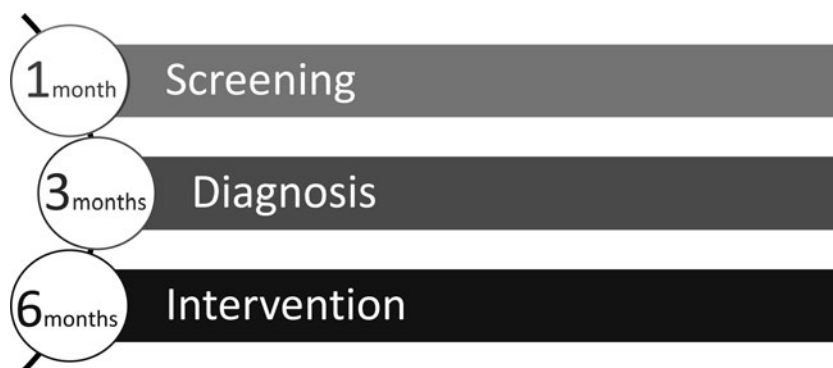
the 1990s, with the improvement and implementation of otoacoustic emissions and auditory brainstem response (ABR) testing, screening protocols with improved diagnostic value and economic administration became possible (White, 2019). Auditory brainstem response testing is a common protocol that uses physiological responses to sounds in order to estimate hearing levels without the need for subjective behavioral responses. An ABR can provide diagnostic information around hearing levels, including type and degree (Purdy & Kelly, 2014). For 50%–60% of infants, a genetic etiology for present hearing levels can be identified (CDC, 2018a). However, etiology is not directly discernible from hearing screening or audiometric assessment alone.

These screenings lay the foundation for the second milestone of EHDI that children who are referred on their NBS receive a diagnostic evaluation and diagnosis if indicated by 3 months of age (White, 2019). If a child’s NBHS results indicate the need for further testing to determine hearing levels, both the child and the family are referred to receive diagnostic assessments that may occur during a separate appointment and potentially at another facility entirely. At this stage of the family’s journey within EHDI, it is possible to track changes in the age of identification that occur during periods where EHDI is enacted to direct children who are D/deaf or hard of hearing to diagnostic services. White (2019) presents a

chart looking at studies from the 1980s into the 21st century reporting on the mean age of identification for children who are D/deaf or hard of hearing. From 1987 to 2013, the mean age of diagnosis dropped from its peak at 35 to 2 months (White, 2019).

Diagnosing children at earlier ages leads directly into the third milestone of EHDI that children who are D/deaf or hard of hearing receive early intervention services by 6 months of age (White, 2019). In 2016, 67.3% of all children who were identified as D/deaf or hard of hearing were enrolled in early intervention services in their state by 6 months of age (CDC, 2018c). This statistic equates to more than half of the children identified as D/deaf or hard of hearing in 2016 enrolling in early intervention programs over a year before their 1987 counterparts would even be identified at, between 19 and 35 months of age (White, 2019). These early months can be used in services to support language development, regardless of modality, and this is regarded as critical for improving the outcomes of these children (Munoz et al., 2011). See Figure 2 for a visual representation of the timeline for these services.

The next three national goals for EHDI transition from service delivery milestones and into systems of care. The fourth goals centers on addressing the needs of children with late-onset, progressive, or acquired hearing loss (National Center for Hearing Assessment and



**Figure 2.** A visual timeline of services related to newborn hearing detection and intervention (AAP, 2018; Cockfield, Garner, & Borders, 2012; Joint Committee on Infant Hearing, 2007).

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Management, 2019a). For these children with late-onset or progressive hearing loss, performance objectives call for identification by all providers of individuals with risk factors and the monitoring of these children at the state level (National Center for Hearing Assessment and Management, 2019a).

For children with acquired hearing loss, a state-level identification program is requisite to move children through the identification and intervention procedures that meet their needs (National Center for Hearing Assessment and Management, 2019a). Of specific relevance for this article are goals five and six, which are centered around the support of a medical home and data tracking and surveillance to address lost to follow-up (National Center for Hearing Assessment and Management, 2019a).

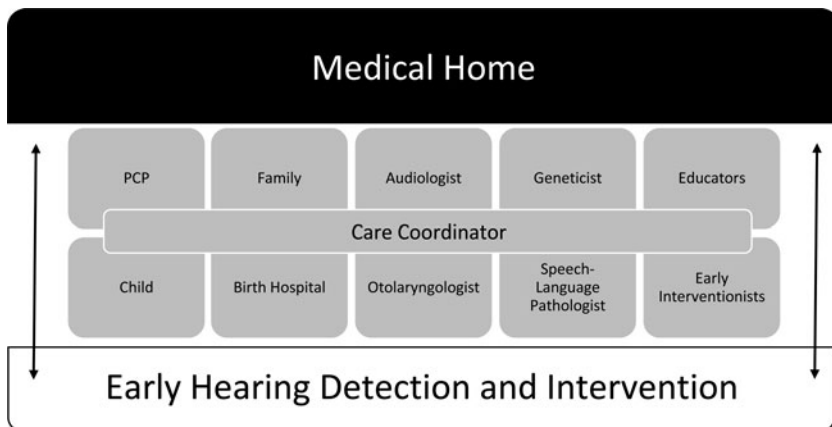
**HOW CAN THE MEDICAL HOME BE INTEGRATED WITH AND BE SUPPORTIVE OF EHDI?**

For children who are diagnosed as D/deaf or hard of hearing, the key members of the care team can include birth hospitals, families, the PCP, audiologists, otolaryngologists, geneticists, speech-language pathologists, educators, early interventionists, and care coordinators all within the medical

home (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007). Other members of the care team who are usually brought in and coordinated by the medical home to meet the specific needs of children with co-occurring diagnoses include ophthalmologists, developmental pediatricians, neurologists, cardiologists, and nephrologists (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007).

With this many components to the EHDI system, the idea of teaming among providers and families co-occurs with the implementation of the medical home, given the shared need for collaboration among these individuals for children who are D/deaf or hard of hearing. This need and overlap are consistent with the fifth national goal of EHDI, to ensure medical homes for all children identified. See Figure 3 to observe overlap in service providers within EHDI and the medical home.

This care team begins assembling at the time of referral when the birth hospital (or transfer hospital) shares the screening results with the family, the PCP, and the state department that implements EHDI. This step is critical, given that one of the performance objectives for EHDI programs includes the documentation of a child’s PCP and documentation that information about NBS has been shared



**Figure 3.** Potentially shared service providers under a medical home and Early Hearing Detection and Intervention. PCP = primary care provider. (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007).

with this provider (National Center for Hearing Assessment and Management, 2019a). Yet, when assessments and screenings, including hearing screenings, are performed external to the PCP, there can be a communication breakdown where results are not provided back to the PCP and the medical home. This lack of communication can limit the PCP's understanding of the need to refer children who are D/deaf or hard of hearing to specialties (such as genetics and otolaryngology; Munoz, Shisler, Moeller, & White, 2009; Munoz et al., 2011).

Challenges in communication are further exacerbated by the lack of knowledge PCPs have reported around hearing-related topics such as hearing aids and cochlear implants (Munoz et al., 2009). Lack of knowledge severely impacts PCPs' ability to follow through with their duty to link families and children to services and is a factor that is used in the evaluation of the medical home for children who are D/deaf or hard of hearing (Bright Futures, 2019; National Center for Hearing Assessment and Management, 2019a). Among this list is a performance indicator for the National EHDI goal of establishing a medical home for every child who is identified as D/deaf or hard of hearing, which is "[d]ocumentation in each family plan or IFSP of collaboration between the early intervention systems and the medical home" (National Center for Hearing Assessment and Management, 2019a). This required documentation supports using the medical home as a means of reducing lost to follow-up by ensuring that the medical home is explicitly tied to early intervention services.

Generally, the birth hospital has the responsibility of ensuring that the state-level agency responsible for the administration of EHDI and the PCP receives the screening results (Connecticut Department of Public Health, 2014; Rhode Island Department of Health, 2014; S. Stone, personal communication, April 24, 2019). These results are then provided to the medical home or PCP. It should be noted that the procedure for the notification of the state-level agency and how

that information is shared with a medical home or PCP may vary from state to state with specific forms/flow charts (e.g., Iowa, Georgia, and Rhode Island), personnel (e.g., Georgia), or more general requirements around sharing these data through letters, newborn, or discharge summaries (e.g., Pennsylvania, Virginia, and Connecticut); however, they all share the same requirement for the sharing of screening results (Connecticut Department of Public Health, 2014; Early Hearing Detection and Intervention Act of 2017; Georgia Department of Public Health, 2013; Iowa's Early Hearing Detection & Intervention System, 2008; Joint Committee on Infant Hearing, 2007; Pennsylvania Department of Health, 2013; Rhode Island Department of Health, 2014; Virginia Department of Health, 2011; S. Stone, personal communication, April, 24, 2019).

For example, specifically in the state of Connecticut's guidelines for EHDI, a medical home should be established when a child is referred for his or her NBHS. The medical home is established by sharing results among the individuals who will comprise the medical home (Connecticut Department of Public Health, 2014). Per state guidance, it is encouraged that the appointment for the child to undergo diagnostic evaluation by an audiologist be scheduled prior to birthing hospital discharge (Connecticut Department of Public Health, 2014). This can be done by the birthing hospital or, once the medical home is established and the role of EDHI is assumed within that care coordination, done so via referral by the PCP. The role the medical home plays in coordination of care is highlighted when the need for specialists to be a part of the care team is present. Of the roughly 50% of children with a genetic etiology for their hearing levels, one third have a syndromic diagnosis (Ridley, 2009). Compounding this with the fact that 30%–40% of all children who are D/deaf or hard of hearing will present with additional developmental delays or disabilities, there is usually a need to have multiple health care specialists and providers on a care team managed in a medical home to appropriately

address the individual needs of the child. For example, an ophthalmologist should be part of the medical home for a child with a diagnosis of Usher's syndrome as it is associated with visual and auditory system differences (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007).

It is the medical home that can follow children and their families throughout the life course and can use referrals to specialists to meet the child's individual needs. Having a medical home that includes the PCP supports the reinforcement of early intervention, diagnostic direction, and communication option messages that can come from all members of the team (American Academy of Pediatrics EHDI Experts and Staff, 2019). When assessing communication between team members, Munoz et al. (2011) found that collaboration between providers is considered one element that strengthens the application of the medical home in EHDI. No one provider can address all areas of need within the family or child. Given the complex nature of pediatric hearing and the number of families served by EHDI, the team-based medical home is requisite to quality health care.

State policies can reinforce the role of the PCP within the medical home. Although not explicitly tied to EHDI implementation, of the 19 states awarded grants for State Disability and Health programs from the CDC, eight refer to medical homes explicitly on their online newborn hearing screening page within the office or department that manages the implementation of EHDI (CDC, 2019b; Iowa Department of Public Health, 2020; Kansas Department of Health and Environment, 2019; Maryland Department of Health, n.d.; Michigan Department of Health & Human Services, 2020; Montana Department of Public Health and Human Services, n.d.; Ohio Department of Health, 2019; Oregon Health Authority, n.d.). Connecticut makes this reference on its web page as well, citing that all provider documents have been "geared toward . . . Medical Home Initiatives for Children and Youth with Special Healthcare Needs networks . . ." (Connecticut Department of Public Health, 2020).

However, across these different states and implementations, the degree that the concept of medical home is included varies (Iowa Department of Public Health, 2020; Kansas Department of Health and Environment, 2019; Maryland Department of Health, n.d.; Michigan Department of Health & Human Services, 2020; Montana Department of Public Health and Human Services, n.d.; Ohio Department of Health, 2019; Oregon Health Authority, n.d.).

Some states have strong statements on the need/inclusion of medical homes, such as the state of Michigan highlights in its affirmation that "[t]he primary care provider (PCP) directs and coordinates the evaluation and referral process within the child's medical home," followed by a list of steps and links to referral signs and risk factors (Michigan Department of Health & Human Services, 2020). Other states also provide explicit practice guidelines/learning opportunities around the integration of the medical home with EHDI such as Montana where providers are linked to the Montana Medical Home Portal with access to practice guidelines, service provision algorithms, and educational resources on hearing and other newborn diagnoses (Montana Department of Public Health and Human Services, n.d.).

State-level policies, recommendations, and guidance documents support the Joint Committee on Infant Hearing's (2007) position statement that encourages birth hospitals to also gather information about a child's PCP at the time of the screening in order to share results and thus reinforce the need for PCP referrals to audiology (Connecticut Department of Public Health, 2014). This sentiment has been echoed by EHDI coordinators. As a group, EHDI coordinators are individuals at the state level who are responsible for the oversight, implementation, and management of grants, laws, and rules around their state's specific implementation of EHDI (National Center for Hearing Assessment and Management, 2019b). Coordinators have reported that involvement of the PCP and other related fields within the administration of



EHDI bolsters the involvement of the medical home from a policy perspective (Munoz et al., 2011).

The medical home is vital for the coordination of services for these children and families. As such, it occupies a position as the central hub for information about the child's health, including hearing. There are various approaches to strengthening the integration of EHDI with the medical home. In this discussion, two strategies that have been implemented in the state of Connecticut are discussed along with one potential extension to further the medical home.

### **FAMILY INCLUSION IN THE MEDICAL HOME THROUGH INFORMATION SHARING AND PARTICIPATION**

Families of children who are D/deaf or hard of hearing play a critical role in service access. Under the current structure of Part C of the Individuals with Disabilities Education Act (IDEA), the Individualized Family Service Plan reaffirms both the inherent connection between families and services and the need for care outside of the patient-centered realm (Individuals with Disabilities Education Act of 2004). Family members are members of the team and actively engaged in the medical home through family-centered care. Within EHDI, there is room for state implementation to learn from the IDEA and Section 504 of the Vocational Rehabilitation Act in terms of family engagement. IDEA and Section 504 have procedures for parents and caregivers to provide input into the planning for their child (request reevaluations or requirements that they are present for planning meetings) in a way that is not explicitly laid out to the same degree in the current federal EHDI guidance (Connecticut Office of Early Childhood, 2016; Connecticut State Department of Education, 2007; Early Hearing Detection and Intervention Act of 2017; Office for Civil Rights, 2018; Rehabilitation Act of 1973; Wells, 2012).

The explicit requirement to include parents and caregivers in the development of an Individualized Education Program (IEP) or

504 plan per federal legislation allows the family to be actively involved and provide insight. Broadly, both IEPs and 504 plans are developed with input from a team that includes the family and delineates the services/accommodations that a child utilizes to access his or her education (Connecticut State Department of Education, 2007; Office for Civil Rights, 2018;). Similarly, in Connecticut, the Family Plan of Care for Infants is a document that can be used voluntarily by parents and providers (Connecticut Department of Public Health, 2018). This document is available for parents and providers to print off the Internet on the Connecticut Department of Health web page (Connecticut Department of Public Health, 2018). It mimics IEPs and 504 plans in terms of family involvement and creates a space for families to note the relevant components of the medical home such as service providers, interventions, and needs (Connecticut Department of Public Health, 2018). This type of document, maintained by or with the family, may provide an opportunity to have consistent messaging around a child's diagnostic status, plans for care, and referrals and can help overcome the communication and education challenges that have been identified by Munoz et al. (2009, 2011) for PCPs when it comes to referral of children and families. However, the major difference is that although the Family Plan of Care for Infants is a recommended tool, it is not required to be used during the process of screening or diagnosis. Because EHDI is the first diagnosis and support program related to hearing for families who will potentially utilize IEPs or 504 plans in the future for their child, continuity of parental involvement across both educational and health systems may be beneficial.

To monitor and assess the extent to which states incorporate EDHI recommendations and expectations for service provision, at the state level, policy makers need to acknowledge their role in the lives of families as the first source of information around their child's hearing and the role that language access plays in development. Families may benefit from

connections to support services and community programs. Such services can include parent-to-parent networks, support groups, and educational programs at local, state, regional, and national levels. Research and programs need to be directed toward the explicit support and empowerment of families during this process and the inclusion of parent support and parent-to-parent representation in the medical home as a part of the care team.

### **ENHANCING PARTICIPATION OF PRIMARY CARE PROVIDERS IN THE MEDICAL HOME THROUGH PROVIDER EDUCATION**

The medical home is an informational hub that can contribute to meeting EHDI screening, diagnostics, and intervention milestones, along with data collection needs. Children need to be appropriately referred to the specialty groups that meet their needs, and physicians, both PCPs and specialists, must be made aware that these co-occurring needs can and do exist in pediatric hearing. From these referrals, the appropriate transition to intervention services may be possible for both the child and the family. This furthering in the involvement of the medical home with EHDI is predicated on PCPs and other members of the medical home having a working knowledge of EHDI and pediatric hearing levels. However, for medical home involvement to be achieved, the gaps in physician training and the resulting educational needs of PCPs must be addressed. From there, specialists can be connected to educational resources and professional development opportunities within the context of the medical home.

An approach that is being implemented in many states, including Connecticut, is AAP's Chapter Champions who serve as liaisons between pediatrician PCPs and the implementation of EHDI (AAP, 2017; Munoz et al., 2009, 2011). Along with early identification of the PCP for communication purposes, the use of Chapter Champions has been perceived by state EHDI coordinators as a means of strengthening the role of the medical home

and EHDI as a whole (Munoz et al., 2011). The role of Chapter Champions is educational and connective in nature (AAP, 2020; Munoz et al., 2009). Chapter Champions are responsible for "educating fellow physicians and other stakeholders through grand rounds, newsletters, and personal contact" while working to influence state-level policy (AAP, 2020; Munoz et al., 2009). The information presented to providers who are part of medical homes needs to be succinct and follow the foundational topics of common missteps in EHDI, such as basic audiological knowledge, hearing management, and outcomes for these children and families (Munoz et al., 2009; Stewart & Bentley, 2019). Although this program is implemented by a pediatrician-based organization, statements around "other stakeholders" imply the potential for branching out and including nonpediatrician care providers.

One possible extension of this educational model that has been implemented is just-in-time education for providers. This approach has been implemented by the EHDI council of Kentucky as a way of providing directed education on pediatric hearing. When a PCP is part of a medical home for a child identified as D/deaf or hard of hearing or having risk factors around hearing levels, information is sent directly to the provider specifically about hearing (Buchino et al., 2019). The state EHDI team sends physicians just-in-time packets on hearing with guidelines for assessment in these populations (Buchino et al., 2019). This approach may be further applicable, given that it comes from a credible source within the provider's state of practice and is not a formal class or meeting, as those can be challenging to access, given the time restraints of being a practicing physician (Munoz et al., 2009).

At the same time, team members of a medical home need to be cognizant of how each provider, within the context of the group, can meet needs associated with decreased access to services in the form of lost to follow-up and lost to intervention. Recent work in South Africa implemented qualitative interviewing to assess the factors that impact decisions to

follow up for newborn hearing services (Kanji & Krabbenhoft, 2018). Parents in this study simultaneously reported that having communication with the audiologist supported them accessing the service while having to travel for appointments in various buildings/locations hindered them (Kanji & Krabbenhoft, 2018). The medical home is already a center for communication and can further capitalize on this strength by working to create location-based networks where services can be accessed as a group or potentially in the same day/area. This impact may further the support that medical homes provide to rural families (Cunningham et al., 2017). Globally, the impact of an EHDI-inclusive pediatric medical home bolsters the goal of EHDI service delivery milestones through the support of continued collaboration between professionals and ultimately appropriate connections to services and providers to ensure needs are met in a family-centered and culturally respectful manner.

### **CENTRALIZATION OF DATA COLLECTION PROTOCOL FOR THE FUTURE**

The federal EHDI system and state-based implementations, taken together as a public health initiative, continue to move toward meeting the screening and diagnosis milestones for children who are D/deaf or hard of hearing. However, these gains in screening and identification have not translated into these children universally enrolling into early intervention services as currently measured. The incorporation of EDHI into the medical home can support the streamlining of data collection and bolster the early intervention milestone of EHDI and national goals around medical home maintenance and data tracking.

Currently, accessing intervention services after diagnosis of hearing levels is calculated by determining the reported number of children who have enrolled in intervention programs provided by Part C of the IDEA and non-Part C services. However, this information is incomplete and does not provide insight into

where children and families are lost in the transition into intervention services. Having a comprehensive indicator for intervention services that delineates specific points of entry into early intervention (e.g., Part C, non-Part C insurance-based, private pay fee for service, community organizations, and informal supports) may help determine where services are being accessed and which services are or are not being utilized to meet the needs of children and families.

Although reported at the national level as enrollment in Part C and non-Part C early intervention enrollments, this may not be representative of the full breadth of data. The services that are accounted for as non-part C in current publications are not delineated at the national level and may vary depending on the state's data collection protocol (CDC, 2018e; National Center on Birth Defects and Developmental Disabilities, personal communication, June 13, 2019, and, July 5, 2019). This variability means that all states may not be reporting intervention data based on the same definition of intervention outside of Part C enrollment. Although this may be measuring some children who pursue interventions based on hearing levels, it may not universally account for those who access private services and are not reporting those who utilize informal supports across state lines. These informal supports may include parent-to-parent organizations or culturally Deaf families that have the infrastructure needed to provide communication access for a child. The current method of noting intervention services could be artificially inflating lost to intervention values and further complicate attempts to improve access and utilization of intervention services.

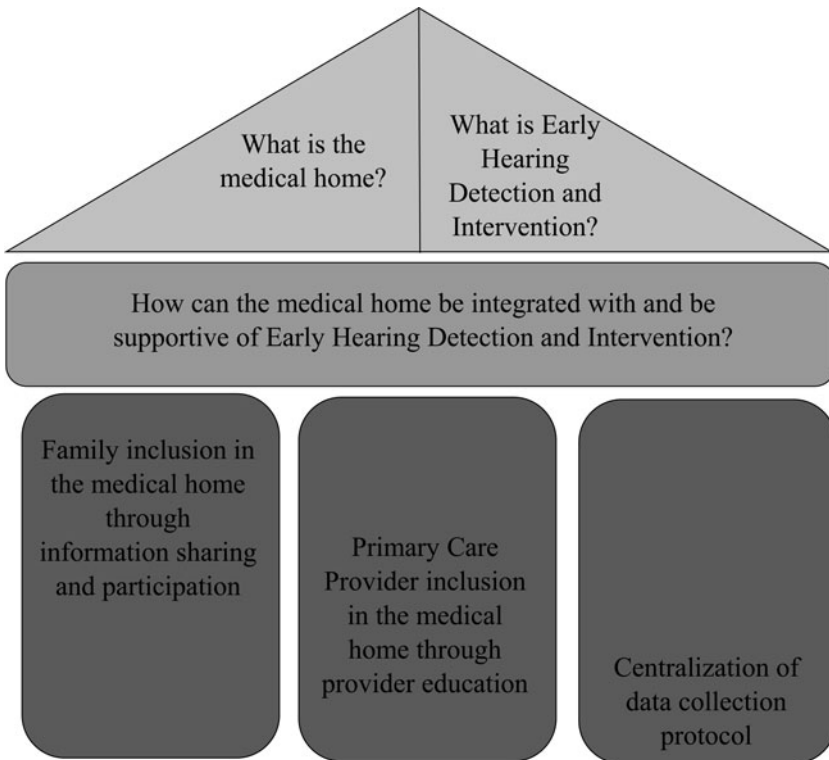
Developing, improving, and supporting data collection procedures to accurately capture all early intervention providers in the state (publicly funded, privately funded, and informal) would be logistically challenging. However, this could be a more comprehensive indicator of actual intervention service utilization and serve to support the continual monitoring of children in an effort to identify those who may be lost to follow up in

the EHDI system. One approach to address the need for streamlined data collection and capturing all early intervention access points would be to move from the current practice to a centralized model of care delivery where the medical home, as the hub for all services, is solely responsible for the input of data into records system(s). The medical home, regardless of the clinical background of the PCP, has access to all relevant providers, should already be following these children, and has a scope of practice that is consistent with data collection (Joint Committee on Infant Hearing, 2007).

The medical home provides services regardless of funding avenue, cultural identity, or specific needs to be met. Questions around development, screenings, and intervention services are consistent with case history expectations as laid out by the CDC (2019a), the AAP's Bright Futures (2019) program,

and the sharing of information that should be occurring within a team regarding services provided. This is the transition of reporting requirements from multiple individuals across every child to the medical home. Thus, this type of reporting does not fundamentally change the clinical encounter of any provider and it intrinsically supports the fifth and sixth goals of EHDI by essentially making a medical home, with the connection to other services and coordinated care, mandated by way of improving data tracking and lost to follow-up.

Centralizing the point of data reporting to the medical home can lead to redundancy in reported information (e.g., a speech-language pathologist sending his or her session notes to the PCP indicating intervention is being pursued and a parent reporting to the PCP that he or she is receiving intervention services within an appointment). This



**Figure 4.** Outline of article and three different approaches to medical home integration with Early Hearing Detection and Intervention.

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redundancy supports the accuracy of data reporting through the use of corroborating sources and limits the impact of parental report while recognizing the wide variety of services and interventions available to families through public and private programs.

## IMPLICATIONS

The implementation of EHDI as part of medical homes can be mutually beneficial. Medical homes are valuable as points of data collection and service coordination for EHDI. Information from EHDI, including screening results, supports the medical home in developing a comprehensive understanding of the unique needs of each child and family and a plan of care to address those needs and others. In addition, EHDI can provide vital hearing-related educational resources to ultimately provide better care to the child within the medical home. This educational resource role of EDHI within the medical home can be further strengthened by the continuing educational opportunities hosted by states, national conferences, and technical assis-

tance agreements. Furthermore, PCPs may not recognize the value of these educational opportunities or, due to their schedules, have the time to access them until there is a need that calls for EDHI-related expertise (Munoz et al., 2009). Based on online state-level publically accessible policies and materials from Connecticut, there is the possibility that policies and initiatives to foster the medical home have been missed or overlooked in this document. However, by reviewing publically accessible materials, this review is poised to operate with similar information readily available to providers and families (Figure 4).

When examining medical home supports, the inclusion of the medical home through information sharing, family participation, and provider education is a step toward full integration with the goal of meeting EHDI-based service provision milestones. The novel approach presented here is consistent with current moves regarding the inclusion of the medical home in EHDI. As support and recognized need for the medical home grow, EHDI is poised to benefit from continued systems improvement.

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