Chapter 28
Marketing EHDI

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In thinking about what makes a successful Early Hearing Detection and Intervention (EHDI) program, marketing is probably not the first thing that comes to mind. However, effective marketing can be a powerful tool in helping an EHDI program reach as many providers and families as possible. Busy professionals may not be aware of the resources available through a community EHDI program, and using some basic marketing strategies can make a real difference. Important marketing concepts include:

- Understanding the provider perspective.
- Getting "buy-in."
- Developing and maintaining personal relationships.
- Developing slogans and branding.

For EHDI stakeholders looking to improve the success of their program, even taking advantage of one or two of these strategies may make a real difference in improving visibility and making meaningful connections.

Understanding the Provider Perspective

Establishing relationships with medical home (primary care) providers in your community is essential. In order to engage your medical home provider as an ally, it is critical to understand how he/she functions on any given business day, and what kinds of time and work pressures are a factor. It is certainly not going to be an effective start to an EHDI partnership if you show up in a provider's office unannounced during the busiest clinical part of the workday!

Medscape is a popular web-based resource for physicians and health professionals and provides resources, such as peer-reviewed journal articles, activities for continuing medical education credit, the publication database from the National Library of Medicine, up-to-date medical news, and medication information. Medscape conducts an annual Physician Compensation Survey not only to learn more about physician earnings but
Parents can also be a valuable partner when trying to reach out to others. They have lived through the experience for which you want to create awareness.

In 2014, more than 24,000 physicians from 25 specialty areas responded to the survey. The results included the following data specifically concerning primary care physicians—who as medical home providers play a significant role in EHDI success:

- Fifty percent of primary care providers reported that on average they have less than 16 minutes per patient visit.
- Up to 35% of physicians reported needing more than 10 hours a week to complete paperwork and other nonpatient care administrative activities.
- Pediatricians are financially the third lowest compensated physicians among all reporting specialties.

The study data supported what most of us already are very much aware—that primary care physicians are extremely busy people in a very challenging field! Even lunch, which is often the only “break” in a physician’s day, is often treated as a work catch-up period and very well may not be a full hour. One patient emergency can derail a provider schedule for the entire day. Having an appreciation for what physicians face in their work and acknowledging their time limitations can be very meaningful in supporting a strong relationship in EHDI.

There are some small things that can be done that can go a very long way in establishing a relationship with a busy healthcare provider. These are merely suggestions, and some strategies may work better with some providers. Table 1 lists some ideas to consider.

### Getting Buy-In

It’s not who you know; it’s who they know. Keep this in mind when you are networking and building your EHDI program. Look at the key players in your state who interact with children who have a hearing loss.

Obvious targets include:
- Audiologists
- Early interventionists
- Pediatricians
- Chapter champions (pediatrician representatives for the American Academy of Pediatrics [AAP] in EHDI)
- Birthing hospitals
- Parents

Consider those “outside of the box”:
- Parents-to-be
- Parents of school-age children
- WIC (Women, Infants, and Children) offices
- Early Head Start programs
- Parents as Teachers
- Midwives
- Perinatal care providers
- Perinatal network or hospital administrators
- Community health departments

There are two obvious targets—chapter champions and parents—who could potentially have the largest impact when creating buy-in of your program. A roster of current chapter champion pediatricians can be found at [http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/EHDIChapterChampionsRoster.pdf](http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/EHDIChapterChampionsRoster.pdf)

Make the most of your relationship with your chapter champion by sitting down with him or her and creating a plan. By working together to see what is feasible and what connections are already in place, everyone will have a clear vision of the tasks at hand and thus can facilitate more buy-in for your EHDI program.

Parents can also be a valuable partner when trying to reach out to others. They have lived through the experience for which you want to create awareness. Many parents want to see system improvements and have an attitude that they want to pay it forward. In Illinois, the EHDI program created partnerships with parent programs, such as the state chapter of Hands & Voices, to train parents to share EHDI resources and materials in person with local contacts.
### Table 1

**Ideas to Help Establish a Relationship with a Busy Healthcare Provider**

<table>
<thead>
<tr>
<th>Going and seeing a provider in his/her office.</th>
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<tr>
<td>It is usually unrealistic for a provider to be able to leave the office even for a brief meeting, given that travel time has to be factored in to an already short break time. Meeting providers for a brief introductory visit in their offices can make a tremendous difference in being able to access them during their busy work days.</td>
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<tr>
<th>Seeing a provider at a scheduled time that is convenient to them.</th>
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<tr>
<td>While the “drop-in” visit can be effective, some providers are significantly maxed out in their schedules and would potentially view an unscheduled visit as a real imposition. Consider speaking to the provider’s scheduler and finding a time that is convenient to their office. Sometimes that is over the lunch break, but just as often it is not. Some providers schedule blocks of time on specific days for nonclinical activities, and a visit from you may fit into that time very nicely.</td>
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<th>Bringing information directly to providers and staff.</th>
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<tr>
<td>Offices constantly are receiving huge quantities of information, such as fliers, mailers, informational brochures, DVDs, and email alerts. While your EHDI program, for example, may have a wonderful informational brochure, if it is simply dropped anonymously in the mail to an office, there is a fair chance that a provider may only briefly look at it, if at all. Bringing important information directly to providers and talking about it for a few minutes makes the information personal and gives it meaning and context in relation to your program. Resist the urge to bring large quantities of brochures and fliers on your first visit. Instead, bring a few samples of your most meaningful information, and find out what the providers would be interested in having more of in their office. You can always send out a mailing of requested information later on, and it will have a much better chance of ending up in a waiting room or on a provider’s desk instead of in the trash!</td>
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<th>Consider presenting at medical school Grand Rounds.</th>
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<td>If you are comfortable with public speaking and looking for a platform that will get you the most “bang for your buck,” look into presenting at a medical school pediatric Grand Rounds. Academic training programs have weekly Grand Rounds, which are a formal lecture that is traditionally attended by the entire department. It is a great way to access a large number of providers at one time. Additionally, pediatric residents and students rotating through pediatrics also usually attend Grand Rounds, so it is an excellent opportunity to reach providers-in-training with current EHDI practices that are clinically relevant. Many academic hospitals post their Grand Rounds information online, so a brief Internet search may be an easy way to obtain contact information for the medical program near you.</td>
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*Photo courtesy of Sound Beginnings/Utah State University*
The goals of this partnership were to create EHDI awareness, educate parents about newborn hearing screening, and reach professionals in a nonthreatening way. By nonthreatening, we mean that parents are respected but not viewed in the same way as someone from public health. Parents can have just as much of an impact, because they speak from the heart, which creates a longer-lasting impression and one that hopefully will inspire actions to be taken rather than forcing action to occur. In the first wave of this partnership, 50 contacts were made to birthing classes, pediatricians, WIC offices, OB/GYN offices, and doulas, to name a few. The responses from the providers were phenomenal—from follow-up phone calls requesting additional materials to implementation about the screening process into parent education classes.

Keep in mind that not every contact has to be made in person. EHDI programs have successfully communicated through list-serves, web-based trainings, and conference calls. Some list-serves, such as Wiggio, allow you to share and edit files; manage a group calendar; poll your group; post links; set up conference calls; chat online; and send mass text, voice, and email messages to your group members. Through such list-serves, you can keep separate lists for different groups. This can help you send targeted messages and keep everyone informed and involved.

Something that has worked quite well for the Illinois EHDI program is their use of web-based trainings. These trainings allow you to experience it once and then share over and over again. The most success has been found in trainings done with birthing hospitals. Trying to get everyone together for an in-person presentation or training may be difficult when shifts vary. Through webinars, staff have been able to share the recordings with everyone on the team, and the employees review it on their own time.

They can complete an online survey after they have watched the recording, which allows you to easily measure the success of the teaching and ensure that they are properly qualified to perform their job.

In Illinois, their parent program, “Guide By Your Side,” offers free “conference calls for all” almost every month. The call starts by sharing events and opportunities that are happening throughout the state and is then followed by a specific topic presented.

Table 2

“Outside of the Box” Providers

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>Description</th>
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<tr>
<td>Parents-to-Be</td>
<td>How do you reach parents-to-be? Some EHDI programs have exhibited at community baby showers, baby fairs, and also had their information distributed at parent education classes.</td>
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<tr>
<td>Early Head Start and Parents as Teachers</td>
<td>The beauty of Early Head Start programs is that they know their community and are located within the community, which makes them easily accessible and utilized by families. Early Head Start programs also understand the issues families are facing and have ideas of how EHDI programs can reach those families and overcome the hurdles that often create loss to follow-up. In addition, EHDI programs have shared that Early Head Start and Parents as Teachers programs are eager to collaborate with EHDI and are willing to brainstorm, provide solutions, and follow through on the collaboration.</td>
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<tr>
<td>Preinatal Care Providers</td>
<td>Perinatal care providers can help pre-teach parents-to-be and new parents, possibly lowering loss to follow-up. Again, use parents to reach out to these providers. The parents live in the neighborhoods these providers serve and count on for referrals. If the perinatal providers prove difficult to connect with, consider reaching out to the perinatal network or hospital administrators. These individuals are often the “keys to the car” and will help facilitate relationships and action plans.</td>
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Lack of timely diagnosis and support services can lead to significant life-long difficulties with cognitive, social, and emotional development. Tools that bring attention to these issues and are helpful to providers in their everyday practice can be particularly effective.

Providers are very busy and have many important issues competing for their attention. There are several tools that can be used to highlight clinical aspects of EHDI that warrant provider attention. Many professionals are not completely aware of the fact that infants born with hearing loss can experience a “developmental emergency.” That lack of timely diagnosis and support services can lead to significant life-long difficulties with cognitive, social, and emotional development. Tools that bring attention to these issues and are helpful to providers in their everyday practice can be particularly effective. Some examples of readily available tools are shown in Table 3.

Developing and Maintaining Personal Relationships

Establishing personal relationships with EHDI stakeholders is critical for ongoing success in the community. Providers are often overwhelmed with the amount of “anonymous” material they receive from drug companies, vendors, medical organizations, and agencies. Developing personal relationships with stakeholders (and their support staff) can sometimes mean the difference between being heard and being overlooked. Some foundations for developing strong relationships with providers:

- **Ask what providers need in their practice.** Providers do not operate by a universal set of rules. Each provider has very unique preferences and needs in terms of running a successful practice. By asking providers what is most helpful for them in their practice, you can provide them with useful information and help them feel supported by community resources at the same time. You will also use your materials most effectively and avoid wasting them where they are not needed.

- **Diligent follow-up.** Providers have often commented that they actually appreciate reminders over time regarding best practices. It is easy to give a one-time presentation or send materials to a provider once and then leave it at that. What eventually happens is that there is good compliance in the short-term, and then practices can fall off as more time elapses from the initial education. By planning to revisit providers at an interval and time that is desirable to everyone involved, information can be revisited, and updated information can be provided as it becomes available. You can also get good feedback from providers on return visits regarding if there have been any changes in their practice or if they have seen any differences in their outcomes with their screenings and diagnoses.

Other tools have been created and utilized by EHDI programs to serve as a reminder of EHDI action items or to support the relationships they have built. Some of these tools are included in Table 4.

Developing Slogans and Branding

Research shows that first impressions form within 2 minutes, become “locked in” within 4, and that it can take six to eight subsequent interactions to overcome a bad first impression. Since first impressions can have such a profound impact on whether a relationship is established, it’s important to look at how providers and families perceive you that “first time.” The first impression that you typically make on families is most likely through a brochure or poster.
Checklists are tools that medical home providers and families can use together to increase shared knowledge and support a “team” approach for caring for infants and children who are deaf or hard of hearing. Checklists are excellent ways to keep track of appointments, specialist providers, and recommended EHDI standards of care. The American Academy of Pediatrics (AAP), in collaboration with the National Center for Hearing Assessment and Management (NCHAM) and the National Association of Pediatric Nurse practitioners, has one such checklist designed for medical home providers who are taking care of deaf and hard-of-hearing patients (see Figure 1). It can be downloaded at http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/Algorithm2_2010.pdf.

NCHAM has compiled statistics that show the incidence of hearing loss compared with other common conditions in the newborn period. By far, the incidence of congenital hearing loss is the most common. Providers are often surprised to learn that at 3 in 1,000 live births, hearing loss is not a “low incidence” condition but is the most common condition of the newborn period. When providers become aware that the incidence is so common in their own practice, they are often motivated to increase their vigilance in monitoring and following EHDI guidelines. NCHAM has produced a presentation slide (see Figure 2) that can be shared with providers that directly compares congenital hearing loss with other common conditions, such as Down syndrome and cleft lip. The slide can also be downloaded as part of a Universal Newborn Hearing Screening update presentation at www.babyhearing.org/Audiologists/presentation/NHS_update_09.ppt.

State-level statistics can be very powerful in enlisting providers to invest in better EHDI practices. Providers are often not aware of the lost to follow-up/documentation issues occurring in their deaf and hard-of-hearing patient population. Honest state statistics can be very motivating in terms of more aggressive monitoring and compliance with EHDI guidelines. State EHDI coordinators usually have access to state statistics regarding EHDI tracking and follow-up. A list of current state EHDI coordinators can be found on the NCHAM website at www.infanthearing.org/status/cnhs.html.

**Table 3**

**Examples of Readily Available Tools for Providers**

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<th>Checklists</th>
<th>Incidence Graph</th>
<th>State Statistics</th>
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**EHDI Guidelines for Medical Home Providers**

The AAP has published a flowchart for the 1-3-6 guidelines as they apply specifically to medical home providers. It includes the screening, diagnosis, and intervention guidelines, but also the Joint Committee on Infant Hearing high-risk indicators for close monitoring and follow-up. This can be extremely helpful for providers in terms of increasing vigilance for both newborn hearing screening follow-up and monitoring of children who are at increased risk for developing late-onset hearing loss (see Figure 3). The flowchart can be downloaded at http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/Algorithm1_2010.pdf.

*Photo courtesy of Centers for Disease Control and Prevention*
Through NICHQ (National Initiative for Children’s Healthcare Quality) participation, many states have created EHDI roadmaps. In Illinois, they chose to create the map from the 3-6 perspective instead of the entire 1-3-6 model. This decision was made, because the intent is to distribute them to the providers who perform follow-up. Because the map had only the 3-6 perspective, it allowed more room to list resources and additional information (see Figure 4). The importance of the 1-3 perspective was not overlooked by Illinois. They also created a crib card to be utilized in the birthing hospital.

The goal behind the creation of the crib card was to create a keepsake for the family—something easy on the eyes that the family would want to hold on to and review again (see Figure 5). If a family gives this “keepsake” a second glance, there should be no question then if their child was screened and what the results were. It also clearly states for the family to bring the card with them to doctor and audiology appointments. By doing this, they continue to remind their primary care physician of the state EHDI program. By having families use and share these materials, they continue to showcase and spread your EHDI program’s branding. The crib card also gives the family awareness of the potential for hearing loss and that, although monitoring hearing development does not replace hearing screening, it is designed to open conversation when there are concerns.

This are another tool for EHDI programs to spread their message. These days, many families are drawn to technology—the latest being the QR (quick response) barcodes that you can scan with your smartphone or even a 3DS handheld game system! Watching a video is a relaxing way to receive information and capture someone’s attention for a longer period of time. There are two videos—one from NCHAM and the other through Hands & Voices headquarters—that you can utilize right away without the expense of creating your own. The NCHAM video walks a family through the steps of how a baby hears to how the tests are administered. The NCHAM video can be found at http://www.infanthearing.org/videos/index.html. The Hands & Voices Loss & Found™ video shares with a family the action steps needed after a child does not pass the screening. The video has a clean look to it, and it uses real parents who share well thought-out action phrases to inspire families to follow-up. In addition, the Loss & Found™ video can be tailored to embed your state-specific information at the end of the video. The Hands & Voices Loss & Found™ video can be found at http://www.handsandvoices.org/resources/video/index.htm

### Table 4
Examples of Tools Created and Utilized by EHDI Programs

<table>
<thead>
<tr>
<th>Roadmaps</th>
<th>Crib Cards</th>
<th>Videos</th>
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<td>Through NICHQ participation, many states have created EHDI roadmaps. In Illinois, they chose to create the map from the 3-6 perspective instead of the entire 1-3-6 model. This decision was made, because the intent is to distribute them to the providers who perform follow-up. Because the map had only the 3-6 perspective, it allowed more room to list resources and additional information (see Figure 4). The importance of the 1-3 perspective was not overlooked by Illinois. They also created a crib card to be utilized in the birthing hospital.</td>
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### QR (Quick Response) Barcodes

QR is a two-dimensional matrix barcode that was first used in the auto industry to track car parts. Since then, it has become almost a standard on everything from bottles of Pepsi to the Unicef trick-or-treat box. While creating your own EHDI QR barcode may seem like an idea outside of the box, it is a clever way to reach today’s technology-driven generation. Many of today’s families use a cell phone for their primary phone number, and their phone goes wherever they go. When you have your QR code at their disposal, they can quickly access and keep your information to view at their leisure. With QR codes, you can choose which information you would like to link to your code. Link to your website, display text, reply with contact information...there are so many possibilities!
When you think social media, you may automatically think Facebook or Twitter, but there are many more options. For instance, if you have a video for your program or as an action item for parents (i.e., Loss & Found™ video), is it on YouTube? If a family doesn’t know who you are or if they can’t remember your name, what if they go to YouTube and search “hearing loss” and your state? Would they be able to find you and get information right away? In our life of drive-thrus, instant foods, and the need for instant gratification, families and providers utilize the Internet. For a family with a child who has just been diagnosed, they may be seeking information from anywhere they can get it and as soon as they can get it. So get your information out there. Whether it’s a page on Facebook or a channel on YouTube, create opportunities for individuals to find and stay connected to you!

Another great marketing option is to create a governor-proclaimed EHDI day in your state. In Illinois, they use EHDI day to recognize professionals and parents that have gone above and beyond in the field. An event such as this allows you to have an open floor with eager participants and is a great way to publicly praise programs and providers that have been actively involved and are consistently meeting your EHDI program goals. This opportunity can also be used to give an EHDI update, to network, or to ask for feedback and/or suggestions. A Parent Achievement Award can also be given during EHDI day. If you want to involve parents, you have to recognize parents—give them something to strive for and a reason to share your name and vision. Arrange for local media to cover your event and spread your focus, brand, and contact information for free!
In the midst of budget cuts, sometimes it’s hard to decide what is necessary. If you’re thinking of cutting out marketing materials . . . don’t!

This may also be true with providers who will often receive letters or emails from you. That is why we are going to focus on branding. Branding is the process involved in creating a unique name and image for a product in the consumer’s mind. Through branding, you are able to create a “total package” that has an unmistakable identity.

Do they really know what you do for them? Yes, you are assisting families to get an early start by screening their child, but after their child is screened, what message do you send? What do you call yourself? Do you use the terms EHDI or Newborn Hearing Screening? I’ve been in meetings where I’ve heard providers ask, “Who’s EHDI?” So when you present or share information with others, please explain to them what EHDI means (even if you think they may know). If you call yourself EHDI, then say EHDI; if you don’t, then stick to what your program is called. Otherwise, it is confusing to those with whom you are meeting. Also, when you present to individuals through an interpreter, spell out EHDI and explain the acronym. Otherwise, they think there’s someone in the office named “EDDIE,” or that you’re possibly talking about the dog from the TV show “Frasier!”

To create a total package, think about slogans. A slogan is a short, striking, or memorable phrase used in advertising. Slogans are also claimed to be the most effective means of drawing attention to one or more aspects of your brand. You want to create a “total package,” so the family will remember and look to you for support if they have concerns or questions. Through your slogan, you can help a family or provider remember you and your role. Think about how many things in our society have a slogan. For example, McDonald’s has, “I’m lovin’ It!” Taco Bell uses, “Think outside the bun.” It’s essential and allows people to put two and two together. They are another way outside of our logo to “brag” about what you do in a quiet kind of way. So when we talk about marketing your program, ask yourself, “Are we more than just our logo?” Try to think of your logo as Batman: You have Batman, but where is Robin? That’s what you need to think of when it comes to logos and slogans. Remember you only have a few seconds to impress, so keep it short. Keep it to one sentence, if possible, and use easy-to-understand words.

So can it be done? Yes! EHDI programs in Texas and Wyoming both have a logo and slogan. They are clear and to the point. Once you successfully pair your logo with a slogan, you need to ensure that they are part of all the items linked to your program. This is essential to successful branding.

In the midst of budget cuts, sometimes it’s hard to decide what is necessary. If you’re thinking of cutting out marketing materials . . . don’t! This is how you can continue to spread your logo and slogan. Table 5 takes a look at three marketing tools and how they really are more than just “giveaways.”

When all is said and done, you want a seamless delivery and memorable image. By creating a “total package,” families and providers will remember you, have a clear understanding of your purpose, and will look to you for support if they have concerns or questions.
Table 5
Marketing Tools from Three EHDI Programs

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<th>Ice Scrapers</th>
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<td>Now I bet they use these a lot in Wyoming! Simply add a witty saying, and you can tie it all together. For instance, you distribute these in a mailing to professionals inviting them to a presentation you are having about your EHDI program. You could have the invitation read, &quot;Let’s break the ice! Come join us for an afternoon of networking, sharing, and educating.&quot; Receiving a package in the mail along with your letter will definitely get opened and is bound to create a longer-lasting impression than the letter you would typically send on its own.</td>
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<th>Baby “Onesies”</th>
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<td>This is the gift that keeps on giving! Imagine families that pass this on to future siblings, and even if they don’t have that opportunity, what if they pass it on to a friend or donate it to a charity? Your brand continues to live on! In addition, Wyoming keeps getting their point across through the phrase, “Don’t forget my annual hearing re-screening!” Every time that baby rolls over or even crawls away, loved ones are reminded of this action item.</td>
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<th>Window Clings</th>
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<tr>
<td>Another simple, cost-effective, and limitless marketing item. The great thing about window clings is that they are easy to mail, and they can be used in high-traffic areas, such as WIC offices, pediatrician or clinic windows, on fish tanks, state vehicle windows, baby nursery windows, and even on the bathroom mirror of the hospital birthing suite. There are so many possibilities that the toughest decision will be how many to order!</td>
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References

# Early Hearing Detection and Intervention (EHDI)

## Patient Checklist for Pediatric Medical Home Providers

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<tr>
<th>Birth</th>
<th>Ongoing Care of All Infants²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital-based Inpatient Screening Results (OAE/AABR)</td>
<td>Provide parents with information about hearing, speech, and language milestones</td>
</tr>
<tr>
<td>(also Home Births)</td>
<td>Identify and aggressively treat middle ear disease</td>
</tr>
<tr>
<td>Left ear:       □ Missed □ Incomplete □ Failed Screen* □ Pass</td>
<td>Vision screening and referral as needed</td>
</tr>
<tr>
<td>Right ear:      □ Missed □ Incomplete □ Failed Screen* □ Pass</td>
<td>Ongoing developmental surveillance/referral</td>
</tr>
<tr>
<td></td>
<td>Risk indicators for delayed-onset hearing loss:</td>
</tr>
<tr>
<td>Before 1 month</td>
<td>(If risk factors are present, refer for audiology evaluation at least once prior to age 30 months)</td>
</tr>
<tr>
<td></td>
<td>Patient Name: ____________________________</td>
</tr>
<tr>
<td>Outpatient Screening Results (OAE/AABR)</td>
<td>Date of Birth: ___ / ___ / ___</td>
</tr>
<tr>
<td>Left ear:       □ Incomplete □ Failed Re-Screen* □ Pass</td>
<td>Service Provider Contact Information</td>
</tr>
<tr>
<td>Right ear:      □ Incomplete □ Failed Re-Screen* □ Pass</td>
<td>Pediatric Audiology:</td>
</tr>
</tbody>
</table>

### Ongoing Care of All Infants

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Vision screening and referral as needed
- Ongoing developmental surveillance/referral
- Risk indicators for delayed-onset hearing loss:
  (If risk factors are present, refer for audiology evaluation at least once prior to age 30 months)

### Service Provider Contact Information

**Pediatric Audiology:**  

**Early Intervention Service Coordinator:**  

**Other:**  

**Other:**

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*In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiology Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.

*All infants are referred to Part C of IDEA at 6 months of age.*

*Early infants who fail screening in only one ear should be referred for further testing of both ears.*

*Includes infants whose parents refused initial or follow-up hearing screening.*

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February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)
Figure 2
NCHAM Incidence of Congenital Hearing Loss (per 10,000)
Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers

**Newborn Screening Birth**
- Identify a Medical Home for every infant

**Hospital-based Inpatient Screening**
- OAE/ABR only
- All results sent to Medical Home and State EHDI Program
- Not performed before 5 days of age

**Outpatient Re-Screening (OAS/ABR)**
- All results sent to Medical Home and State EHDI Program
- Family history of permanent childhood hearing loss
- Neonatal intensive care unit stay of more than 5 days duration, or any of the following (regardless of length of stay):
  - ECMO
  - Mechanically-assisted ventilation
  - Exchange transfusion for hyperbilirubinemia
  - Ootoxic medications or loop diuretics
  - In utero infections such as cytomegalovirus
  - Herpes, rubella, syphilis, and toxoplasmosis
  - Postnatal infections associated with hearing loss, including bacterial and viral meningitis
  - Craniofacial anomalies, particularly those that involve the pinnas, ear canal, ear tags, ear pits, and temporal bone anomalies
  - Findings suggestive of a syndrome associated with hearing loss (Waardenburg, Airport, Jervell and Lange-Nielsen, Pendred)
  - Syndromes associated with progressive or delayed-onset hearing loss (neurofibromatosis, osteogenesis imperfecta, Usher Syndrome)
  - Neurodegenerative disorders (such as Hunter Syndrome) or sensori motor neuropathies (such as Friedrich’s ataxia and Charcot Marie Tooth disease)
  - Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
  - Chemotherapy

**Screening Completed Before 1 Month**
- Pediatric Audiologic Evaluation* with Capacity to Perform:
  - OAE
  - ABR
  - Frequency-specific tone bursts
  - Air & bone conduction
  - Sedation capability (only needed for some infants)

**Diagnostic Evaluation Before 3 Months**
- Audiologist Reports to State EHDI Program
- Every child with a permanent hearing loss, as well as all normal follow-up results
- Refer to IDEA* Part C
- Coordinating agency for early intervention
- Team Advises Family About:
  - All communication options
  - Different communication modes
  - Assistive listening devices
  - Hearing aids, cochlear implants, etc.
  - Parent support programs
- Medical & Otolologic Evaluations
- To recommend treatment and provide clearance for hearing aid fitting
- Pediatric Audiology
- Hearing aid fitting and monitoring

**Intervention Services Before 6 Months**
- Continued enrollment in IDEA* Part C
  - Coordination to Part B at 3 years of age
- Referrals by Medical Home for specialty evaluations, to determine etiology and identify related conditions
- Otorhinolaryngologist (recommended)
- Pediatric Ophthalmologist (recommended)
- Geneticist (recommended)
- Developmental pediatrician, neurologist, cardiologist, audiologist, physical therapist (as needed)
- Ongoing monitoring

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Ongoing Care of All Infants*: Coordinated by the Medical Home Provider

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Provide vision screening (and referral when indicated) as recommended in the AAP* “Bright Futures Guidelines, 3rd Ed.”
- Provide ongoing developmental screening (and referral when indicated) per the AAP* “Bright Futures Guidelines, 3rd Ed.”
- Refer promptly for audiology evaluation when there is any parental concern regarding hearing, speech, or language development
- Refer for audiology evaluation (at least once before age 2 months) infants who have any risk indicators for delayed-onset hearing loss:
  - Family history of permanent childhood hearing loss
  - Neonatal intensive care unit stay of more than 5 days duration, or any of the following (regardless of length of stay):
    - ECMO
    - Mechanically-assisted ventilation
    - Exchange transfusion for hyperbilirubinemia
    - Ootoxic medications or loop diuretics
    - In utero infections such as cytomegalovirus
    - Herpes, rubella, syphilis, and toxoplasmosis
    - Postnatal infections associated with hearing loss, including bacterial and viral meningitis
    - Craniofacial anomalies, particularly those that involve the pinnas, ear canal, ear tags, ear pits, and temporal bone anomalies
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    - Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
    - Chemotherapy

*Denotes risk indicators of greater concern. Earlier and/or more frequent referral should be considered.

February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)
Figure 4
EHDI Roadmap (front and back)

Illinois Early Hearing Detection & Intervention (EHDI)

Next Steps

- Your child has a confirmed hearing loss. A copy of these results will be sent to your child’s primary care provider and the Illinois Department of Public Health. Please talk with your child’s primary care provider for further assistance.

Test Results

- No-hearing loss
- Mild
- Moderate
- Moderately Severe
- Severe
- Profound

The next steps are:

- Enrollment in Early Intervention (EI). Contact EI for your local Child & Family Connections (CFC) office 1-877-706-1991
- Enrollment with Division of Specialized Care for Children (DSCC). Contact DSCC for your regional office 1-800-322-3722
- Receive an evaluation by an ENF specialist (Ear, Nose and Throat doctor)
- Contact Guide By Your Side for family support 1-866-655-4586
- Call to receive the free “Children and Hearing Loss” notebook from CHOICES for Parents 1-866-733-8729
- Discuss the use of personal amplification options with an Audiologist with experience in working with infants.
- Learn more about communication www.communicationwithyourchild.org

No Later Than 6 Months

- Enroll in Early Intervention services with providers that have experience serving children who have a hearing loss.
- “Children who participate in early intervention prior to six months of age can have age-appropriate skills by preschool age.”
- Regular visits with your Audiologist and medical providers.
- Evaluations to discuss with your baby’s physician (Medical Home):
  - Otolaryngologist (Ear specialist)
  - Genetic Specialist
  - Other Medical specialists (for example: heart, development, kidney, etc.)

Here to Help

Illinois Early Hearing Detection and Intervention (EHDI) Program Coordinators:

- Illinois Department of Public Health
  1-217-782-4733
  Email: dph.newbornhearing@illinois.gov
- UIC Division of Specialized Care for Children
  1-800-322-3722
  Email: infone@uic.edu
- EHDI website
  www.illinoisoundbeginnings.org

Division of Specialized Care for Children (DSCC)

- 1-800-322-3722
  - www.uic.edu/healthcare

Hearing & Vision Connections (HVC):

- 1-877-733-8729
- www.morgan,k12.illinois.edu/hvc

Early Intervention (EI):

- 1-217-782-1991
  - www.dhs.state.il.us/ei
ei

Guide By Your Side (GBYS):

- 1-866-655-4586
  - 1-800-345-9673
  - www.healthychildren.org/GBYS

For assistance finding audiology providers in your area, please call the Division of Specialized Care for Children toll-free at 1-800-322-3722

Statewide Resources

- CHOICES for Parents (866) 733-8729 www.choicestoparent.org - CHOICES for Parents helps families locate resources and connect with appropriate programs for families with children who have a hearing loss.
- Illinois Early Intervention (EI) 217-782-1991 www.dhs.state.il.us/ei - EI’s mission is to assure that families who have children who are deaf or hard of hearing, have access to appropriate and effective services and supports to help them help their children.
- Illinois Early Hearing Detection and Intervention Program (IEHDP):
  - 1-800-322-3722
  - www.dhs.state.il.us/ei

National Resources

- Family-friendly websites where you can learn more about hearing loss and what you can do:
  - www.healthyhearing.org
  - www.cdc.gov/mmb/ebird/CDROM
  - www.communicationwithyourchild.org
  - www.healthierchildren.org
  - www.healthyhearing.dhch.state.il.us

Congratulations! As a parent of a precious baby, you have a wonderful journey ahead. The fact that your child has a hearing loss is only one part of that journey.

Parents have lots of different feelings when they find out their child has a hearing loss. There are so many questions about what to expect and what to do next. Remember that parenting is always a journey that you take together.

Children who are deaf or hard of hearing communicate in many ways, but just like children, it is a bit if they start when they are very young.

Children who get help before six months of age can often learn language at the same pace as hearing children. They can do well in school and become whatever they want to be in the future. Their success depends on getting timely care from family members and professionals.

As a parent, do not want your child to feel left out of anything! Right now is your child’s time to start learning more about communicating and how to get the help and support you need for your baby.

Chiild’s Name: ____________________________
Mother’s Name: ____________________________
Date of Birth: ____________________________
Birth Hospital: ____________________________
Figure 5
Crib Card Used in Birthing Hospitals
(front and back)