Improving Follow-Up after Newborn Hearing Screening

An Action Kit for Audiologists
About this Action Kit

This Action Kit is designed to help audiology practices provide more reliable follow-up care after newborn hearing screening. The kit includes promising practices based on ideas and tested improvement strategies developed by providers during a series of national collaboratives. It is designed to help providers create an efficient and reliable system of diagnosis and referral and ultimately improve outcomes for infants who are deaf or hard of hearing and their families. The kit is divided into two parts:

1. Part One is an Assessment Tool designed to help you compare your current practice to best practice and thereby develop clear priorities for improvement.
2. Part Two contains comprehensive best practice ideas and solutions gleaned from extensive improvement work in this area.

Formal research has not yet validated these ideas, and this resource does not represent all possible ideas for improvement within each area. This Action Kit does represent promising improvement strategies that have been shown to be effective in audiology practices throughout the United States.

The Case for Improving Follow-up after Newborn Hearing Screening

Hearing loss is one of the most frequent birth defects in the United States\(^1\). Early diagnosis and intervention improves language, social communication, and academic performance\(^2\)\(^-\)\(^5\). The importance of family involvement in supporting the best outcomes cannot be understated\(^6\).

Every state and territory in the United States has an Early Hearing Detection and Intervention (EHDI) program that is responsible for ensuring that all newborns are screened for hearing loss; that infants who do not pass the hearing screen receive appropriate audiological diagnostic assessment; and that timely and appropriate early intervention services are available for all infants and young children diagnosed as deaf or hard of hearing. In 2000, the Joint Committee on Infant Hearing (JCIH) set national standards related to EHDI, with the goal of optimizing outcomes for infants who are deaf or hard of hearing.

These standards include: completion of screening before 1 month of age, obtaining a diagnostic evaluation before 3 months of age and beginning early intervention before 6 months of age\(^7\). In the past decade, the U.S. has made impressive progress in the first step in this process, with screening rates increasing from 47% in 1999 to 97% in 2013\(^8\). However, the two critical follow-up steps of diagnosis and entry into early intervention are not happening at the same level of reliability as the initial screening. The 2013 data from the Centers for Disease Control and Prevention (CDC) indicates that 32% of the babies that “refer” after hearing screening do not have a documented hearing status, and that 37% of babies diagnosed with hearing loss are not documented as having entered intervention services\(^8\)\(^,\)\(^9\).

The net result is that the majority of babies who do not pass their hearing screening may not be receiving proper follow-up or intervention services. Implementing timely and reliable systems for these critical follow-up steps will improve providers’ capacity to meet the national standards for early diagnosis and entry into appropriate intervention, and ultimately improve outcomes for children with hearing loss.
Furthermore, improving this system will affect the overall experience for families and infants, ensuring infants get the care they need through a family-centered approach.

**Background**

To help state EHDI programs improve their state EHDI systems, with specific emphasis on reducing loss to follow-up, the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB) provided opportunities for states and territories to participate in Learning Collaboratives organized and supported by the National Institute for Children’s Health Quality (NICHQ).

NICHQ has partnered with MCHB to engage state EHDI programs in five learning collaboratives designed to help EHDI programs better meet their program goals of screening, diagnosis and intervention by 1, 3 and 6 months, respectively. Participating teams, which included 49 states and 3 territories, employed quality improvement (QI) methods to test and implement changes to improve the quality and timeliness of follow-up care to newborns with hearing loss. These methods identified promising change strategies for system improvement and helped states improve data collection and reporting, engage parents, and reduce loss to follow-up and documentation.

Prior to participating in the collaborative, audiologists, early interventionists, and hospitals reported concentrating on improving their own service, but had little opportunity to improve the connections between services. Parents perceived a system of disconnected parts, with limited, if any, communication between groups.

Participants in the collaboratives developed and documented processes that addressed these and other concerns by eliminating waste, improving flow and communication, and standardizing care processes across the entire EHDI system. The series of promising practices and ideas that emerged are now being shared with a wider network of providers through this Action Kit.

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**About NICHQ**

NICHQ (National Institute for Children’s Health Quality) is an independent, nonprofit organization working for more than a decade to improve children’s health. NICHQ helps organizations and professionals who share this mission make breakthrough improvements so children and families can live healthier lives.

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**What Is a Learning Collaborative?**

A learning collaborative is a quality improvement approach in which teams from diverse organizations come together to accomplish a shared objective – in this case to improve follow-up after newborn hearing screening. Teams work together over a period of time to learn how to test changes within their system on a small scale. Each team collects and reports data on a monthly basis throughout the collaborative to track improvement and identify successful change strategies that can then be spread more widely. Learning is accelerated as the collaborative teams work together and share their experiences through regular calls and in-person meetings.
PART ONE: ASSESSING YOUR ORGANIZATION

Part One of this Action Kit is an Assessment Tool designed to help your audiology practice identify opportunities to improve follow-up after newborn hearing screening, while also creating efficiencies. The tool establishes four potential improvement areas:

1. Pre-Appointment Activities  
2. Appointment Procedures  
3. Reporting Results  
4. Next Steps Following Diagnosis

The strategies listed in each of these improvement areas have been shown to improve organizational processes and outcomes for infants with hearing loss and their families. These steps promote high quality care for infants, ensure information is shared among providers, focus on effective communication with families, and strengthen the state EHDI safety net.

Audiologists play a key role in caring for children with hearing loss and ensuring they receive timely follow-up. The Assessment Tool enables you as a provider to consider the ideas that make the most sense for your setting given the context and constraints in your environment.

Who Should Complete this Assessment? 
A team of people familiar with the policies, procedures, and day-to-day practice of the organization should complete the Assessment Tool. A representative from the state EHDI program should participate on this team. Team members may choose to fill out the assessment individually first, and then discuss the scoring during a group meeting. Ultimately, the team should reach consensus on the score of each component prior to moving on to the next area of potential improvement.

It should take no more than 60 minutes to complete this assessment. While this is just the first step in the process, it is essential to a successful start toward improving care for infants and families.

How to Rate Your Organization 
Rate your organization’s current practice for each of the improvement strategies listed using this rating scale:

X - Not part of standard work in the practice and it is not feasible to add it to standard practice.
1 - Not part of standard work but it is feasible and the practice may be interested in testing ideas in this area now or in the future.
2 - Has been implemented but the practice is unsure how reliably infants/families are receiving this element of care.
3 - Part of standard work and the practice is confident that at least 50% of infants/families experience this; may occur frequently but may not be documented or not built into policy/procedure.
4 - Included in the policy/procedures and the practice is confident that at least 90% of infants/families experience this; documentation for this item can be found in the infant’s medical record.
# Follow-Up After Newborn Hearing Screening Assessment Tool

## Pre-Appointment Activities
1. The Audiology practice receives results of the birth hearing screening and/or re-screen before the appointment
2. The Family receives written pre-appointment instructions in the mail, in the family’s first language, prior to the appointment
3. The Family receives an appointment reminder call that confirms the appointment time, confirms the location and logistics, verifies two points of contact for the family (phone, email, etc.), and offers answers to any questions
4. The Primary Care Provider is documented in the medical record

## Appointment
1. Results of the diagnostic appointment are explained verbally to the parent(s)/caregiver(s) (in the family’s first language whenever possible)
2. Results of the diagnostic appointment are given to the parent(s)/caregiver(s) in a written document (in the family’s first language whenever possible)
3. The family is able to restate the next steps following the diagnostic appointment
4. When further appointments are required: the next audiology appointment is scheduled before the family leaves the current appointment

## Reporting Results
1. Results of diagnostic audiology appointment(s) are sent to the primary care physician and noted in the infant’s medical record
2. Results of diagnostic audiology appointment(s) are sent to the state EHDI program
3. Results of the diagnostic audiology appointment(s) are sent to the state EHDI program within 7 business days of the appointment
4. Results of the diagnostic audiology appointment(s) are reported to the state EHDI program using a standard form and method

## Next Steps Following Diagnosis
1. A referral to Early Intervention is made following diagnosis of permanent hearing loss for children ages 0-3
2. A referral to Early Intervention is made within 7 business days of the appointment during which permanent hearing loss was identified
3. The Family of an infant with hearing loss is given information about Early Intervention prior to leaving the appointment (in the family’s first language whenever possible)
4. A referral to Parent-to-Parent support organizations is made where formal agreements exist (e.g., Hands & Voices Guide By Your Side Program)

<table>
<thead>
<tr>
<th>Improvement Area</th>
<th>Improvement Strategies</th>
<th>Using the scale on page 4, rank your organization’s current practice</th>
<th>To calculate Improvement Area Score: ____%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Appointment Activities</td>
<td>1. The Audiology practice receives results of the birth hearing screening and/or re-screen before the appointment</td>
<td>X 1 2 3 4</td>
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<tr>
<td></td>
<td>2. The Family receives written pre-appointment instructions in the mail, in the family’s first language, prior to the appointment</td>
<td>X 1 2 3 4</td>
<td></td>
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<tr>
<td></td>
<td>3. The Family receives an appointment reminder call that confirms the appointment time, confirms the location and logistics, verifies two points of contact for the family (phone, email, etc.), and offers answers to any questions</td>
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<td>Appointment</td>
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<tr>
<td></td>
<td>2. Results of the diagnostic appointment are given to the parent(s)/caregiver(s) in a written document (in the family’s first language whenever possible)</td>
<td>X 1 2 3 4</td>
<td></td>
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<tr>
<td></td>
<td>3. The family is able to restate the next steps following the diagnostic appointment</td>
<td>X 1 2 3 4</td>
<td></td>
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<tr>
<td></td>
<td>4. When further appointments are required: the next audiology appointment is scheduled before the family leaves the current appointment</td>
<td>X 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>Reporting Results</td>
<td>1. Results of diagnostic audiology appointment(s) are sent to the primary care physician and noted in the infant’s medical record</td>
<td>X 1 2 3 4</td>
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<tr>
<td></td>
<td>2. Results of diagnostic audiology appointment(s) are sent to the state EHDI program</td>
<td>X 1 2 3 4</td>
<td></td>
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<tr>
<td></td>
<td>3. Results of the diagnostic audiology appointment(s) are sent to the state EHDI program within 7 business days of the appointment</td>
<td>X 1 2 3 4</td>
<td></td>
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<tr>
<td></td>
<td>4. Results of the diagnostic audiology appointment(s) are reported to the state EHDI program using a standard form and method</td>
<td>X 1 2 3 4</td>
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<td>3. The Family of an infant with hearing loss is given information about Early Intervention prior to leaving the appointment (in the family’s first language whenever possible)</td>
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<td></td>
<td>4. A referral to Parent-to-Parent support organizations is made where formal agreements exist (e.g., Hands &amp; Voices Guide By Your Side Program)</td>
<td>X 1 2 3 4</td>
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</tbody>
</table>

To calculate the Improvement Area Score, divide the total number of self-ranked points in each section by the total number of possible points in that section. Do not include items rated with an X. For example, there are 16 total possible points in an improvement area if no items are scored as X and there are 12 possible if one item is scored as X.
Scoring Results
In scoring this assessment, you will end up with 2 scores: (1) a score for each individual improvement strategy and (2) a cumulative percentage for each of the four improvement areas. See below for more detail:

<table>
<thead>
<tr>
<th>IMPROVEMENT STRATEGY SCORE</th>
<th>IMPROVEMENT AREA SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Each improvement area (e.g., Pre-Appointment Activities) is composed of four individual improvement strategies. Your organization should have a score for each individual strategy found in all four improvement areas</td>
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<tr>
<td>• The opportunity for improvement is lowest on any strategy scored “X” because the team recognizes this practice as not currently feasible.</td>
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<tr>
<td>• Any strategy scored between “1” and “3” represents a potential opportunity for improvement.</td>
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<tr>
<td>• Any strategy scored “4” is a clear organizational strength and therefore not recommended for improvement at the current time.</td>
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<tr>
<td>The Improvement Area Score is the cumulative total score for each individual improvement strategy divided by the total number of possible points in that section.</td>
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<tr>
<td>• Any score less than 100% in any improvement area indicates an opportunity for improvement.</td>
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<tr>
<td>• The lower the score, the greater the opportunity for improvement.</td>
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</tbody>
</table>

REMINDER: Do not include items rated with an X in the denominator. There are 16 total possible points in an improvement area if no items are scored as X. There are 12 possible if one item is scored as X.

Once you have completed and scored each of the four improvement areas, you could:

1. **Conduct a chart review on the last 10 infants seen at the practice.** We strongly recommend this as the next step to both verify the results of the Assessment Tool and to assess the root cause of your lower scores. This step will help you prioritize key areas for improvement and prepare you to choose the right changes for your system.

2. **Choose the improvement area with the lowest score.** This area presents the greatest opportunity for improvement, and also allows for the greatest flexibility in deciding how improvement will be accomplished. (Example: the summary score in the "Reporting Results" area is 50%, so the organization works to improve the scores in all four strategies in this area.)

3. **Focus on one strategy with a score of 1.** A score of 1 indicates that this item is not part of current practice, but there is an opportunity to begin to integrate this into the organization’s work. Focus the improvement efforts on that one strategy, rather than the entire improvement area (Example: work to improve making pre-appointment reminder phone calls, rather than working to improve all items in the "Pre-Appointment" section.)

Regardless of which option you choose, it is important to focus your improvement efforts to ensure measurable and sustainable improvement can be accomplished over time. Although you may identify several areas that are in need of improvement, achieving improvement in several
areas simultaneously is often impractical for any organization. You will need to prioritize your efforts to ensure they lead to improved outcomes while minimizing burden and resistance from staff.

References
PART TWO: BEST PRACTICE IDEAS AND SOLUTIONS

Each of the best practice improvement areas included in the Assessment Tool is presented in more detail in this section. An overview of the specific area is provided, as well as a case for why this particular improvement area is important to improving both care and outcomes for infants and families. Following this overview, are a number of “change ideas” that you may consider trying in order to improve your organization’s process. These promising practices have been tested across a variety of populations and conditions, and have proven effective for organizations participating in NICHQ/HRSA learning collaboratives.

While we believe that these ideas are translatable to other locations and providers across the country, your results may vary. We encourage you to choose the ideas that seem most appropriate based on your scores in the Assessment Tool and your organization’s capacity to accomplish improvement in these specific areas.

Your organization may be interested in testing just one or several of the ideas below. You should decide what is most feasible. You may notice some ideas are repeated across multiple improvement areas. This occurs when an idea is applicable to more than one improvement area.

Below are a brief summary of each change idea, potential measures to track improvement, and tools—when available—that can be used or altered to support that specific idea. These tools, developed by teams that participated in the NICHQ/HRSA quality improvement learning collaboratives, can be used as a guide to spark ideas, but will likely need to be altered to serve your local needs.

Tip: Be sure to focus your organization’s improvement efforts. Although you may find several areas in need of improvement, attempting to improve all of them at the same time is impractical. Your improvement work should unfold over time. To build momentum, start with a few areas that you are confident you can improve.

In evaluating potential next steps, you should refer back to your organization’s scores on the Assessment Tool. There will be four separate scores, one for each best practice improvement area. For more detail around scoring please refer to Scoring Results section.

When reviewing your scores, consider this: Are specific elements on the Assessment Tool truly not occurring for the infants and families you serve, or does the organization lack a process to document their occurrence? The participants in the NICHQ/HRSA learning collaboratives found that often the lack of a clear mechanism for documentation lowered overall scores. Conversely, once they began to accurately document care processes, many organizations learned that previous assumptions about the reliability and consistency of care were wrong. The most useful way to assure timely and accurate documentation may be unique to each system. We encourage you to consider these possibilities as you begin to focus the next steps of your improvement efforts.

USING QUALITY IMPROVEMENT TO IMPROVE CARE
As with any Quality Improvement (QI) effort, you will need three key components to accomplish improved care and outcomes for children with hearing loss: (1) Will – the energy and intent to change, (2) Ideas – found throughout this document, (3) Execution – testing specific ideas within your organization and using your data to determine if improvement is realized over time.

There are many models that create a specific framework on how QI skills and techniques can be applied to improve care and outcomes. The approach to organizing and carrying out the improvement work in the NICHQ/HRSA learning collaboratives was based upon The Model for Improvement, developed by Associates in Process Improvement. The Model for Improvement is a simple yet powerful tool for accelerating improvement and has been used successfully by hundreds of healthcare organizations to improve a variety of different healthcare processes and outcomes. For information and resources related to The Model for Improvement and other Quality Improvement approaches and tools, go to http://www.nichq.org/about/expertise/improvement-science.

FORMING A TEAM

Relying on one person within an organization to move improvement work forward is rarely successful. Effective Quality Improvement work requires a team approach and a shared vision of improvement. For information and guidance on how to form an improvement team, implement the team’s work and support the team’s growth, go to http://www.nichq.org/CanDoPlaybook/story.html (Strategy 1).
IMPROVEMENT AREA #1:
PRE-APPOINTMENT PROCEDURE

OVERVIEW

According to 2013 data from the U.S. Centers for Disease Control and Prevention (CDC)\(^1\) 31% of babies who did not pass their hearing screening did not receive diagnostic follow-up by 3 months of age. There are several factors that affect whether or not this goal is met, including the availability of appointments, timeliness of appointments, proximity of the diagnostic facility to the family, and family understanding about the importance of follow-up and how to prepare their baby for the follow-up appointment.

Audiology practices are often frustrated by the “no show” rate for diagnostic follow-up appointments. Missed appointments are costly and inefficient for the practice, and significantly affect the practice’s ability to provide babies with their diagnostic evaluation by 3 months of age.

Preparing families for what to expect prior to a diagnostic appointment is a core component of ensuring successful completion of necessary diagnostic care. Diagnostic follow-up must happen shortly after birth, when the family is experiencing the many changes that come with a new baby. At this point it is critical that families understand what to expect of this appointment, how to prepare the baby for the appointment and the logistics of getting to and from the appointment. Without a comprehensive understanding of these details the likelihood of a missed or incomplete diagnostic evaluation appointment grows. As the infant ages, the potential for successful natural sleep evaluations decreases, resulting in the increased need for sedation. The sedation requirement can result in an additional host of barriers on both the clinical and family side of the equation, often resulting in additional delays in care or family refusal of follow-up care.

# How To Improve

<table>
<thead>
<tr>
<th>Improvement Strategy</th>
<th>Change Idea</th>
<th>Summary</th>
<th>Potential Measures to Track Improvement</th>
<th>Tools (if available)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. The Audiology Practice Receives Results of the Birth Hearing Screening and/or Re-screen Before the Appointment</strong>&lt;br&gt;&lt;br&gt;<strong>Definition:</strong> The results of the birth screening or re-screening are received by the audiology practice prior to the first appointment with any infant</td>
<td>Request results when hospital staff schedules appointments</td>
<td>Many hospital systems have begun scheduling the diagnostic appointment at the point of screening (i.e., prior to hospital discharge). When the hospital staff calls to schedule this appointment, audiology staff should ask for a copy of the screening results to be faxed to the office. This immediate transfer of information helps prepare the diagnostic team for the appointment with an infant and enables the transfer of key demographic information for the family.</td>
<td>• % of children for whom screening results data is requested&lt;br&gt;• % of children for whom screening results data is received % of appointments where screening results are received ahead of time</td>
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<tr>
<td>Create a standardize location for screening results within the EMR</td>
<td>Having a standardized location for all screening results helps scheduling staff determine which infants’ screening results have been received and which are outstanding. Standardizing the location of these results helps build a system to ensure all results are received prior to the first appointment. Providers will also be able to flag charts with missing results for follow-up. For audiology practices that share an EMR with the referring hospital, standard location creates efficiencies when locating the results and reliability when determining whether they are absent.</td>
<td></td>
<td>• % of children for whom screening results data is requested&lt;br&gt;• % of children for whom screening results data is received&lt;br&gt;• % of children for whom screening data is saved in the standardized location&lt;br&gt;• % of appointments where screening results are received ahead of time</td>
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<tr>
<td>Utilize electronic transfer of information to share results</td>
<td>Providers participating in large health care networks often have the ability to share information electronically. Utilizing this system to share screening results supports effective diagnostic care while</td>
<td></td>
<td>• % of children for whom screening results data is requested</td>
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</table>
simplifying the transfer of screening results.

Providers who are not part of a connected electronic system should consider creating a standard process for electronic information transfer. An example may be the utilization of a data encrypted email to send scanned copies of the screening results to a diagnostic provider.

| Develop a system to document results received prior to the infant’s first appointment | To ensure all screening results are received prior to the first appointment, a practice will need to set up a process to document if the results are received and track how reliably this is happening in advance of the first appointment. Since some EMR’s will not allow documentation prior to the first appointment, organizations must develop a system to both track what has been done prior to the first appointment and provide an alert if the results are missing or incomplete. This information should be then transferred into the EMR once the system allows. | • % of children for whom screening results data is received  
• % of appointments where screening results are received ahead of time | Pre-Appointment Checklist (Word)  
Pre-Appointment Checklist Data collection tool (Excel) |

| 2. THE FAMILY RECEIVES WRITTEN PRE-APPOINTMENT INSTRUCTIONS IN THE MAIL, IN THE FAMILY’S FIRST LANGUAGE, PRIOR TO THE APPOINTMENT | Develop and test a reminder system to ensure that instructions are sent at least 7 days prior to the appointment | The practice should set up a process to record whether this is happening reliably for each baby and to review this information. Data can be documented in the chart, Electronic Heath Record, through use of a checklist (see tool), or other means. The checklist tool can be tailored to your practice’s needs. | • % of children for whom provision of pre-appointment instructions is documented  
• % of families where written instructions were sent at least 7 days prior to appointment | Missouri’s Daily log template |
| Definition: Pre-appointment instructions are mailed to all families of infants and toddlers (through age 2) prior to the first appointment. These instructions should be available in the families’ primary language whenever possible. These instructions should include what is needed for the appointment to be successful, what to expect during the appointment and who to call if they have questions. | Develop and test written instructions for the family prior to the appointment that include:  
- what is needed for the appointment to be successful  
- what to expect during the appointment  
- how to have questions answered  
- information about when sedation is required | Written instructions provided ahead of time ensure that the family understands the diagnostic process and that the baby shows up ready for the test, thereby increasing the number of evaluations that can be completed. Instructions should be specific, especially around the need for the baby to be asleep for testing. | • % of children for whom provision of pre-appointment instructions is documented  
• % of families who report receiving written instructions  
• % of babies arriving prepared for hearing screening | Written materials are available in languages other than English (as needed for the population served by the organization), are culturally sensitive, and directed to the needs of the local populations (rural, urban, insured, migrant, etc.) | Providers should ensure the appropriate materials are available so that each family receives information in their primary language, and in a way that is culturally attuned to local needs. Knowing the family’s primary language prior to mailing this information is critical. Providers may utilize various local resources to help with this process, including:  
- Hospital/clinic staff interpreters  
- Parent partners in the EHDI system  
- Bilingual EHDI staff  
- Community leaders | • % of families who have their primary language identified prior to first appointment  
• % of families receiving written information in their first language  
• % of parents reporting the written material was useful (of those who report receiving written material)  
• % of babies arriving prepared for hearing screening | Idaho’s Your Baby’s Hearing Test  
Minnesota’s Preparing for Your Baby’s Audiology Visit |
| Include a letter from a parent of a child with hearing loss in your pre-appointment instructions | Family members report that hearing from a parent who has “been in their shoes” empowers them to proactively manage their child’s care. This letter helps to reinforce the importance of this visit and encourages families to follow through with necessary testing. | • % of children for whom provision of a parent letter is documented  
• % of families who report receiving letter  
• % of babies arriving prepared for hearing screening | ND Parent Letter Marshfield Clinic’s Preparing Your Baby for a Hearing test Children’s hospital letter |
|---|---|---|---|
| Verify correct contact information when scheduling appointment | When an appointment is scheduled following a newborn hearing screening, it is critical to verify multiple (at least 2) contact points for the family. Contact information may include:  
• Mailing address  
• Email address  
• Home phone number  
• Cell phone number  
• Friend or relative contact information | • % of families for which contact details are verified | |
| 3. THE FAMILY RECEIVES AN APPOINTMENT REMINDER CALL THAT CONFIRMS THE APPOINTMENT TIME, CONFIRMS THE LOCATION AND LOGISTICS, VERIFIES TWO POINTS OF CONTACT FOR THE FAMILY (PHONE, EMAIL, ETC.), AND | Develop and test a reminder system to ensure that the family receives a reminder call at least 2 days prior to the appointment | • % of families who receive a reminder call | Pre-Appointment Checklist (Word) Pre-Appointment Checklist Data collection tool (Excel) |
| Create a script or checklist for reminder calls that includes:  
• date/time of appointment | Receiving a reminder phone call prior to an upcoming appointment supports families in understanding the importance of this appointment and may reduce barriers that prevent families from keeping the appointment. | • % of families receiving a reminder call  
• % of families receiving a reminder call at least 2 business days prior to appointment  
• % no-show appointments | North Dakota’s Parent Survey Questions For Reminder Call |
| OFFERS ANSWERS TO ANY QUESTIONS | • why appointment is important  
• discussion of potential barriers  
• answers to last minute questions (e.g., parking, gas or transportation vouchers) | Pre-appointment calls are correlated to a reduction in missed appointments and a decrease in infant age at first diagnostic appointment. | • % of parents reporting the call was useful (of those who report receiving a call) |
|---------------------------------|---------------------------------------------------------------|-----------------------------------------------------------------|------------------------------------------------------------------|
| Definition: Families of infants and toddlers (through age 2) receive a phone call prior to the first appointment. Verification that families are reached is required. This phone call can be made by an automated machine or by a live person. | Ensure that language is not a barrier to effective reminder calls | Providers should ensure the appropriate materials are available so that each family receives information in their primary language and in a way that is culturally attuned to local needs. Knowing the family’s primary language prior to mailing this information is critical. Providers may utilize various local resources to help with this process, including:  
  • Telephone interpreting (e.g., language line)  
  • Hospital/clinic staff interpreters  
  • Parent partners in the EHDI system  
  • Bilingual EHDI staff  
  • Community leaders | • % of families who have their primary language identified prior to first appointment  
• % of families who receive a reminder call but need another follow-up call due to language barriers  
• % of non-English speaking families receiving a reminder phone call in their first language |
| Test different individuals making the reminder call | There are advantages and disadvantages to having a machine vs. a person make reminder phone calls. Machines are reliable, efficient and cost effective. However, a person can respond to parent questions and clarify any confusion. | • % of families receiving a reminder call  
• % of families receiving a reminder call at least 2 business days prior to appointment  
• % no-show appointments |
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<thead>
<tr>
<th>An audiologist, office staff member, or parent could make the call and all have different advantages. An audiologist might be best able to reinforce the importance of the appointment and answer questions. A parent of a child with hearing loss can discuss the appointment and expectations from the parent perspective, and this might be more cost-effective than an audiologist making the call. Office staff may have more availability and understanding of office policies.</th>
<th>• % of parents reporting the call was useful (of those who report receiving a call)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test different days and times for reminder calls – mornings, afternoons, evenings, weekends</td>
<td>Parents are often unavailable during business hours. Calling them at other times can increase the likelihood of a successful call.</td>
</tr>
</tbody>
</table>
| Ascertain two points of contact for families of infants who "did not pass" | One of the greatest obstacles to the successful completion of a pre-appointment reminder call is inaccurate and/or incomplete contact information. Hospital staff should identify at least two points of family contact and share this information with the audiology clinic staff. The second contact can be the phone number of a relative or friend. Practice staff should verify all points of contact at each interaction with the family. | • % of families for which there are 2 points of contact  
• % of families for which the 2 points of contact are accurate and current |
<table>
<thead>
<tr>
<th>4. THE PRIMARY CARE PROVIDER IS VERIFIED AS ACCURATE IN THE MEDICAL RECORD AT EACH CONTACT WITH THE FAMILY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition:</strong> Current and accurate primary care provider is documented for the infant prior to diagnostic appointment. This information is verified at each point of contact with a family (telephone and appointments) and all changes are reflected in the infant’s medical record.</td>
</tr>
<tr>
<td><strong>Develop and test a system to document that the Primary Care Provider is correctly identified</strong></td>
</tr>
<tr>
<td>The practice should set up a process to record whether this is happening for each baby and to review this information. Data can be documented in the chart, Electronic Health Record, through use of a checklist (see tool), or other means. The checklist tool can be tailored to your practice’s needs.</td>
</tr>
<tr>
<td>• % of infants for whom it is documented whether the primary care provider was confirmed</td>
</tr>
<tr>
<td>• % of infants with the correct PCP identified in their medical record</td>
</tr>
<tr>
<td>Pre-Appointment Checklist (Word)</td>
</tr>
<tr>
<td>Pre-Appointment Checklist Data collection tool (Excel)</td>
</tr>
<tr>
<td><strong>Ensure the child’s Primary Care Provider is correctly Identified</strong></td>
</tr>
<tr>
<td>PCPs are often not recorded or recorded incorrectly, and they can change. Without correct identification, it is not possible to ensure screen and diagnostic results are communicated to the PCP. The PCP may be verified at:</td>
</tr>
<tr>
<td>• Hospital discharge</td>
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<tr>
<td>• Appointment scheduling</td>
</tr>
<tr>
<td>• Appointment check-in</td>
</tr>
<tr>
<td>• Appointment completion</td>
</tr>
<tr>
<td>• % of infants with the correct PCP identified in their medical record</td>
</tr>
<tr>
<td>• % of infants whose PCP is notified of upcoming diagnostic appointments</td>
</tr>
<tr>
<td>Washington’s PCP Referral Fax</td>
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</table>
IMPROVEMENT AREA #2:  
INFORMATION SHARING WITH FAMILIES

OVERVIEW

Providers are appropriately focused on conducting high quality clinical care during an appointment. Often there is less emphasis and time given to ensuring that families understand the outcome(s) of the appointment and any necessary next steps. The diagnostic evaluation of an infant’s hearing can be a confusing and overwhelming experience for families. Although providers know these diagnostic appointments are critical to both confirming the hearing status of the infant and ensuring the infant receives any necessary follow-up, it is sometimes difficult for families to prepare for this experience. Helping families understand the expectations during the diagnostic appointment, the types of testing that will occur, and what the results of these tests mean both immediately and in the future is critical to effective audiological care.

Within this section are ideas and strategies focused on successfully sharing information with families during a diagnostic appointment. These ideas are not focused on clinic tests, protocols, or processes for assessing hearing status. Rather, these ideas are focused on the communication with families, both verbally and in writing, concerning the outcome of the appointment and any potential next steps.

After talking to and learning from family experiences throughout the country, Hands & Voices, a non-profit, parent-driven organization dedicated to supporting families of children who are deaf or hard of hearing, developed a few tips for working with families during diagnostic appointments.

- When explaining testing results it is important to give families the technical information/outcomes, and to explain the results of a test in a variety of ways (i.e., beyond audiogram information).
- Use of terminology such as mild, moderate, severe, profound may not be meaningful for families unless explained carefully.
- Each family has a unique capacity for the amount information they can effectively receive at a diagnosing appointment. Ask the family directly, “Am I giving you too much or too little information for what you need today?” A family then can guide the process of how much they need at that particular time. Reassure them that they can access additional information after they leave. “Here is my email address. Send me any questions that come up and we can go over them at baby’s next appointment on Wednesday 12/1. If you need me to respond before then, please put ‘Important’ in the subject line and I will do my best to respond by the next business day.”
- Families often have to share the information they are just absorbing with others in their lives. When speaking with families it is important to ask who else they will need to share information with, and in what form would the information be most helpful to share with others.
- Using open-ended questions and waiting for the answers that demonstrate understanding is a good technique to assure families understand the information you shared. Avoid yes/no questions.
- Families may express a range of emotions. Providers should be prepared to support families in a non-judgmental way regardless of the emotions or lack of emotional expression that may occur during the appointment.

### HOW TO IMPROVE

<table>
<thead>
<tr>
<th>Improvement Strategy</th>
<th>Change Idea</th>
<th>Summary</th>
<th>Potential Measures to Track Improvement</th>
<th>Tool (if available)</th>
</tr>
</thead>
</table>
| 1. RESULTS OF THE DIAGNOSTIC APPOINTMENT ARE EXPLAINED VERBALLY TO THE PARENT(S)/CAREGIVER(S) (IN THE FAMILY’S FIRST LANGUAGE WHENEVER POSSIBLE) | Modify Electronic Health Record (EHR) to document verbal delivery of results | A process for documenting a conversation with a family regarding the results of a diagnostic evaluation often does not exist. This is often complicated by the use of EHR. It may be necessary to change organizational processes so that there is a clear location for documenting verbal results in order for an organization to truly understand how reliably this improvement strategy occurs. | • % of families with verbal explanation of results  
• % of families who received verbal explanation who also had it documented | |
| | Schedule two diagnostic appointments at the time of initial diagnostic appointment | When the initial diagnostic appointment is scheduled, there is an opportunity to schedule a second appointment within two weeks of the first appointment. One appointment is often not enough to complete the necessary testing and to adequately communicate the results of this testing with the family. Initially scheduling two appointments ensures the family has access to prompt follow-up, allows adequate time to review the results, and limits scheduling delays. If the second appointment is not necessary, it can be cancelled at the end of the first appointment. | • % of families with 2 appointments scheduled at the time of initial appointment  
• % of families with second appointment within 2 weeks of first appointment  
• % of families needing second appointment  
• % of families keeping second appointment | |
| **Utilize a checklist/script to ensure results are explained to families in a uniform manner** | Using a checklist to explain the results of a diagnostic appointment ensures all elements of the results are presented to all families in a uniform manner during the appointment. This tool will reduce variation among providers and serve as a reminder to ensure all necessary information and next steps are explained to a family. A checklist allows for some flexibility so that providers can remain consistent in the information provided, while also being sensitive to the individual needs of each family and situation. | • % of families with documentation of verbal explanation of results  
• % of families receiving a message that covers all points on a checklist  
• % of families able to teach back next steps from appointment | CDC’s What Else Checklist  
Arizona’s Scripts For Primary Care Providers When Communicating Newborn Hearing Screening Results to Parents/Families |
|---|---|---|---|
| **Ensure that language is not a barrier to effective results conversations** | Ensuring each family receives results in their primary language is critical. The primary language must be identified prior to the appointment. Providers may utilize various local resources to help with this process, including:  
• Telephone interpreting (e.g., language line)  
• Hospital/clinic staff interpreters  
• Parent partners in the EHDI system  
• Bilingual EHDI staff  
• Community leaders | • % of families who have their primary language identified prior to first appointment  
• % of non-English speaking families receiving results in their first language | |
| **Make necessary referrals prior to appointment completion and explain these referrals to the family** | Referrals to other providers (e.g., ENT’s, Genetics, Medical home, etc.) should be made for the family before the family leaves the appointment. Once these referrals are made the | • # of families receiving information on referrals | |
referrals should be explained and it should be clear which referrals are necessary (e.g., for medical clearance for hearing aids) and which are at the discretion of the families (e.g., genetics).

| 2. RESULTS OF THE DIAGNOSTIC APPOINTMENT ARE GIVEN TO THE PARENT(S)/CAREGIVER(S) IN A WRITTEN DOCUMENT (IN THE FAMILY’S FIRST LANGUAGE WHENEVER POSSIBLE) | Provide written information describing the results of the diagnostic testing during the diagnostic appointment | The family should be provided specific written information that describes the findings of their infant’s hearing test. This documentation helps build the family’s knowledge and provides a resource to refer to and share with family and friends at a later time. The clinical information should include definitions and eliminate any jargon or abbreviations that may be confusing to the family. | • % of families seen who receive information in writing  
• % of families seen who have documentation of information received in writing  
• % of infants requiring another appointment following current appointment  
• % of families seen who receive appointment information in writing  
• % of families seen who receive appointment reminder with written summary |
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<tbody>
<tr>
<td>Definition: The results of the diagnostic appointment are given to the family in writing before the end of the appointment. This happens at each appointment and should occur in the family’s primary language.</td>
<td>Written information and/or appointments summaries provided to the family includes a location to write in the next appointment date and time</td>
<td>It is highly likely that an infant will need another diagnostic appointment following the current appointment. The appointment summary should include a space where the provider can indicate when the next appointment will be. This gives the family written next steps and keeps the information clearly organized.</td>
<td></td>
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</tbody>
</table>
Idaho’s Your Baby’s First Year – Hearing, Understanding and Talking Checklist  
Wisconsin’s Babies and Hearing Loss  
Wisconsin’s Los bebés y la pérdida auditiva |
### Written information is mailed to families within one week of the diagnostic appointment

When a facility requires written test results to be sent separately to the parents (i.e., not delivered at the appointment), it should be made clear to the family when and from whom they can expect to receive test results. The clinical information should include definitions and eliminate any jargon or abbreviations that may be confusing to the family.

- % of families seen who receive mailed test results
- % of families seen who receive mailed test results within 10 days of appointment

### Written materials are available in languages other than English (as needed for the population served by the organization), are culturally attuned, and directed to the needs of the local populations (rural, urban, insured, migrant, etc.)

Written materials are available in languages other than English (as needed for the population served by the organization), are culturally attuned, and directed to the needs of the local populations (rural, urban, insured, migrant, etc.). Providers should ensure the appropriate materials are available so that each family receives information in their primary language and in a way that is culturally attuned to local needs. Knowing the family’s primary language prior to mailing this information is critical. Providers may utilize various local resources including:

- Hospital/clinic staff interpreters
- Parent partners in the EHDI system
- Bilingual EHDI staff
- Community leaders

- % of families who have their primary language identified
- % of families receiving written information in their first language
- % of families reporting that the written material was useful (of those who report receiving written material)

### Referral recommendations to other providers are given in writing.

Referral recommendations to other providers are given in writing. Referrals made to other providers are in writing with an explanation of why the family needs/may want to see a particular provider (e.g., ENT, family doctor, ophthalmologist, genetic specialist, etc.).

- % of families receiving follow-up referrals
- % of families receiving written instructions on referrals

### 3. THE FAMILY IS ABLE TO RESTATE THE NEXT STEPS

Modify Electronic Health Record (EHR) to document a process for documenting a conversation with a family regarding the results of a diagnostic evaluation.

- % of families who receive a verbal conversation

Wisconsin’s Los bebés y la pérdida auditiva
**FOLLOWING THE DIAGNOSTIC APPOINTMENT**

*Definition: Before the end of the appointment the family is able to restate to the audiologist or other office staff what the next steps will be following the current appointment*

<table>
<thead>
<tr>
<th>family’s ability to restate next steps</th>
<th>often does not exist. This is often complicated by the use of EHR. It may be necessary to change organizational processes so there is a clear location for this documentation in order for an organization to truly understand how reliably this improvement strategy occurs.</th>
<th>regarding next steps</th>
</tr>
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<tbody>
<tr>
<td>Utilize the “Teachback” method to have the family confirm their understanding of next steps</td>
<td>Having the family restate the next steps confirms that you have explained information in a manner that they understand and identifies the need for more information. Documentation of this change is critical to assessing how reliably this method is utilized with a family.</td>
<td>% of families documented to have received teachback to discuss next steps</td>
</tr>
</tbody>
</table>
| Develop and test a "Next Steps" checklist for families of children that are newly identified with hearing loss | The checklist should be simple, with clear instructions, including:  
- See PCP  
- See hearing aid specialist  
- Call Early Intervention  
- Contact parent group(s)  
Include contact information on the checklist for EI and parent group(s). The checklist should be available in the family’s primary language and should be reviewed with the family to ensure they understand next steps. | % of families provided a checklist |
| Written materials are available in languages other | Providers should ensure the appropriate materials are available so that written materials are available in languages other than English and should be provided to the family in languages other than English. | % of families who have their primary language available |

**Teachbacktraining.org**

- New Jersey’s Next Steps Checklist
- Tennessee’s Next Steps Document for Audiologists
- Alaska's infant hearing loss checklist (Alaska NHS packet)
- CDC’s What Else Checklist
| than English (as needed for the population served by the organization), are culturally attuned, and directed to the needs of the local populations (rural, urban, insured, migrant, etc.) | that each family receives information in their primary language and in a way that is culturally attuned to local needs. Knowing the family’s primary language prior to mailing this information is critical. Providers may utilize various local resources to help with this process, including: • Hospital/clinic staff interpreters • Parent partners in the EHDI system • Bilingual EHDI staff • Community leaders | language identified • % of families receiving written information in their first language • % of parents reporting the written material was useful (of those who report receiving written material) |

| 4. WHEN FURTHER APPOINTMENTS ARE REQUIRED: THE NEXT AUDIOLOGY APPOINTMENT IS SCHEDULED BEFORE THE FAMILY LEAVES THE CURRENT APPOINTMENT | Schedule two diagnostic appointments immediately, no longer than two weeks apart | When the initial diagnostic appointment is scheduled, there is an opportunity to schedule a second appointment within two weeks of the first appointment. One appointment is often not enough to complete the necessary testing and to adequately communicate the results of this testing with the family. Initially scheduling two appointments ensures the family has access to prompt follow-up, allows adequate time to review the results, and limits scheduling delays. If the second appointment is not necessary, it can be cancelled at the end of the first appointment. | • % of families with 2 appointments scheduled immediately • % of families with second appointment within 2 weeks of first appointment • % of families needing second appointment • % of families keeping second appointment |

<p>| Create a process so that scheduling staff are able to prioritize appointments for infants | The creation of a designated schedule slot for infant diagnostics can reduce wait times, while making scheduling easier for staff. Electronic schedules can be designed to allow for a variety | Marshfield Clinic Referral Form |</p>
<table>
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<th>Table Cell 1</th>
<th>Table Cell 2</th>
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<tbody>
<tr>
<td>of appointment types by timeslot, ENT coordination or procedure (ENG, ABR, HA fitting, etc.). As an example, an audiology clinic may designate Friday mornings for infant diagnostics. If the slot is not filled one week in advance for an infant, the appointment slot can be released and filled by another appointment type. If the slot remains open, the time can be used for paperwork/charting.</td>
<td>scheduled prior to leaving current appointment • % infants with Diagnostic appointment by 3 months of age</td>
</tr>
<tr>
<td>Create a checkout process at appointment completion that alerts scheduling staff of next steps</td>
<td>The appointment checkout is the final point of contact with the family and a key opportunity to ensure they understand the immediate next steps. It is critical that checkout staff are aware of the next steps following each appointment. The organization should develop a system to alert checkout staff of the appropriate next steps, including appointment scheduling. As an example, organizations may add information slots to the checkout paperwork that indicate the next appointment type and timeframe on the billing sheet.</td>
</tr>
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</table>
IMPROVEMENT AREA #3: REPORTING RESULTS

OVERVIEW

Audiologists are responsible for reporting child-specific results of all hearing screens (pass or refer) and diagnostic evaluations (hearing loss or within normal limits) that are performed as part of early hearing detection activities. Results should be reported in a timely and systematic manner to both the infant’s primary care provider and the State EHDI program.

WHY IS IT IMPORTANT TO REPORT RESULTS TO THE FAMILY PRIMARY CARE PROVIDER?

The infant's primary care provider (PCP) can be a powerful ally for families as they navigate a potentially complex system of referrals and follow-up appointments. However, for PCPs to provide support to families in their care they must reliably receive the results of the screening tests (pass, did not pass, missed), as well as diagnostic appointments and results.

A robust information sharing process supports a seamless transition for families, allowing the family an opportunity to focus on other important aspects of the process beyond just care coordination.

WHY IS IT IMPORTANT TO REPORT RESULTS TO THE STATE EHDI PROGRAM?

EHDI Programs rely on timely and accurate reporting from local providers to perform their important surveillance and monitoring role. When the State EHDI Program has access to this kind of data, they can often be an ally to the local providers in assisting families in getting into follow-up services. The sooner outreach can occur, the more effective it is and the more likely it is that infants meet the recommended milestones of diagnosis by 3 months and entry into early intervention by 6 months.

The State EHDI Program is also responsible for reflecting the work of the local providers in the annual aggregate data analysis provided to the federal and often local governmental agencies.

According to the 2013 CDC Early Hearing Detection and Identification (EHDI) Survey, 32% of infants who did not pass their newborn hearing tests were lost to follow-up in the system. This 32% is composed of infants who:

- do not receive the needed follow-up re-screening and/or diagnostic evaluations to determine their hearing status; or
- have received this follow-up testing, but the documentation of this care was never shared with the state’s EHDI office, the primary care provider or early intervention.
The ability to differentiate between loss to follow-up versus loss to documentation can be greatly improved through the simple process of results sharing.

**HOW TO IMPROVE**

<table>
<thead>
<tr>
<th>Improvement Strategy</th>
<th>Change Idea</th>
<th>Summary</th>
<th>Potential Measures to Track Improvement</th>
<th>Tool (if available)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. RESULTS OF DIAGNOSTIC APPOINTMENT(S) ARE SENT TO THE PRIMARY CARE PHYSICIAN AND NOTED IN THE INFANT’S MEDICAL RECORD</strong></td>
<td>Ensure the child’s Primary Care Provider is correctly identified</td>
<td>Infants “referred” on their newborn hearing screening often do not have their Primary Care Provider correctly identified at the birth hospital. Without correct identification, it is not possible to ensure that screen and diagnostic results are communicated to the PCP.</td>
<td>% of infants with their PCP identified in the medical record</td>
<td>Washington’s PCP Referral Fax</td>
</tr>
<tr>
<td>Definition: The results of the diagnostic appointment, regardless of the outcome, are sent to the primary care physician and there is documentation of the physician receiving the results. Results may be sent electronically, through fax, or other methods.</td>
<td>Modify Electronic Health Record (EHR) to document that results of the diagnostic appointment were sent to the primary care provider</td>
<td>A process for documenting the sharing of information following diagnostic evaluation often does not exist. This is often complicated by the use of an EHR. Changing organizational process so that there is a clear location for the documentation of this information sharing is often a needed step before an organization can truly understand how reliably this best practice occurs.</td>
<td>% of infants with results sent to the PCP</td>
<td>% of infants with documentation of results sent to the PCP</td>
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<td></td>
<td>Utilize a fax back form to ensure the child’s primary care provider RECEIVED all results</td>
<td>A fax-back process requires that the PCP receiving the results return a fax to the sending provider to verify receipt or the results. A fax-back process could be utilized for any screen and/or diagnostic</td>
<td>% of infants with faxback utilized to share results with the PCP</td>
<td>Referral Fax Back Form PCP to Audiology</td>
</tr>
</tbody>
</table>
results, and could be utilized with a variety of providers.

% of forms returned
% of forms returned within 48 hours

Create a results-sharing checklist to ensure results are shared with all necessary providers

Following a diagnostic appointment there are often a series of next steps a provider could and should take.

Because diagnostic appointments with infants can be an infrequent event for providers, utilizing a checklist helps to ensure all appropriate next steps are completed.

This checklist can remind providers what steps may be necessary, serve as a visual cue to ensure they do occur, and document which steps have been taken.

% of infants with next steps checklist utilized
% of infants with documentation of next steps checklist utilized
% of infants documented to have a next steps checklist provided to the family
% of total next steps completed

Create an alert system to flag Medical Records that require results to be sent to the PCP

Having a standardized location for documenting when results have been shared with the PCP is the first step to an effective system for sharing information across providers.

Providers should build in systems to alert and/or flag charts where the information has not been sent to the PCP. These alerts may be electronic or paper mechanisms such as placing a sticker on the paper medical record indicating the need to fax results to the

% of infants with results shared to the PCP
% of infants with documentation of results sent to the PCP

New Jersey’s Next Steps Checklist

Idaho’s Reminder Sticker
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<tr>
<th>2. RESULTS OF DIAGNOSTIC AUDIOLOGY APPOINTMENT(S) ARE SENT TO THE STATE EHDI PROGRAM</th>
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<tr>
<td><strong>Definition:</strong> The results of the diagnostic appointment, regardless of the outcome, are sent to the state EHDI program, and there is documentation that EHDI received the results. Results may be sent electronically,</td>
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<tr>
<td><strong>Utilize a standard form for sharing diagnostic results with EHDI</strong></td>
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<tr>
<td>through fax, or other methods</td>
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<tr>
<td>Utilize a fax-back form to request results and/or ensure that EHDI received the results</td>
</tr>
<tr>
<td>Create a results sharing checklist to ensure results are shared with all necessary stakeholders</td>
</tr>
<tr>
<td>Create an alert system to flag Medical Records that require results to be sent to EHDI</td>
</tr>
<tr>
<td><strong>3. RESULTS OF THE DIAGNOSTIC AUDIOLOGY APPOINTMENT(S) ARE SENT TO THE STATE EHDI PROGRAM WITHIN 7 BUSINESS DAYS OF THE APPOINTMENT</strong></td>
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<tr>
<td>Utilize electronic transfer of information to share results</td>
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<tr>
<td><strong>Definition: The results of the diagnostic</strong></td>
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**appointment are sent to the state EHDI program within seven days of the appointment. Results may be sent electronically, through fax, or other methods**

<table>
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<tr>
<th>Utilize electronic transfer of information to expedite the sharing of results</th>
<th>Utilizing an electronic system often expedites any organization’s ability to share information. When providers participate in large health care networks, there is often an ability to share information, electronically, to streamline care provision. Utilizing this system to share results will support effective diagnostic care while simplifying the system. When providers are not part of a connected electronic system there is an opportunity to standardize a process for electronic information transfer. An example may be the utilization of a data encrypted email to send scanned copies of the results to a diagnostic provider.</th>
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</table>
| 4. RESULTS OF THE DIAGNOSTIC AUDIOLOGY APPOINTMENT(S) ARE REPORTED TO THE STATE EHDI PROGRAM USING A STANDARD FORM AND METHOD
*Definition: The results of the diagnostic appointment are sent to the state EHDI* | Create a standard document for sharing diagnostic results with EHDI Creating a standard process to ensure all necessary information regarding the diagnostic testing is shared with EHDI is a critical first step to improving the frequency with which these results are sent. This document should be created in partnership with EHDI staff to ensure the information provided is adequate, while limiting reporting burden for providers. | % of infants with results sent to EHDI % of infants with results sent to EHDI utilizing standard form % of infants with documentation of results sent to EHDI | New Mexico’s Report of Audiological Results Nebraska’s Newborn Hearing Screening Program Audiologic Screening and Diagnostic Report Form Arizona’s Diagnosis/Referral Tracking Form |

| % of infants who’s results were faxed to EHDI | % of infants who’s results were faxed to EHDI within 7 days |
| Program within seven days of the appointment. Results may be sent electronically, through fax, or other methods. | Utilize a fax back form to ensure the EHDI received all results | A fax-back process requires EHDI to return a fax to the sending provider to verify receipt of the results. A fax-back process could be utilized for any screen and/or diagnostic results, and could be utilized with a variety of providers. | % of infants with faxback utilized to share results with EHDI  
% of forms returned  
% of forms returned within 48 hours |
| Utilize electronic transfer of information to share results | When providers participate in large health care networks, there is often an ability to share information, electronically, to streamline care provision. Utilizing this system to share results will support effective diagnostic care while simplifying the system.  
When providers are not part of a connected electronic system, there is an opportunity to standardize a process for electronic information transfer. An example may be the utilization of a data encrypted email to send scanned copies of the results to a diagnostic provider. | % of infants with results shared with EHDI  
% of infants with documentation of results sent to EHDI |
The primary goal of universal hearing screening for congenital hearing loss and early diagnosis is to assure optimal developmental outcomes for identified infants. Research indicates that children identified and enrolled in early intervention programs by six months of age can develop language, communication, cognitive, and social-emotional skills that are consistent with their cognitive abilities and commensurate with their hearing peers. And yet, according to the Centers for Disease Control and Prevention (CDC), in 2013 37% of those babies diagnosed with permanent hearing loss were not enrolled in an early intervention program. It is not enough to screen and diagnose children with hearing loss. As audiologists, you must create reliable referral mechanisms and assure that families are educated and aware of the preventive benefits of early intervention. Early intervention providers are allies and partners. They have the ability to reinforce your recommendations, assist families with knowledge and use of technology, and educate on habilitation methods that will lead to long-lasting success for your patients. Remember, the reason to screen is to intervene.

As clinicians, you must often place heavy emphasis on obtaining accurate diagnostic results and providing appropriate amplification. However, as a primary provider for families of infants with hearing loss, you have an additional role in assuring the child’s on-going developmental success. Within this section are a series of ideas and strategies focused on family education and care coordination, especially as it relates to the Part C Early Intervention program and parent-to-parent support programs such as Guide By Your Side. Families have reported increased satisfaction with audiology providers who support them beyond the initial diagnosis and amplification fitting, who partner with their early intervention providers and become an informed and trusted member of their child’s hearing healthcare team. Below are strategies to improve the consistency with which you are effective and supportive partners in this post-diagnosis part of the EHDI continuum of care.

**HOW TO IMPROVE**

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<th>Summary</th>
<th>Potential Measures to Track Improvement</th>
<th>Tool (if available)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A REFERRAL TO EARLY INTERVENTION IS MADE FOLLOWING DIAGNOSIS OF PERMANENT</td>
<td>Develop and test a system to document that children with permanent hearing loss are referred to Early Intervention (EI)</td>
<td>To ensure this is happening reliably, your clinic will need to set up a process to record whether this is happening for each infant, and to review this information.</td>
<td>% of children with permanent hearing loss referred to EI</td>
<td>Audiology Diagnostic Appointment Checklist (in Word)</td>
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<td></td>
<td>Audiography Diagnostic Appointment Data Collection Tool (in Excel)</td>
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<table>
<thead>
<tr>
<th>HEARING LOSS FOR CHILDREN AGES 0-3</th>
<th>Definition: All children with confirmed permanent hearing loss are referred to the Part C Early Intervention program within the state</th>
<th>Data can be documented in the chart, Electronic Heath Record, through use of a checklist (see tool), or other means. The checklist tool can be tailored to your practice's needs.</th>
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</thead>
<tbody>
<tr>
<td>Develop a relationship with your Early Intervention system</td>
<td>In the NICHQ Collaboratives, teams reported that one of their most important activities was an improved relationship with their EI program, with increased communication at the local level. Enhancing this relationship allows the audiologist to more effectively explain the importance of participating in EI and provides EI a greater understanding of the impact of hearing loss on infants. Increased understanding frequently results in increased referrals and ultimately increased participation of infants with hearing loss in EI programs. Improved relations will facilitate the sharing of information on specific children, and development of tools to support sharing information across settings (i.e., shared document/spreadsheet, etc). A key first step is identifying a point of contact at your clinic and at the EI program and allowing EI staff to visit your clinic to see how babies are</td>
<td>% of team meetings with an EI representative present. % of referrals to EI that “enroll” in EI</td>
</tr>
<tr>
<td>Action</td>
<td>Description</td>
<td>Data</td>
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<tr>
<td>Develop/utilize standard template for referrals to EI</td>
<td>The creation of a standardized form will make the process of making referrals easier, improve accuracy, and ensure that all necessary information is provided. Your EI program may already have a standard form, or a form that you can use as a template. Referrals could be made through telephone contact, email, fax, or through a connected electronic health information system.</td>
<td>% of children with permanent hearing loss referred to EI</td>
</tr>
<tr>
<td>Educate families to contact EI as a next step following appointment</td>
<td>It is important to ensure that families have information on EI, including services provided and contact details, and to instruct them to contact EI directly. This information should be provided verbally and in writing.</td>
<td>% of families provided written information on EI</td>
</tr>
<tr>
<td>Work with EI to develop a process for EI to notify your clinic about enrollment outcome</td>
<td>Developing a process for EI to share the Individualized Family Service Plan (IFSP) with your audiology clinic can help you with the auditory management of the infant. This could be a fax-form or a phone call. You could also assist the EI program to standardize their releases so that they can ask for Audiology records from you and provide you with IFSP records.</td>
<td>% of children with permanent hearing loss enrolled</td>
</tr>
<tr>
<td>2. A REFERRAL TO EARLY INTERVENTION IS MADE WITHIN 7 BUSINESS DAYS OF THE APPOINTMENT WHERE PERMANENT HEARING LOSS WAS IDENTIFIED</td>
<td>Improve utilization of the state EHDI IS to automate referral to EI following diagnosis</td>
<td>Utilize the EHDI IS, when possible, to make an electronic referral to the Early Intervention System.</td>
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<td>Definition: Those children referred to Part C Early Intervention are referred within seven business days from the point of hearing loss confirmation. In states where degree and/or configuration of hearing loss is required to determine eligibility, then the referral may occur within seven days of when the type and degree of hearing loss has been established.</td>
<td>Create an alert system to flag Medical Records that require referral to EI</td>
<td>Having a standardized system for documenting when a child requires a referral to EI is the first step to an effective system for sharing information across providers. Providers should build in systems to alert and/or flag charts where the referral has not been made. These alerts may be electronic or paper mechanisms such as placing a sticker on the paper medical record indicating there is a need to refer the infant to EI. These alerts can also ensure all referrals are made within 7 days.</td>
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<tr>
<td>Families are asked to sign all necessary consent forms at audiology office to expedite referral process</td>
<td>The process of referring a family to early intervention may require the signing of one or more consent forms. This requirement is state- and/or organization-specific. Before beginning this change reach out to your local EI and EHDI programs to know what is currently available. Having families sign the necessary consent forms while they are at the appointment expedites the referral process, eliminates delays due to</td>
<td>% of families signing consent forms prior to appointment completion</td>
</tr>
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3. THE FAMILY OF INFANT WITH HEARING LOSS IS GIVEN INFORMATION ABOUT EARLY INTERVENTION PRIOR TO LEAVING THE APPOINTMENT (IN THE FAMILY’S FIRST LANGUAGE WHENEVER POSSIBLE)

**Definition:** When a child is identified to have permanent hearing loss the family is notified that they will be referred to Early Intervention and given written information about Early Intervention.

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<th>Action</th>
<th>Details</th>
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<tr>
<td>Develop and test a system to document that families of children with hearing loss are given information about EI prior to leaving the appointment.</td>
<td>Data can be documented in the chart, Electronic Health Record, through use of a checklist (see tool), or other means. The checklist tool can be tailored to your practice’s needs.</td>
</tr>
<tr>
<td>Develop an easy-to-use checklist to support families in understanding the specific next steps following diagnosis. This should be simple, including:</td>
<td>% of families of children with permanent hearing loss given information about EI prior to leaving the appointment.</td>
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<td>- see PCP</td>
<td>% of families provided a checklist.</td>
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<td>- see hearing aid specialist</td>
<td>Parent satisfaction with the checklist, reported utilization of the checklist.</td>
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<td>- call EI</td>
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<td>- contact parent group(s)</td>
<td></td>
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<tr>
<td>Include contact information on the checklist for EI and parent group(s). The checklist should be reviewed with the parent to ensure they understand next steps.</td>
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<tr>
<td>Make available in the family’s primary language</td>
<td>New Jersey’s Next Steps Checklist</td>
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<td></td>
<td>Tennessee’s Next Steps Document for Audiologists</td>
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<td></td>
<td>Alaska’s infant hearing loss checklist (Alaska NHS packet)</td>
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| prior to leaving the audiology appointment | Develop a packet of information to provide families about what to expect from EI | The process of referral and enrollment into EI can be confusing for parents. Ensure that you have written materials explaining the process, available supports, and where parents can turn for help/with questions. Be sure to make the packet available in the family's primary language. Your EHDI system or state EI program may have already developed a packet, or might be able to assist in development. | % of families provided written EI materials | CDC’s Questions You May Want t o Ask your Early Interventionist

Sites for family resources:
http://www.infantheari ng.org/workshop/index.html
http://www.handsandvoices.org/resources/products.htm#boc

| Create a list of resources for families of infants with hearing loss organized by region, and distribute to families (and make available online) | Include services and tools families can use such as care plans, roadmap, parent-to-parent supports, and access to deaf/hard of hearing adults. Your EHDI system or parent support organization may have already developed many of these materials, or might be able to assist in their development. | % of families provided list of resources
Parent report of utility and utilization of the resources and supports | “Just In Time” Hearing-Related Resources for Families

| Utilize a roadmap tool to help parents see the care pathway, including steps taken and remaining journey | Parents have reported that a "Road Map" can help them navigate the system and ensure that next steps are completed. Road map can include:
- screening results,
- evaluation results
- next steps if the baby has hearing loss, such as other recommended medical referrals
- Early Intervention | % of families provided the roadmap
Nebraska’s Roadmap: [http://dhhs.ne.gov/publichealth/EHDI/Docume nts/NICHQFamilyChecklis t-Roadmap-6-09.pdf](http://dhhs.ne.gov/publichealth/EHDI/Docume nts/NICHQFamilyChecklis t-Roadmap-6-09.pdf)
Illinois Roadmap: |
| Written materials are available in languages other than English (if and as needed for the population served by your clinic), are culturally attuned, and directed to the needs of the local populations (rural, urban, insured, migrant, etc) | Providers should ensure the appropriate materials are available so that each family receives information in their primary language, and culturally attuned to the local needs. To do this, knowing the families’ primary language prior to mailing this information is critical. To create materials for specific populations a provider may utilize various local resources including:  
- Hospital/Clinic staff interpreters  
- Parent partners in the EHDI System  
- Bi-Lingual EHDI staff  
- Community leaders | % of families who have their primary language identified  
% of families receiving written in their first language  
% of parents reporting the written material was useful (of those who report receiving written material) |  
http://www.improveehdi.org/il/roadmap.cfm  

| 4. A REFERRAL TO PARENT-TO-PARENT SUPPORT ORGANIZATIONS IS MADE WHERE FORMAL AGREEMENTS EXIST (E.G. HANDS & VOICES GUIDE BY YOUR SIDE PROGRAM) | Develop and test a system to document that families of children with hearing loss are referred to parent-to-parent support | Data can be documented in the chart, Electronic Heath Record, through use of a checklist (see tool), or other means. The checklist tool can be tailored to your practice's needs. | % of families of children with permanent hearing loss referred to parent-to-parent support | Marshfield’s Post Diagnosis Checklist  
New Jersey’s Next steps checklist  

Develop a relationship with parent-to-parent support organizations | Know who your parent-to-parent organizations are, what services they provide, how to contact them, and have a contact person to reach out to with referrals and questions. |  |  |  |
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<tr>
<th>Definition: When a child is identified to have permanent hearing loss, the family is offered a referral to parent-to-parent support services. Best practice suggests that families should be offered this referral at periodic intervals in their post-diagnostic audiology care. Families should always be offered a referral at the time the hearing loss is confirmed. However, as families may not be emotionally ready to accept the referral at that time, the benefits of parent-to-parent support and the option to make the referral should be re-visited often during the child’s first year in your care (both prior to leaving the diagnostic</th>
<th>Create a standardized form to provide referral to parent-to-parent supports (i.e., Hands &amp; Voices, Guide By Your Side programs)</th>
<th>A standardized form will make referrals easier, and ensure that all necessary information is provided. Your local parent-to-parent support group may already have a standardized form, or may be able to assist in developing one</th>
<th>Texas’s electronic Guide By Your Side Request For Services Form in English and Spanish <a href="http://www.formstack.com/forms/GBYS-request">http://www.formstack.com/forms/GBYS-request</a> <a href="http://www.formstack.com/forms/GBYS-requestSP">http://www.formstack.com/forms/GBYS-requestSP</a></th>
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<tr>
<td>Provide written materials that include background on parent-to-parent support, contact details and benefits</td>
<td>The parent-to-parent support group very likely already has these materials; ensure that you have them at your clinic and that they are provided to families.</td>
<td>% of families provided written materials</td>
<td>Wisconsin’s Guide By Your Side Brochure Washington’s Guide By Your Side Referral Form</td>
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<tr>
<td>Program materials are available in languages other than English (if and as needed for the population served by your clinic), are culturally attuned, and directed to the needs of the local populations (rural, urban, insured, migrant, etc)</td>
<td>Providers should ensure the appropriate materials are available so that each family receives information in their primary language, and culturally attuned to the local needs. To do this, knowing the family’s primary language is critical. To create materials for specific populations a provider may utilize various local resources including:  - Hospital/Clinic staff interpreters  - Parent partners in the EHDI System  - Bi-Lingual EHDI staff  - Community leaders</td>
<td>% of families who have their primary language identified % of families receiving written information in their first language % of parents reporting the written material was useful (of those who report receiving written material)</td>
<td>ASL Guide By Your Side Program Description. <a href="http://www.youtube.com/watch?v=XryWy5S9xc">http://www.youtube.com/watch?v=XryWy5S9xc</a> Washington’s Guide By Your Side Brochures available in Spanish <a href="http://www.wahandsdvoices.org/gbys/">http://www.wahandsdvoices.org/gbys/</a></td>
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appointment and at each encounter immediately following identification).