



**WISCONSIN SOUND BEGINNINGS**  
**2012 ANNUAL REPORT**



Wisconsin's Early Hearing Detection and  
Intervention Program

*"promoting hearing health...one baby at a time"*

February 2014

# WISCONSIN SOUND BEGINNINGS

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# WISCONSIN SOUND BEGINNINGS

## TABLE OF CONTENTS

Overview.....	4
WSB Mission, Vision and Guiding Principles.....	5
State of the State Overview.....	6
Total Lost-To-Follow-Up Rate (LTFU).....	7
LTFU Never Screened.....	8-9
LTFU Did Not Pass.....	10-12
Hearing Loss Diagnosis and Intervention.....	13-15
WSB Innovation.....	16-17
WE-TRAC.....	18-19

# WISCONSIN SOUND BEGINNINGS

## OVERVIEW

**Wisconsin Sound Beginnings (WSB)** is the State's Early Hearing Detection and Intervention (EHDI) program, ensuring that all babies born in Wisconsin are screened for hearing loss at birth, receive timely diagnosis of hearing loss and are referred for early intervention. WSB strives to meet the Joint Committee on Infant Hearing recommendations for newborn hearing screening and intervention. These goals are known as the **1-3-6 model**: babies are screened by **1** month of age; diagnosed by **3** months of age; and receive early intervention services (in Wisconsin, this is the Birth to 3 Program) by **6** months of age.

WSB monitors, manages and measures Wisconsin's hearing screening, loss-to-follow-up and diagnosis rates through the web-based data system, **WE-TRAC (Wisconsin EHDI-Tracking Referral And Coordination)** system). When a hospital or midwife submits a newborn blood screening card (which includes hearing screening results and other information) to the Wisconsin State Laboratory of Hygiene, the information from that card is electronically transferred into WE-TRAC. Hearing screening results come in on the blood card; are updated by WE-TRAC users (hospitals, midwives, audiologists); or users submit a request to add a case to their queue. Each WE-TRAC organization has its own queue where users enter results, update cases and refer cases that need additional hearing-related services to other organizations. Audiologists can enter diagnostic information and refer to early intervention through WE-TRAC. WE-TRAC includes information for babies born in Wisconsin (regardless of residency) but typically does not include information for Wisconsin resident babies born in other states.

Information in this report is generated from WE-TRAC. Most data from this report was calculated in August and September 2013.

# WISCONSIN SOUND BEGINNINGS

## OVERVIEW

### **Mission**

Wisconsin Sound Beginnings (WSB) will identify all babies with hearing loss by working as a team to increase the number of Wisconsin infants who are screened and receive timely, individualized follow-up care. We will increase access to hearing-related services by nurturing existing collaborations and forging new ones and providing innovative outreach and nonbiased education to families, healthcare providers and community partners. By advancing early hearing detection and quality interventions, we provide children the opportunity to develop communication skills, cognitive abilities and social-emotional well-being.

### **Vision**

All families will have equal access to a seamless system of early and continuous hearing screening, skilled and timely diagnostics and quality interventions to enable children with hearing loss to thrive.

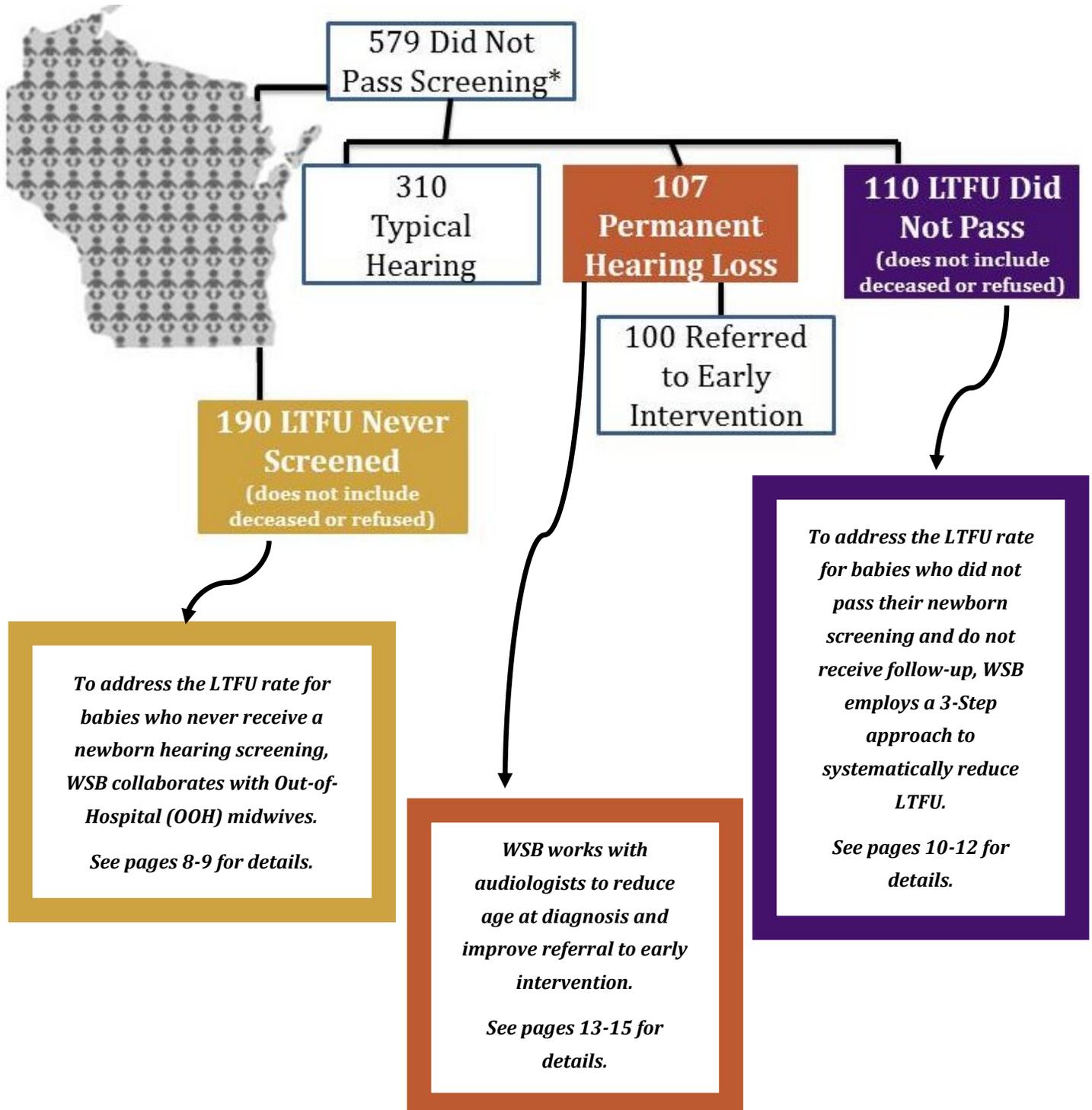
### **Guiding Principles**

- ◆ We meet families where they're at without judgment or bias.
- ◆ We drive change and decision-making through the use of sound and valid data collection.
- ◆ We work on behalf of the well-being of children and strive to optimize their potential.
- ◆ We are dedicated to innovative development and sustainable solutions.
- ◆ We respect ourselves, our team, our clients and our community.
- ◆ We forge new and nurture existing creative collaborations and promote partnerships.
- ◆ We value parent perspectives in family support, program design and process improvement.

# WISCONSIN SOUND BEGINNINGS

## 2012 STATE OF THE STATE OVERVIEW

In 2012, hospitals and midwives screened 99 percent of babies born in Wisconsin.



\*the 579 reflects the total number of babies who "Did Not Pass Screening" and includes babies who did not pass and died or refused follow-up and those who received follow-up and were diagnosed with a transient conductive hearing loss.

# WISCONSIN SOUND BEGINNINGS

## SYSTEMATICALLY REDUCING LOSS TO FOLLOW-UP

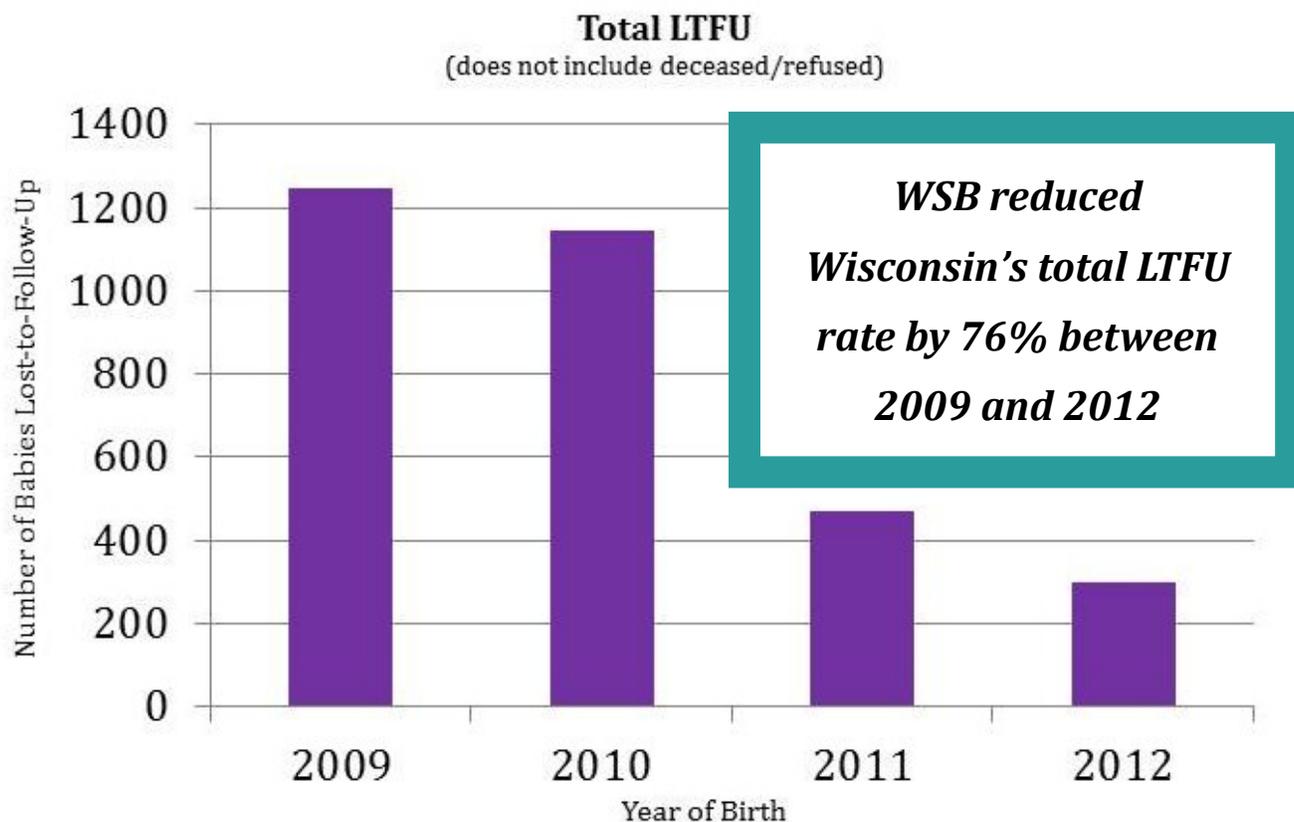
Wisconsin Sound Beginnings identifies two populations as “lost to follow-up” (LTFU):

1. Babies who never had their hearing screened (*never screened*).
2. Babies who were screened but did not pass and have not received follow-up (*did not pass*).

Wisconsin Sound Beginnings (WSB) works to reduce LTFU among these two populations in separate ways, targeting interventions to meet each group’s unique needs.

However, to get a global picture of babies who need a service but did not receive it (either an initial screen or a follow-up screen/diagnosis), WSB combines these two populations to calculate our Total LTFU rate.

WSB’s efforts targeting the *never screened* population and the *did not pass* population have systematically reduced Wisconsin’s LTFU rate (see the following pages for details).



# LOST TO FOLLOW-UP

## NEVER SCREENED

Wisconsin Sound Beginnings uses a three-pronged approach to decrease the number of babies who never receive a hearing screening. In Wisconsin, babies who do not receive a screening are predominantly born out-of-hospital (OOH).

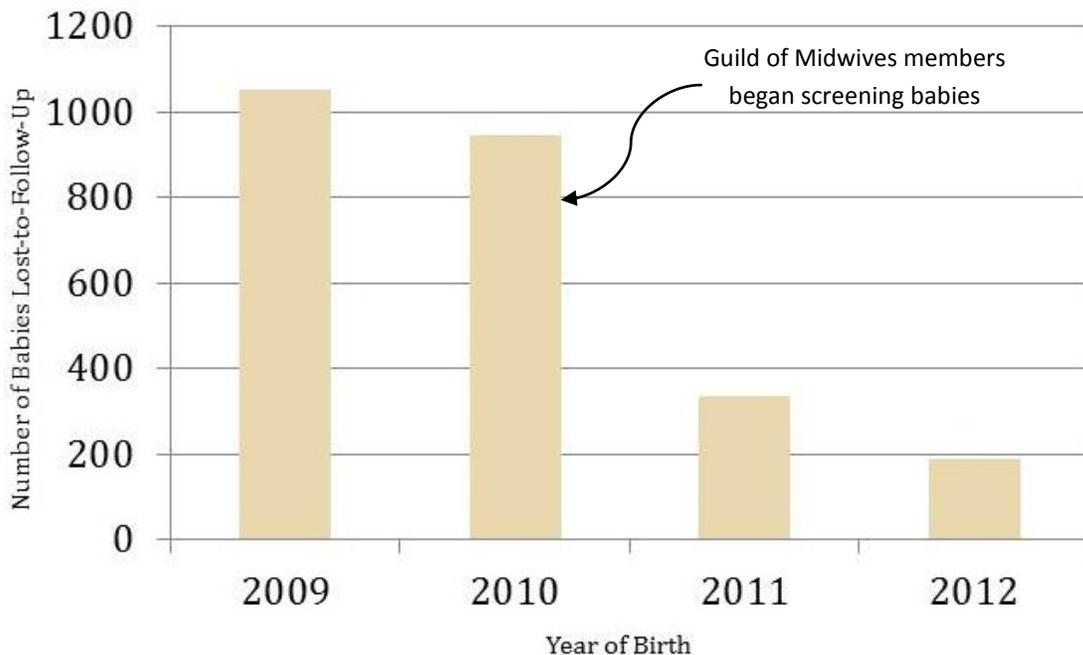
To reach OOH families, WSB collaborated with the Wisconsin Guild of Midwives, providing them with OAE (otoacoustic emissions) screeners that 24 Licensed Midwives share. Babies attended by these OOH midwives typically receive initial hearing screening within two weeks of delivery. Babies who do not pass twice on OAE are referred to audiology for follow-up. For those families who have financial, cultural or transportation barriers to audiology care, they are referred to WSB staff for an in-home ABR (automated brainstem response) screen. Since 2010, **five OOH babies have been identified with hearing loss.** The Guild has a sustainability plan to maintain the OAE screeners and manages the screener program themselves.

“Having access to hearing screeners and a system to refer babies to gives me the opportunity as a provider to remain up-to-date with the community standard of care and be part of a larger medical and public health system that benefits all babies born in our state.”

OOH Licensed Midwife

Another part of WSB’s OOH outreach to reduce the never screened LTFU rate is **Plainclothes Outreach** to the Amish and Mennonite (plainclothes) populations. Many families in these communities choose to have unattended deliveries or seek care from Amish birth attendants. WSB staff has attended meetings and sponsored a training for Amish birth attendants as part of a multi-disciplinary team collaborating with the Plainclothes communities to provide access to newborn hearing, blood and pulse oximetry screening.

**LTFU for Babies Who Were Never Screened**  
(does not include deceased/refused)



# LOST TO FOLLOW-UP

## NEVER SCREENED

WSB also conducts OOH Screening Clinics to reach families in areas served by a midwife not participating in the Guild of Midwives hearing screening program. WSB works with these midwives to provide clinics in collaboration with University of Wisconsin-Madison and Waisman Center audiologists and students. Since 2009, **we have held eight clinics in four locations, serving 190 people.** In 2012, WSB began serving a new community in collaboration with Eau Claire City-County Public Health and local providers, traditional birth attendants, midwives and stakeholders.

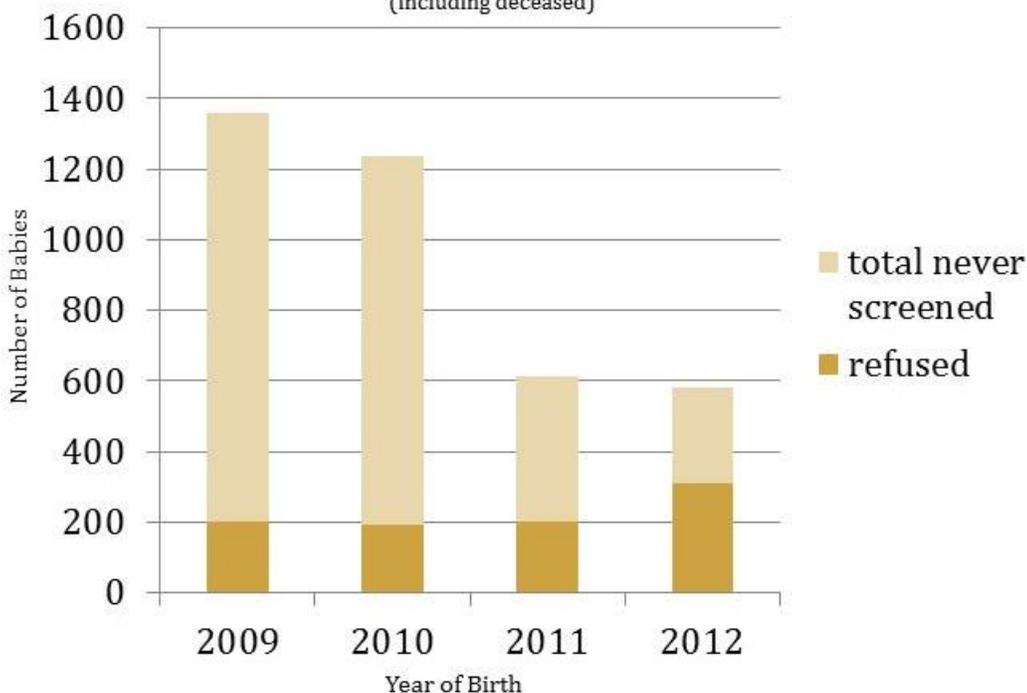
“I host a daylong hearing screening clinic at my home for babies born in my midwifery practice. I want to make sure it is understood how much this service is appreciated by me and the families I serve. It means a lot to be able to offer this service to my clients in a setting that is familiar and comfortable for them. ‘This is so much nicer than going to a hospital or clinic!’ one mother remarked. I am convinced that many of these babies and toddlers might not otherwise be screened.”

OOH Midwife

**An Emerging Issue:** WSB’s efforts to address the never-screened population have primarily focused on access to hearing screening, dramatically decreasing the number of babies who are never screened. However, the number of families refusing the initial screening has increased. Refusing screening has emerged as an area of concern. This apparent increase in refusals may be due in part to improved documentation (see page 12 for details regarding case-closed definitions). While a case may have previously been closed in WE-

TRAC as “lost-to-follow-up” or “other,” the case is now closed more accurately as “refused.” With this apparent increase in the number of families refusing screening, future efforts may include promotional and educational activities or campaigns to address this issue.

**Number of Families Refusing Hearing Screening Compared to the Total Number of Babies Never Screened**  
(including deceased)



# LOST TO FOLLOW-UP

## DID NOT PASS

The second at-risk-to-LTFU group of babies that WSB targets are those babies who are screened at birth but do not pass and have not received follow-up by 30 days of age.

Wisconsin Sound Beginnings employs an innovative **3-Step-Follow-Up (3SFU)** process to target these cases:

**STEP 1: Medical Home Outreach:** WSB identifies babies at risk for LTFU (babies in WE-TRAC who did not pass the inpatient screen and have not received follow-up by 30 days of age); reaches out to birth units, medical homes (primary care providers) and audiology clinics to determine if the child has received follow-up; and informs primary care and medical home of hearing screening results and the need for follow-up.

All babies who are identified as at-risk-to-LTFU pass through this step. Cases can be resolved at Step 1 or, if needed, they move on to either Step 2 or Step 3. For some babies in designated areas, cases skip Step 2 and move on to Step 3 for an in-home or in-community screen or more intense case management.

**STEP 2: Parent-to-Parent Outreach:** For those cases that were not resolved during Medical Home Outreach, the case moves on to Step 2. WSB provides parent-to-parent outreach to families with at-risk babies to encourage follow-up, address concerns and answer questions. Parent Guides contact families by phone or letter and are available to support parents as they move through the Early Hearing Detection and Intervention (EHDI) continuum of care.

If a Parent Guide is unable to reach a family or for those families who cannot or will not access the traditional healthcare system, the case moves on to Step 3.

***“Thank you for coming here. I just couldn’t afford another co-pay at the doctor’s office.”***

—Family receiving in-home re-screen

***“Thanks for calling me, I didn’t even know you could test a baby’s hearing!”***  
—Mother receiving parent-to-parent outreach

**STEP 3: Regional Outreach:** After passing through Steps 1 and 2, the most difficult cases move on to Step 3 for additional outreach and/or case management. WSB provides in-home or in-community rescreens for those families experiencing barriers (cultural, linguistic, logistical, etc.) to accessing the health care system. WSB Regional Outreach Specialists frequently collaborate with local public health departments, WIC clinics or community service agencies to help reach families or coordinate care.

# LOST TO FOLLOW-UP

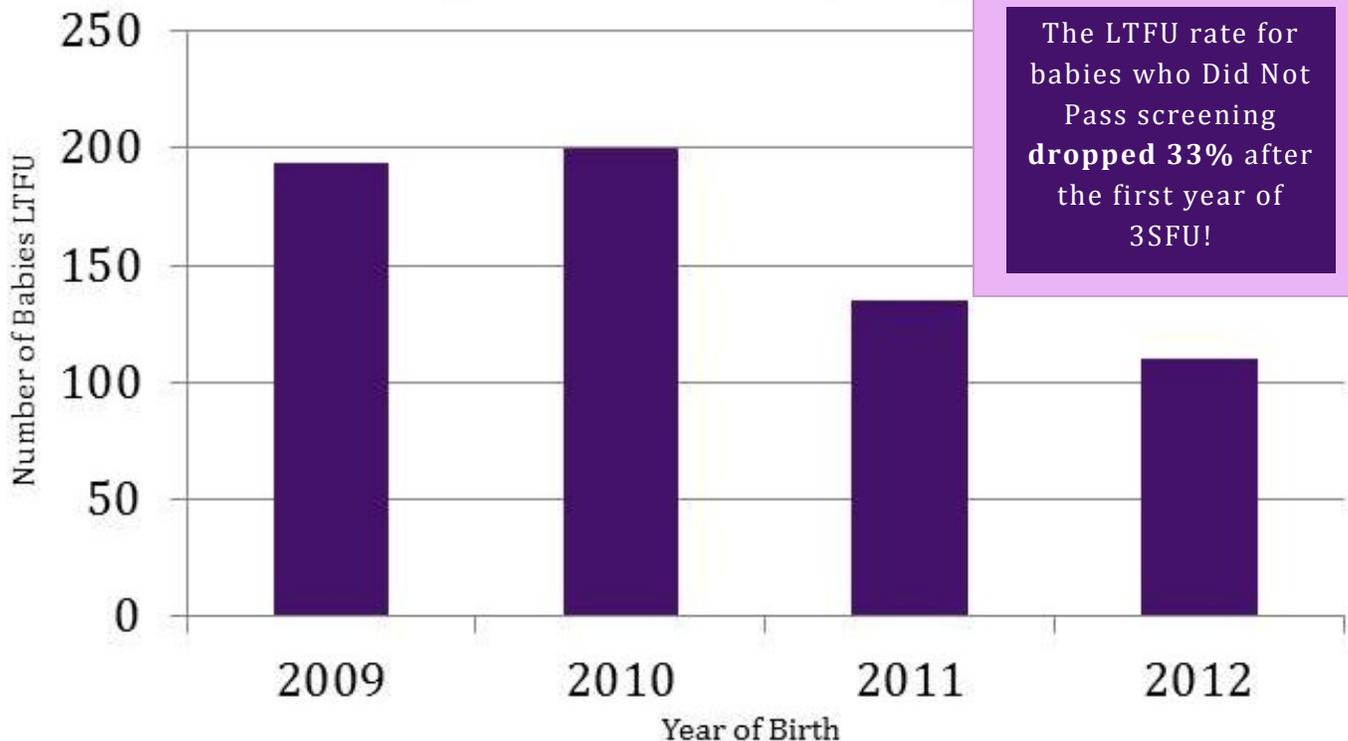
## DID NOT PASS

Of Wisconsin babies born in 2012, WSB identified 387 as at-risk-to-LTFU after they reached 30 days of age without receiving rescreening or diagnostic services as documented in WE-TRAC. In 2012, more than half of those babies who Did Not Pass screening were identified as at-risk for LTFU and required WSB's 3-Step-Follow-Up intervention.

***In 2012, 67% of babies who Did Not Pass were deemed at-risk-to-LTFU and went through 3SFU.***

WSB assisted in successfully resolving 342 of these at-risk cases (88% success rate). All 342 cases went through Step 1 (Medical Home Outreach) of 3SFU. Only those cases that required additional WSB loss-to-follow-up prevention intervention moved on to the next steps. Of these 342 resolved cases, 218 required only Step 1 to be resolved (64%); 79 cases were resolved at Step 2 (23%); and 45 cases were resolved at Step 3 (13%). Of those cases resolved at Step 3, 26 cases went through Steps 1 and 2, while 19 went directly from Step 1 to Step 3.

**LTFU for Babies Who Did Not Pass Screening & Did Not Receive Follow-Up**  
(does not include deceased/refused)



# LOST TO FOLLOW-UP

## DID NOT PASS

Similarly to 'refusing screening' emerging as a reason for babies never being screened, reasons for case closure for babies who Did Not Pass have been changing as well. In WE-TRAC, users have several

### WE-TRAC Case-Closed Definitions:

\*Non-resident birth: Child was born in a Wisconsin facility, but lives and receives follow-up in another state.

\*Moved out of state: Child was born and lived in Wisconsin, but moved.

\*Refusal of hearing-related care: Family states they do not want hearing-related care for their child.

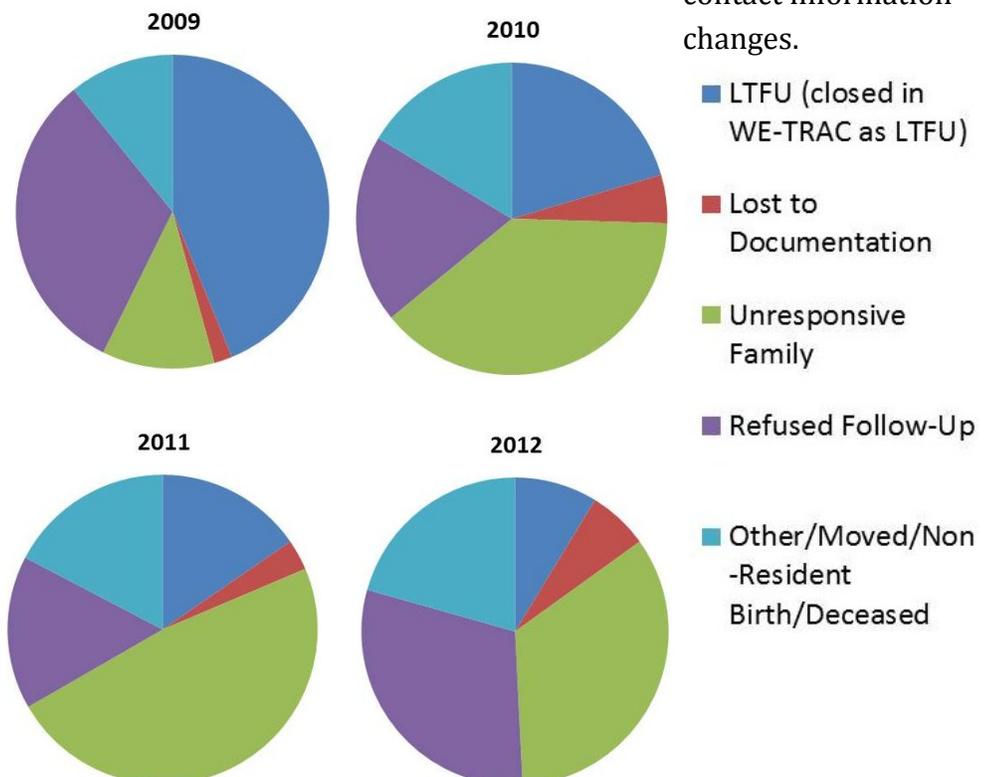
\*Unresponsive family: Family has been unresponsive to follow-up efforts including missing appointments, failing to return phone calls, not responding to mail, etc.

\*Lost to documentation: There is reason to believe that child received appropriate follow-up, but no documentation has been found.

\*Lost to follow-up: Unable to contact the family, phone is disconnected, address is wrong, etc.

options for how to close a case (that has not been successfully completed). The WSB safety net extends to closed cases as well. WSB modifies case-closed reasons when appropriate and reaches out to users for clarification. WSB reopens cases for babies who refer and have not gone through 3SFU or for those cases that merit additional outreach or investigation. This has resulted in fewer closed cases and more accurate data. To address lost to documentation, WSB collaborates with other states to document results for babies receiving follow-up at non-Wisconsin clinics that do not report to WE-TRAC. WSB also follows up with primary care providers to get documentation if a family reports being screened somewhere. WE-TRAC also has a function to allow users to request that a baby seen in their facility but whose case is not on that facility's queue be placed there. To address unresponsiveness, WE-TRAC collaborates with WIC and the State Vital Records Office to identify additional phone numbers or addresses for families, improving WSB's ability to reach at-risk families whose

contact information changes.



# HEARING LOSS

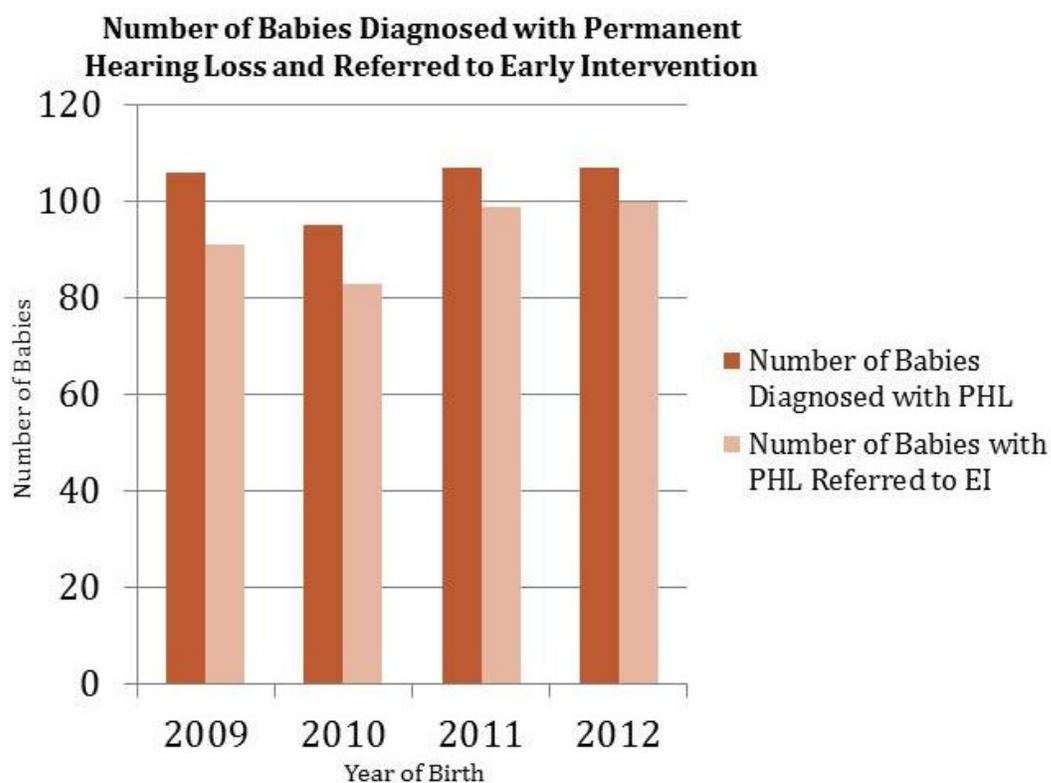
## DIAGNOSIS AND INTERVENTION

For those children who are screened, do not pass and receive diagnostic audiology follow-up, WSB routinely evaluates the number of children diagnosed with permanent hearing loss (PHL), how quickly they are diagnosed (the goal being by 91 days of age) and whether they are referred to Early Intervention. These data inform our efforts to improve the process of getting to diagnostic audiology services (reduce LTFU), increase the percentage of children diagnosed by three months (91 days) of age and ensure that those children who are diagnosed are referred to Early Intervention.

According to national incidence data, approximately 140 to 200 babies should be identified with congenital hearing loss in Wisconsin each year. Since 2008, the Wisconsin birth rate has been in steady decline. In 2009 there were 70,824 births, whereas preliminary data suggests there were only 66,035 babies born in 2012. Therefore, we would expect a possible decrease in the number of babies identified with hearing loss between 2009 and 2012. Instead, the number of babies identified has remained fairly consistent at around 100 each year.

Evidence indicates that along with early identification, enrollment in high-quality Early Intervention (EI) programs leads to improved outcomes for children who are deaf or hard-of-hearing. Audiologists are able to refer families automatically to local Birth to 3 programs through WE-TRAC. In 2012, WSB and Birth to 3 created an automated mechanism for WE-TRAC to receive information regarding a family's Individualized Family Service Plan (IFSP) date and participation status. However, issues remain with the validity of these data fields.

Future directions for improvement include reviewing and exploring this data transfer. Future WSB efforts will additionally address EI referrals, enrollment and retention rates.

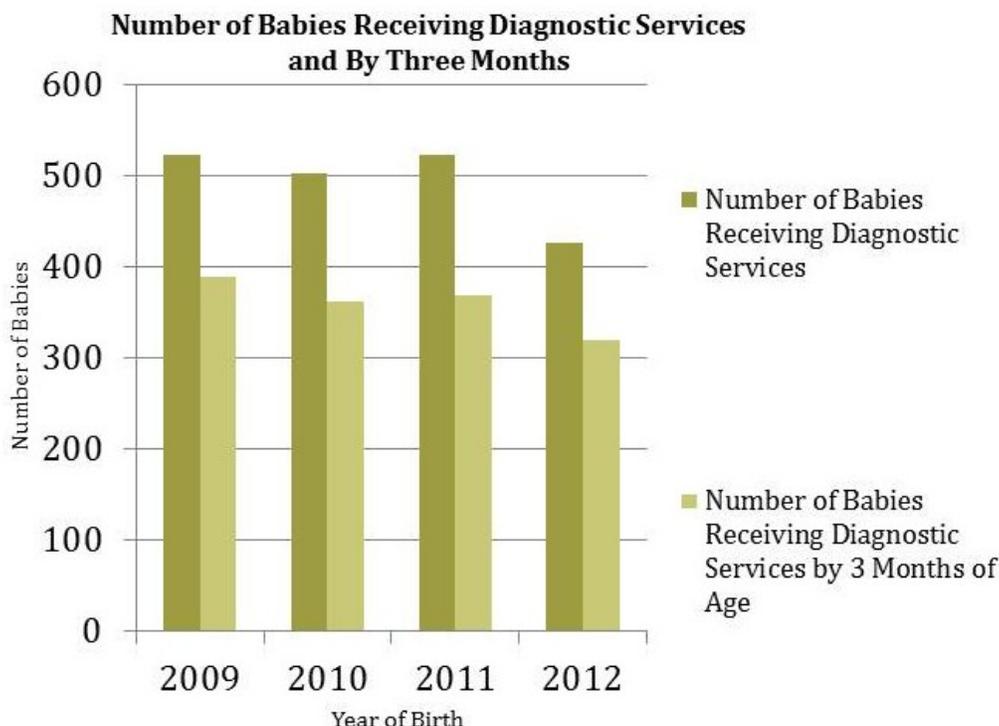


# HEARING LOSS

## DIAGNOSIS AND INTERVENTION

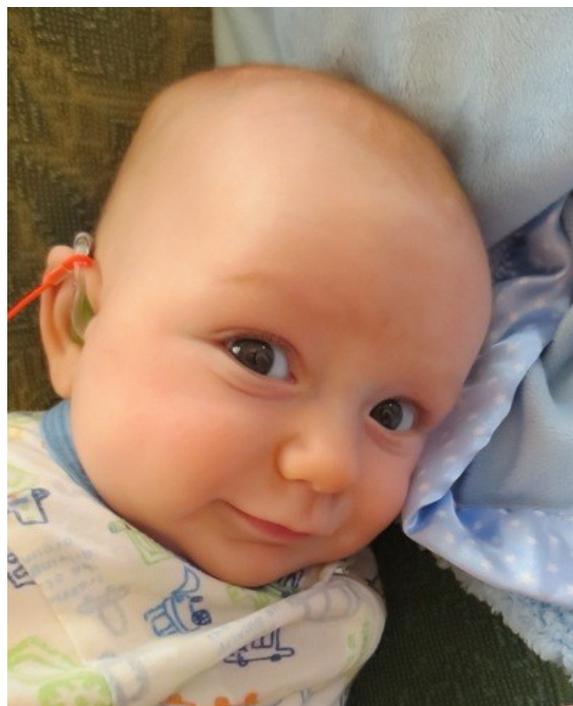
The percentage of babies receiving diagnostic services, *regardless of diagnostic outcome* (within normal limits, permanent/transient hearing loss), by three months of age has hovered around 72 percent for the last four years (2009-2012). WSB reaches out to audiology clinics to encourage accurate and timely

data reporting to help ensure that what is being reported in WE-TRAC reflects what occurred in the clinics. WSB promotes best practice as reporting information and results in WE-TRAC within one week of the child's appointment. WSB also provides quality improvement technical assistance to clinics that need or request it. Audiology clinics can access reports through WE-TRAC so they can monitor their clinic's performance. One of the workgroups of the



Newborn Screening Advisory Group Hearing Subcommittee focuses on improving the diagnostic process. This treatment and management workgroup is also examining ways to improve the collaboration between ENT and audiology to ensure that families receive efficient hearing screening, follow-up, appropriate medical management and a unified message about hearing-related care.

In 2012, WSB added optional treatment and management data items in WE-TRAC. The goal is for audiologists to routinely enter this information in WE-TRAC. These data items include: referrals to other providers (ENT/Ophthalmology/Genetics); hearing aid or assistive device recommendations and fittings; and dissemination of information to parents.



# HEARING LOSS

## DIAGNOSIS AND INTERVENTION

While the percentage of babies receiving diagnostic services, regardless of outcome, by three months of age has stayed relatively steady at 72 percent, this is not the case for those babies *diagnosed with a hearing loss* (and referred to Early Intervention). For these babies in 2012, the percentage who received a hearing loss diagnosis by three months of age was just **51 percent**.

Although most of the diagnoses occurred around 100-200 days from birth (3-6 months of age), a handful of babies weren't diagnosed until more than a year after birth. Of the babies diagnosed after 200 days, *67percent had four or more appointments*. Some babies had more than six appointments, including one baby who was screened five times prior to diagnosis.

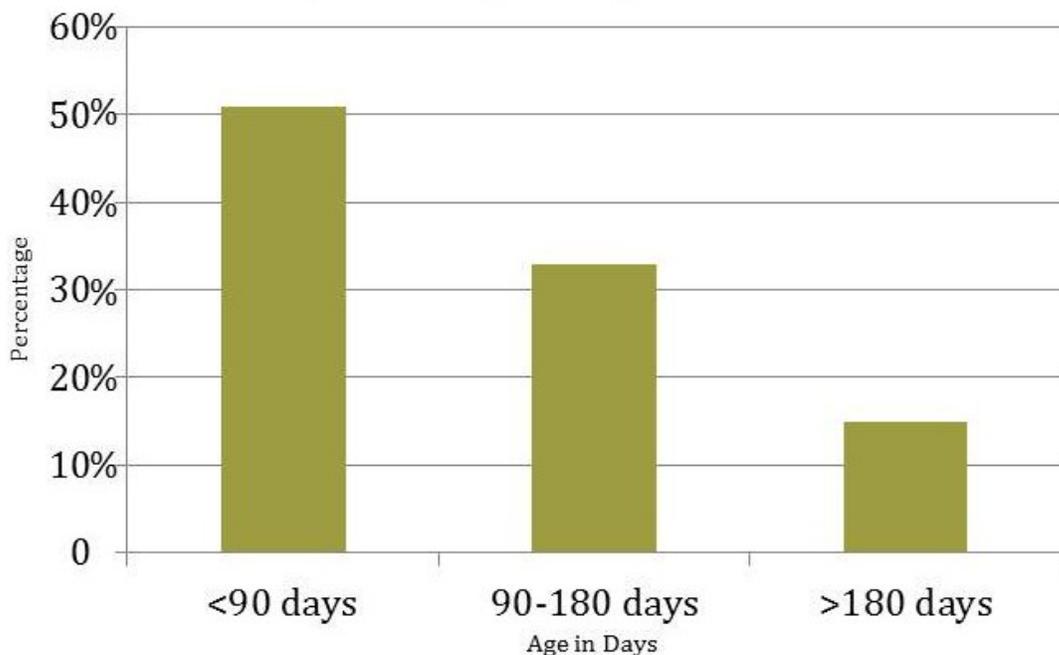
Factors associated with delayed diagnosis include repeated rescreens and deviations from recommended follow-up protocol; repeated rescreens due to suspected middle ear involvement; and multiple ENT appointments due to suspected middle ear involvement.

**In 2012, only 51% of babies with hearing loss were diagnosed by 3 months of age.**

In 2012:

- ⇒ Average number of days from birth to final hearing loss diagnosis: 116
- ⇒ Median number of days from birth to final hearing loss diagnosis: 89
- ⇒ Minimum number of days: 4
- ⇒ Maximum number of days: 528

Age of Hearing Loss Diagnosis in 2012



# WSB INNOVATION

## AEIOU

AEIOu (Assessment of Early Intervention Outcomes) tracks developmental outcomes of early-diagnosed children who are deaf or hard of hearing and enrolled in Wisconsin Birth to 3 in the areas of general, communication and social development; the early intervention they receive; and the variables that affect positive outcomes. With this information, in the future we may be better able to understand and help parents and service providers meet the needs of children who are deaf or hard of hearing.

When a diagnosed child is one year old, WSB contacts the child's family to invite them to participate in AEIOu and offer additional support or information about services, such as Guide By Your Side. To participate, families complete three developmental questionnaires and send WSB staff copies of their child's Individualized Family Service Plans (IFSP) and audiological reports. Families participate when their child is approximately 14 months old and again at approximately 30 months. Participating families and their Birth to 3 providers then receive a summary of the child's development.

To date, 19 children have successfully completed assessments at both 14 and 30 months of age. Seven of these children have hearing loss only and five have additional disabilities. All are English-speaking. For the seven children who have hearing loss only, the time between the first assessment (at 14 months) and the second assessment (at 30 months) averaged 21 months. For the five children who are deaf/hard of hearing with additional special needs, the average time elapsed between phase 1 and phase 2 was 20 months. For a typically developing child, we would expect to see equal growth per months of time (so for a 21-month time period, we would expect 21 months of growth). From the preliminary data, shown below, we see that children who are deaf or hard of hearing are making progress, but for the majority of those who have completed the study, not at a month-to-month rate. This is an ongoing study and more results will be available as more children participate and complete both phases.

<b>Assessment Tool</b>	<b>Average Growth in Months Over an Average of 21 Months of Time (Deaf/Hard of Hearing Only)</b>	<b>Average Growth in Months Over an Average of 20 Months of Time (Deaf Plus Additional Special Needs)</b>
Minnesota Receptive Language	15 months	6.1 months
Minnesota Expressive Language	22 months	5.5 months
MacArthur-Bate Expressive Vocabulary	13.6 months	6.8 months

AEIOu is coordinated by the Waisman Center at the University of Wisconsin-Madison and is part of a national project called the National Early Childhood Assessment Project at the University of Colorado-Boulder.

# WSB INNOVATION

## WIC

WSB has a Memorandum Of Agreement with Wisconsin WIC (Special Supplemental Nutrition Program for Women, Infants and Children), allowing WSB access to WIC's statewide data system. WSB divided the state's 92 WIC sites into follow-up protocols A and B. As part of 3SFU, WSB places an alert in the WIC file for any WIC participant baby at risk for LTFU. WSB removes the alert after the baby receives follow-up. WSB began placing, tracking and removing alerts in December 2011. WSB tracks alerts and their outcomes to evaluate the alert protocols and document any emerging trends.

The WIC alerts are fully integrated into the 3SFU protocol. Those cases with WIC A alerts pass through all 3 Steps (Medical Home Outreach, Parent-to-Parent Outreach and Regional Outreach). Those cases with WIC B alerts go directly from Step 1 (Medical Home Outreach)

	WIC A	WIC B
<b>Total Number of Alerts</b>	114	32
<b>Successfully Completed Cases</b>	84 (74% success rate)	23 (72% success rate)
<b>Still Active Cases</b>	12	4
<b>Cases Receiving an In-Home/Community Screen</b>	26	10

to Step 3 (Regional Outreach). Since 2011, WSB has placed 146 total alerts (for babies at risk to LTFU at 1 month of age).

**WIC A: HEARING SCREENING ALERT: Baby did not pass newborn hearing screening and needs follow-up. Give family Hearing Screening Follow-up Letter and review it when you interact w/family.**

**WIC B: HEARING SCREENING ALERT: Baby did not pass newborn hearing screening. Wisconsin Sound Beginnings can conduct a hearing screen with baby's next WIC appointment. Call Susan 414-555-1234 to coordinate care.**

WSB, in collaboration with the Waisman Center, was recently awarded a Research Grant from the Centers for Disease Control and Prevention. This grant, Determining Successful Strategies for Improving Newborn Hearing Screening Follow-Up through a WIC/EHDI/UCEDD Partnership, is to further investigate the impact the alerts have on WSB's LTFU.

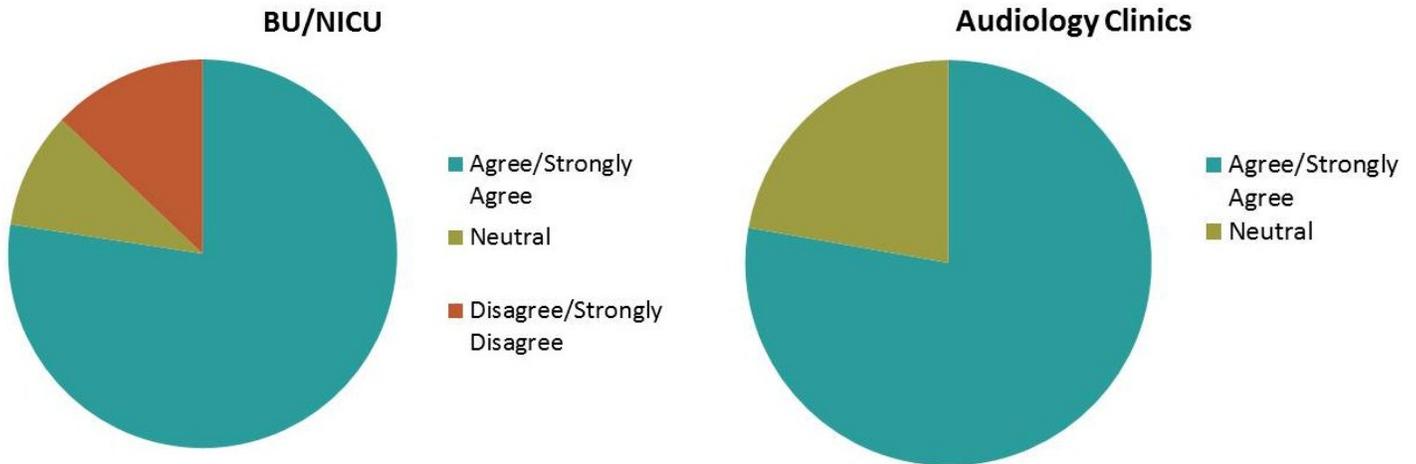
# WE-TRAC

## WISCONSIN E<sub>H</sub>DI TRACKING REFERRAL AND COORDINATION

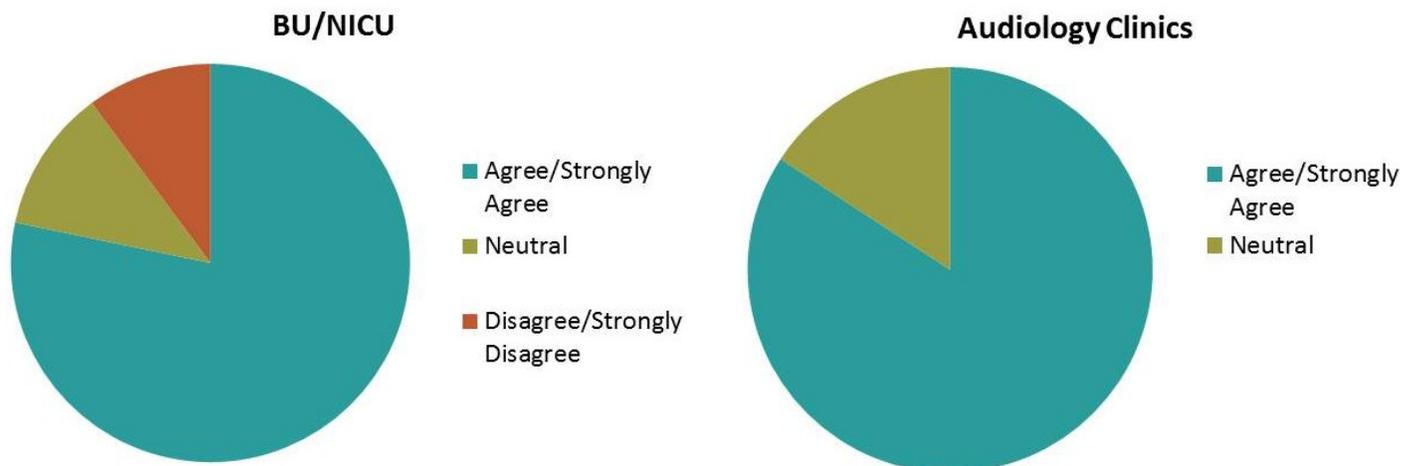
In 2012 and 2013, the WE-TRAC workgroup of the Newborn Screening Advisory Group Hearing Subcommittee created a survey for all Birth Unit (BU), NICU (neonatal intensive care unit) and Audiology Clinic users. The survey queried users about their satisfaction with WE-TRAC, their confidence in WE-TRAC's data and WE-TRAC's role in Wisconsin's EHDI program.

Based on a response rate of 20 percent, some of the survey results were:

### Data Found in WE-TRAC is Complete and Valid



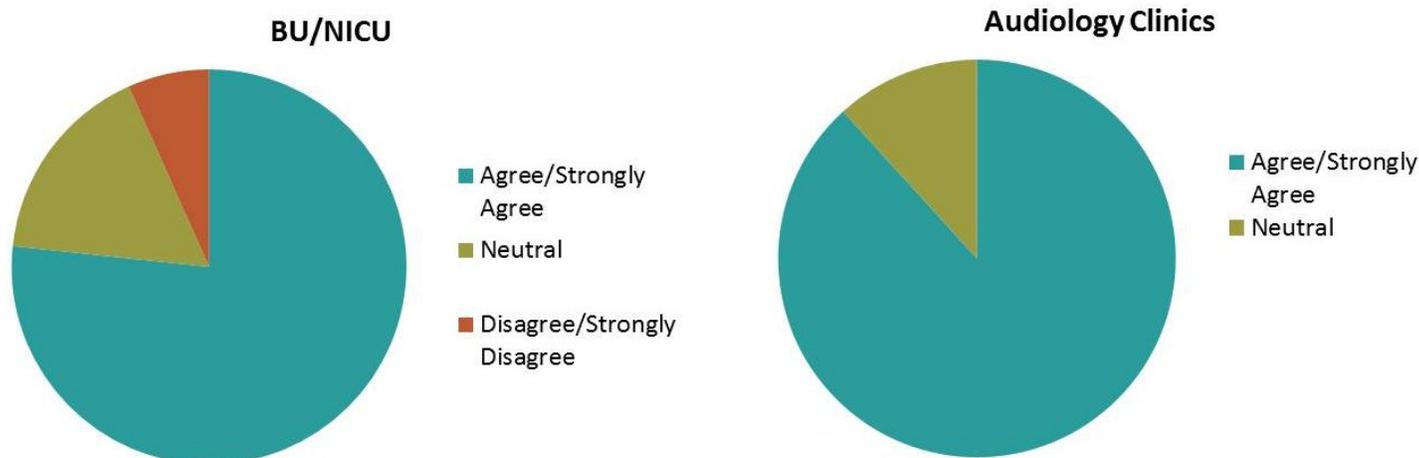
### WE-TRAC is a Useful Tool in Assuring that Babies Receive Timely and Appropriate Follow-Up Hearing-Related Care (Don't Fall Through the Cracks)



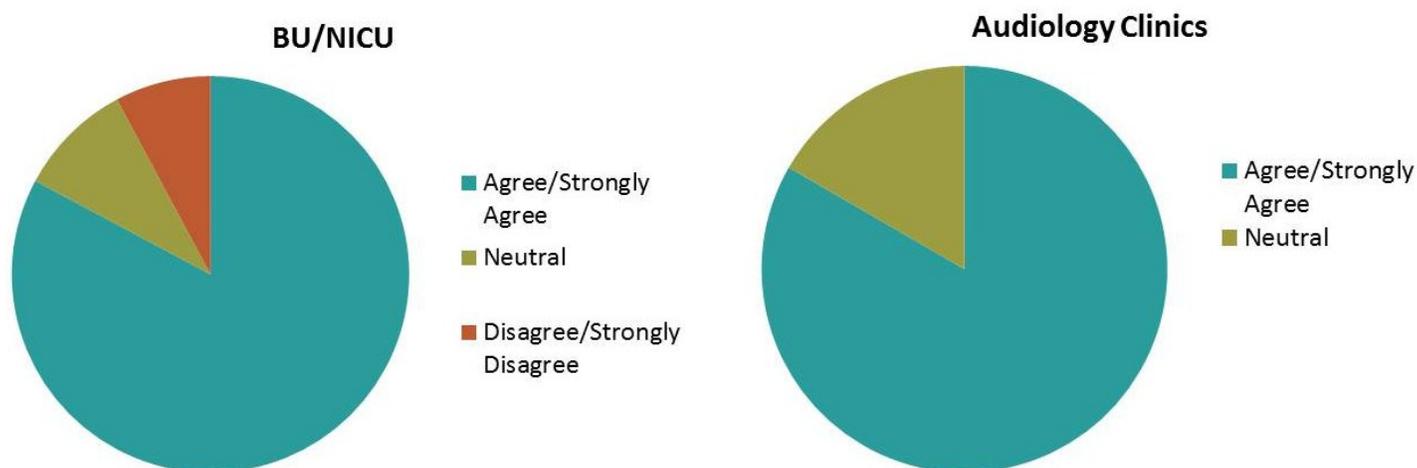
# WE-TRAC

## WISCONSIN E<sub>H</sub>DI TRACKING REFERRAL AND COORDINATION

### WE-TRAC Accurately Reflects the Speed Between Steps in the E<sub>H</sub>DI System



### WE-TRAC is an Effective Mechanism for Measuring How Many Babies Born in Wisconsin Are Screened, Referred and Diagnosed with Permanent Congenital Hearing Loss



### WE-TRAC Survey Lessons Learned:

- Both Audiology Clinics and BU/NICU users reported that WE-TRAC was easy to use/access.
- Users reported not knowing how the cases arrive in WE-TRAC in the first place; users also requested functions in WE-TRAC that already exist or described problems that WE-TRAC already has an ability to fix. These findings reveal a need for continued education, information and support.
- There are interesting differences between audiology users and BU/NICU users concerning their responses about the accuracy of the information in WE-TRAC. This is an issue that might merit further investigation.



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Wisconsin Sound Beginnings

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