


# Wisconsin Sound Beginnings 2014 Annual Report



Ensuring  
Newborn  
Hearing  
Screening

Reducing  
Loss to  
Follow-Up  
for Babies  
Who Did  
Not Pass  
their  
Hearing  
Screening

Providing  
Additional  
Outreach  
and  
Screening

Reducing  
Time to  
Diagnosis

Supporting  
Early  
Intervention  
and  
Improving  
Outcomes

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## 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

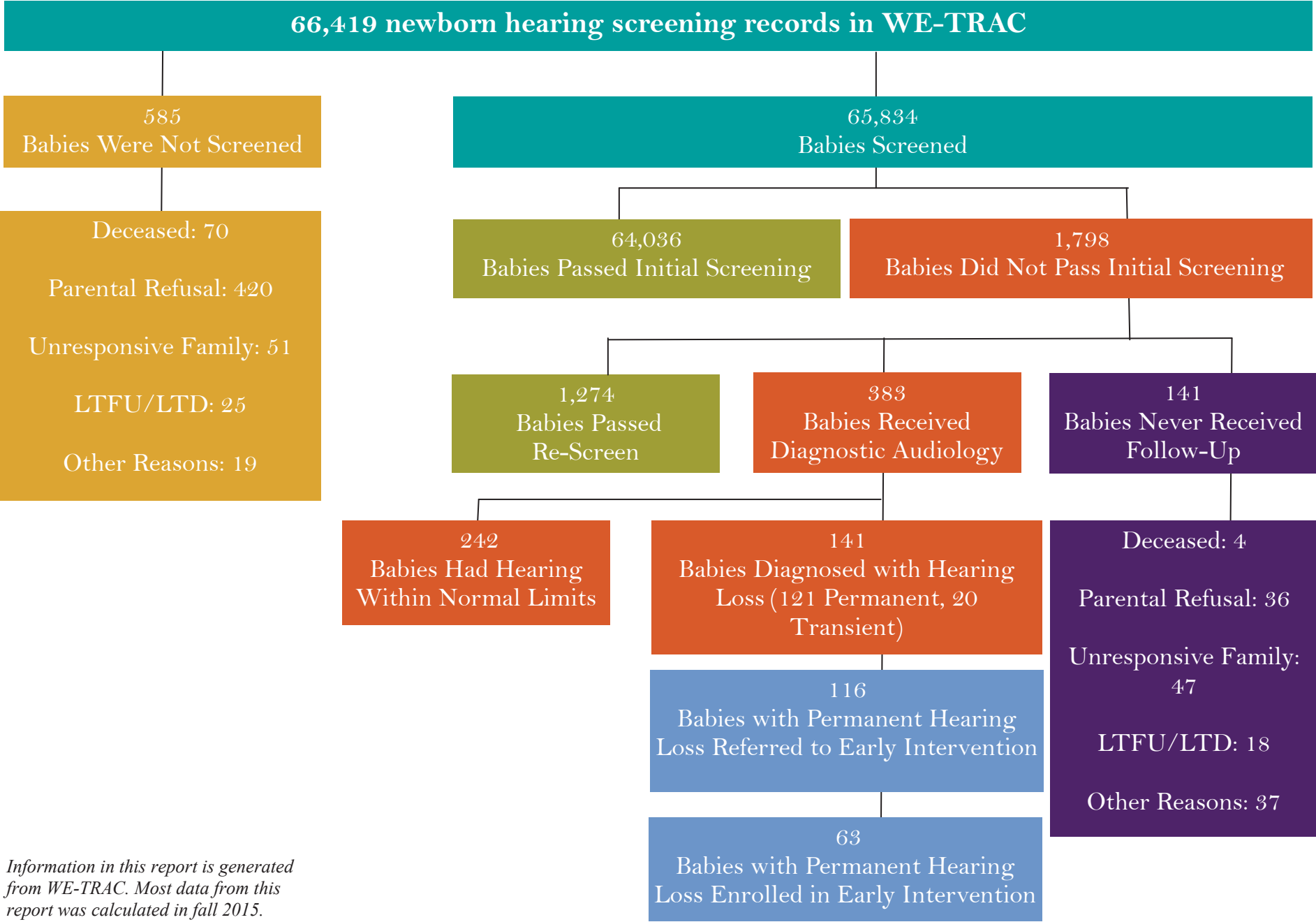
- We meet families where they're at without judgment or bias.
- We drive change and decision-making through the use of sound and valid data collection.
- We work on behalf of the well-being of children and strive to optimize their potential.
- We are dedicated to innovative development and sustainable 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.



**The Wisconsin Sound Beginnings Team**

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# 2014 Screening and Diagnostic Numbers



*Information in this report is generated from WE-TRAC. Most data from this report was calculated in fall 2015.*

**Wisconsin Sound Beginnings** is the state’s Early Hearing Detection and Intervention (EHDI) Program, ensuring that all babies born in Wisconsin are screened for hearing loss, receive timely diagnosis of hearing loss, and have access to quality early intervention services. WSB strives to ensure Wisconsin meets 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 by **6** months of age. WSB monitors, manages, and measures Wisconsin’s hearing screening, loss to follow-up, and diagnosis rates through its data system, **WE-TRAC** (Wisconsin EHDI-Tracking, Referral and Coordination). WSB is administered collaboratively through contracts between the Department of Health Services and the University of Wisconsin-Madison Waisman Center University Center for Excellence in Developmental Disabilities, State Laboratory of Hygiene, Chippewa County Health Department and the City of Milwaukee Health Department.

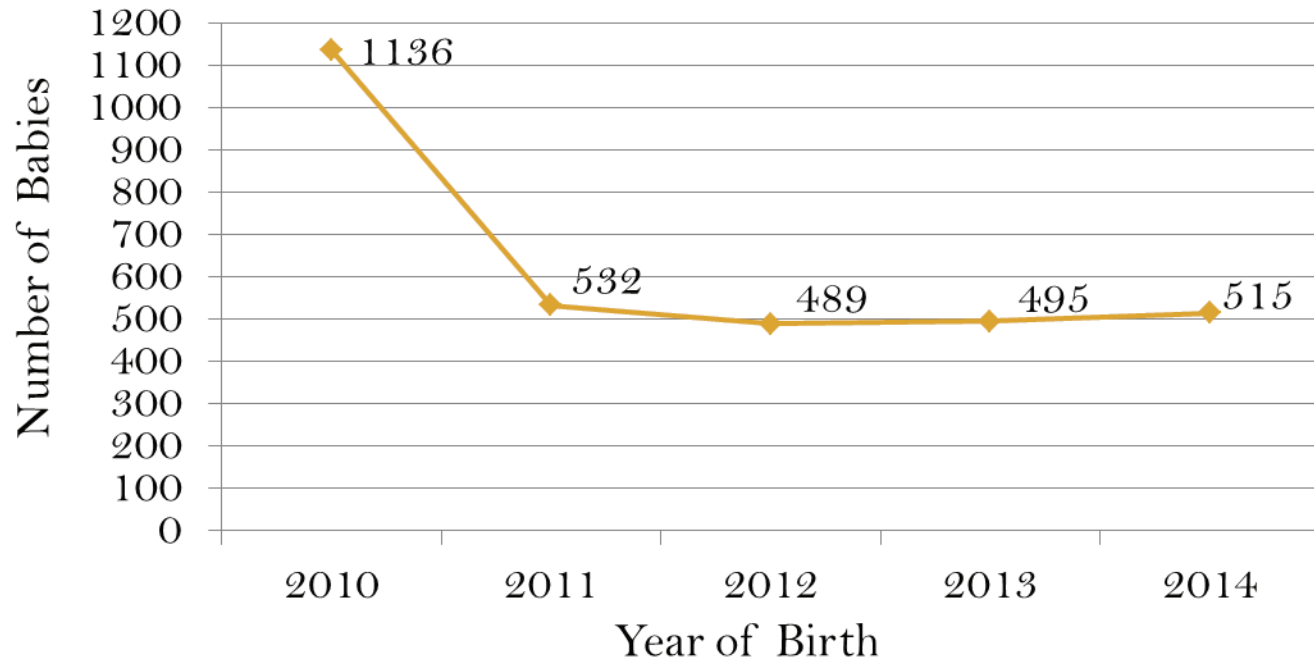
**Wisconsin Sound Beginnings** works to:

- *Ensure All Babies Are Screened or Have Documented Refusal*
- *Reduce Loss to Follow-Up (LTFU) for Babies Who Did Not Pass their Newborn Hearing Screening*
- *Reduce the Time to Diagnosis for Babies Who Need Diagnostic Services*
- *Support Early Intervention and Improve Outcomes for Babies Diagnosed with Hearing Loss*

<b>National Targets</b>	<b>2014 Wisconsin</b>
Refer rate: ≤4%	Refer Rate: 2.5%
Screen rate: 100%	Screen Rate: 99%
All Babies Screened by 1 Month	All Babies Screened by 1 Month: 98%
Diagnosed by 3 Months	Diagnosed by 3 Months: 50%
Enrolled in Early Intervention by 6 Months	Enrolled in Early Intervention: 54% Of those who enrolled, 71% enrolled by 6 Months

# Ensuring Newborn Hearing Screening

## Number of Babies Not Receiving Hearing Screening (not including deceased)



WSB focused efforts to increase screening among babies born out of hospital (OOH) and/or to members of the Plain Community (Amish/Mennonite) in 2014 by:



- Holding two outreach clinics in key areas of the state, providing screening and/or diagnostic services for 32 children.
- Providing in-home screenings to 95 babies born OOH.
- Providing more than 20 hands-on trainings/technical assistance to traditional birth attendants or midwives.
- Participating in two community meetings with 325 attendants to establish and strengthen local partnerships to educate providers and community members and ensure access to newborn screenings.

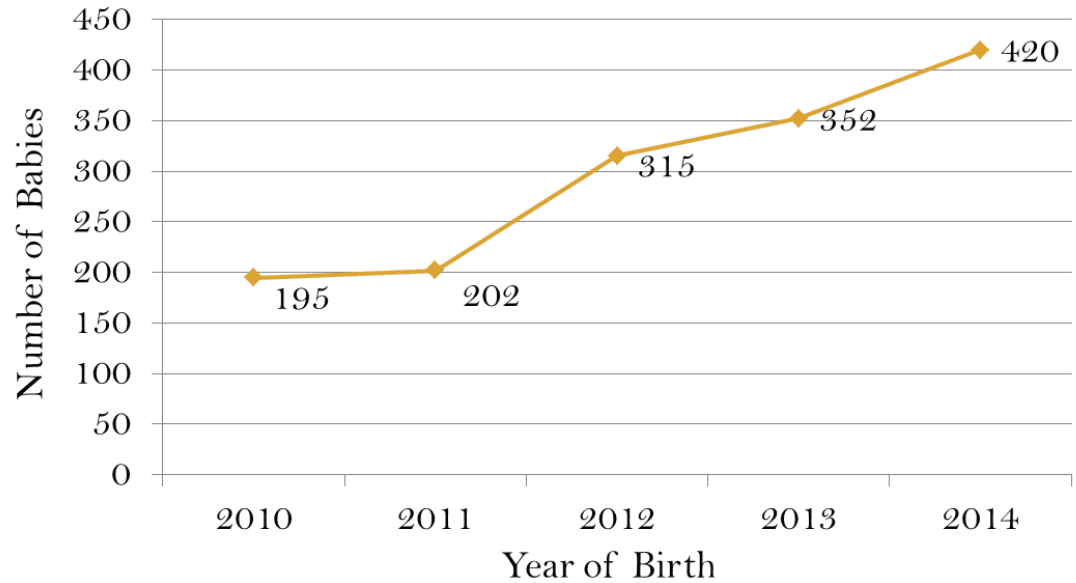


Despite efforts to increase hearing screening rates, the number of families documented as having refused newborn hearing screening has more than doubled from 195 in 2010 to 420 in 2014. This may be due in part to better documentation.

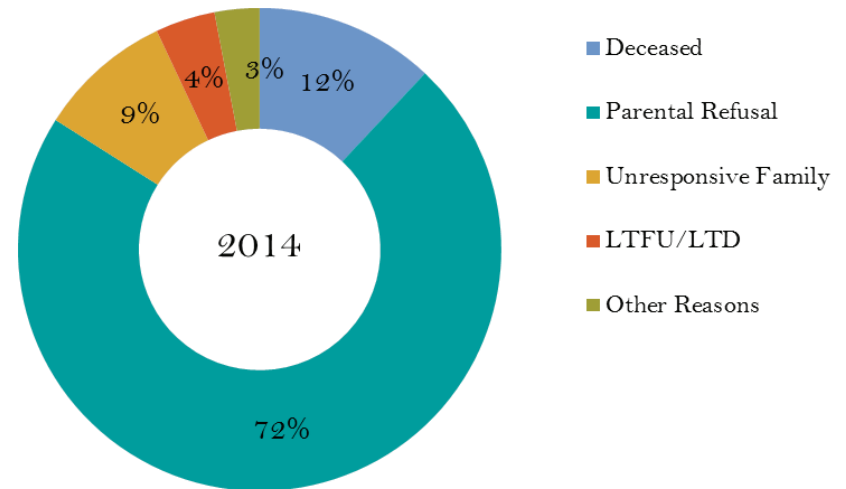
In 2014, 87% (366/420) of the babies whose parents refused the screening were born out of hospital and/or were likely members of the Plain Community. Community outreach and building local providers' competence and support for newborn screening continues to be a key component in WSB's work.

Along with evaluating refusal rates, Wisconsin uses its web-based data system WE-TRAC to monitor all reasons a baby may not have been screened. The majority of babies without screening results are because the parents refused or the baby has died. The percentage of babies whose contact information/status is unknown remains small at 4%. The majority of families have received some contact by providers and/or WSB, resulting in 8.5% unresponsive family and 71.5% refusal. The remaining reasons included in 'other' include babies on hospice or palliative care, babies who have been adopted, out-of-state residents, babies who moved out of state, and still active cases.

## Number of Families Refusing Newborn Hearing Screening



## Reasons Babies Were Never Screened for Hearing Loss



# Reducing Loss to Follow-Up for Babies Who Did Not Pass their Hearing Screening

WSB reduces LTFU for babies who did not pass their initial hearing screening through a 3-Step-Follow-Up (3SFU) process. WSB identifies babies who did not pass their hearing screening at the hospital and have not received follow-up in WE-TRAC by one or three months of age. These babies are deemed at-risk for LTFU and go through 3SFU.

**STEP 1 Medical Outreach:** WSB reaches out to birthing units, audiology clinics, and primary care providers to determine if the child has received follow-up or has follow-up scheduled. WSB ensures that primary care providers know the child's hearing screening results and need for follow-up. Sixty percent of cases entering 3SFU never require support beyond Step 1. This percentage has remained consistent each year.

**STEP 2 Family Outreach:** For babies whose cases need additional outreach and support beyond Medical Outreach, WSB provides direct outreach to families to encourage follow-up, address concerns, and answer questions.

**STEP 3 Regional Outreach:** WSB provides care coordination, outreach, and an in-home or in-community rescreen for families experiencing barriers to accessing the health care system. WSB collaborates with local public health departments, WIC clinics, or community service agencies to help reach families and/or coordinate care. Families receiving a WSB-provided re-screen are typically those most at risk for LTFU.

**83% of 3SFU cases were successfully resolved (426/511).**

As part of the 3SFU process, WSB collaborates with WIC (Special Supplemental Nutrition Program for Women, Infants and Children). For babies at risk for LTFU and participating in WIC, WSB places an Alert in their WIC file requesting that WIC staff contact WSB to assist with ensuring follow-up.

Step 3: 13% successfully resolved at Step 3 (56/426)

Step 2: 14.5% successfully resolved at Step 2 (62/426)

Step 1: 72% successfully resolved at Step 1 (308/426)



WSB's 3-Step-Follow-Up process serves as a safety net to prevent LTFU for babies who did not pass their hearing screening. WSB began this process in 2011.

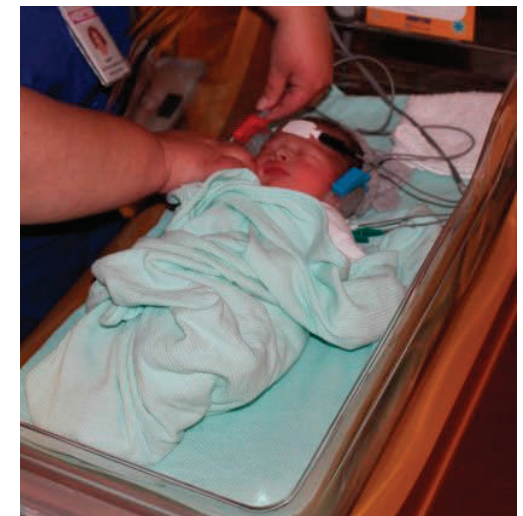
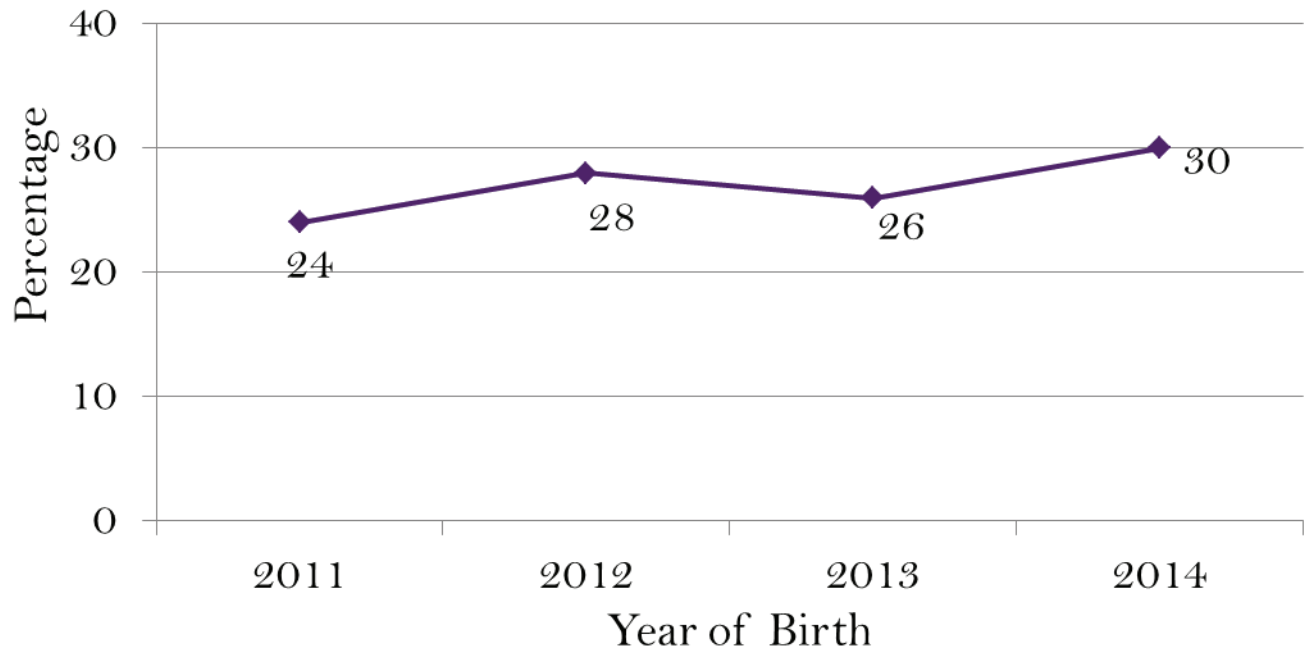
While Wisconsin's LTFU rate has decreased (see next page), due in large part to 3SFU, the percentage of babies requiring WSB's 3SFU efforts has not. In fact, the percentage of babies entering 3SFU has increased.

In 2014, 511 babies required 3SFU. This represents 30% of the 1,713 babies who did not pass their newborn hearing screening at the hospital and did not receive follow-up by the time they reached one or three months of age.

In 2015, WSB began targeted quality improvement outreach efforts to birthing units whose cases involved a high percentage of 3SFU involvement in an effort to decrease the percentage of babies requiring WSB LTFU prevention.

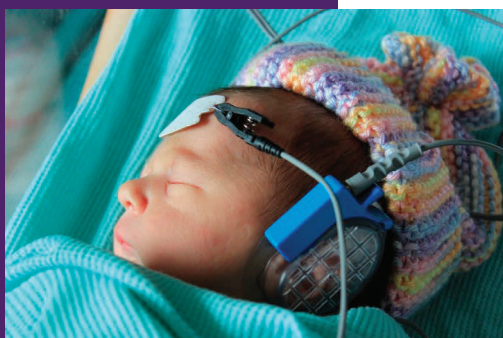
From 2011 to 2014, WSB provided LTFU prevention for nearly 2,000 babies through 3SFU.

## Percentage of Babies Who Did Not Pass Hearing Screening at a Hospital and Required 3SFU



# Reducing Loss to Follow-Up for Babies Who Did Not Pass their Hearing Screening

**Percentage of Babies Who Did Not Receive Follow-Up After Baby Did Not Pass Initial Hearing Screening (does not include deceased)**



WSB’s efforts to reduce LTFU for babies who did not pass their hearing screening include 3SFU (see pages 8-9) and additional LTFU reduction efforts separate from 3SFU. WSB’s LTFU prevention efforts have successfully reduced and maintained its LTFU rate since they were first implemented in 2011.

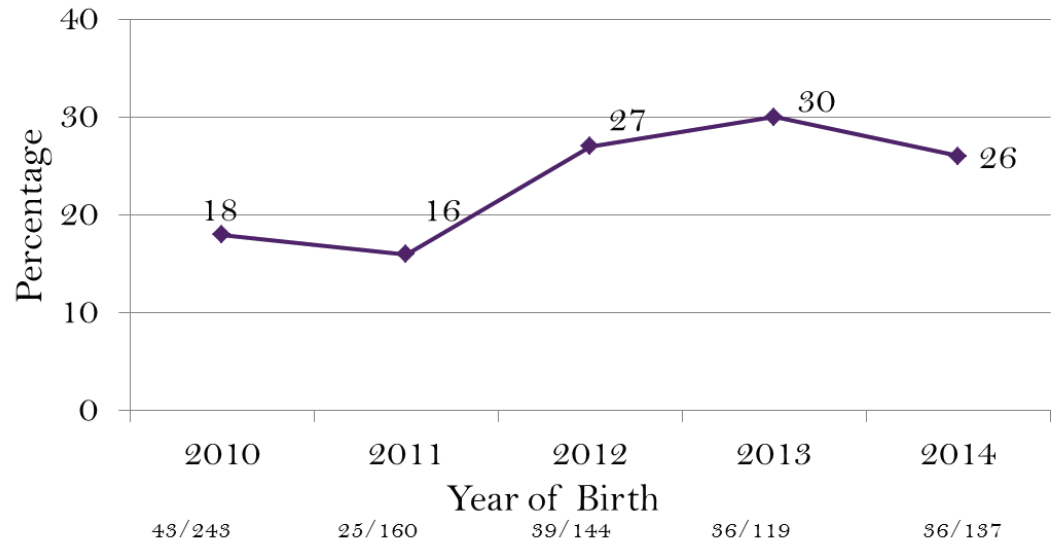
WSB continues to explore additional ways to identify babies at risk for LTFU after not passing their hearing screening and effective and efficient outreach to increase follow-up.

Similarly to reasons a baby may not receive a hearing screening, WSB evaluates reasons why a baby did not receive follow-up after not passing their hearing screening. From 2011-2013, the percentage of families refusing follow-up care after their baby did not pass was increasing. However, in 2014, this percentage went down.

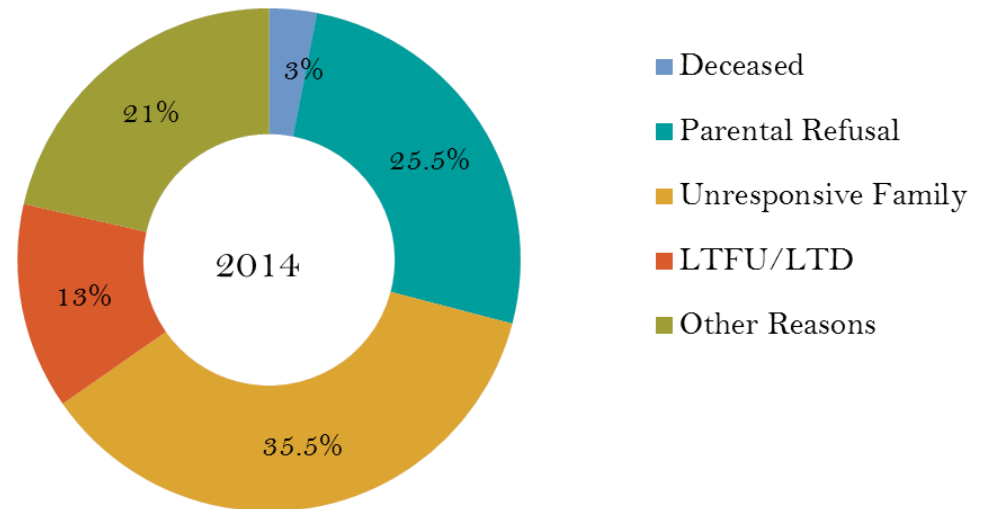
Along with evaluating refusal rates, Wisconsin monitors all reasons a baby did not receive follow-up. The percentage of babies whose contact information/status is unknown remains small at 12%. The majority of families have received some contact by providers and/or WSB, resulting in 29% unresponsive family and 23% refusal. The remaining reasons in 'other' include babies receiving hospice or palliative care, babies who were adopted, out-of-state residents, babies who moved out of state, and still active cases.



**Percentage of Families Refusing Follow-Up After Baby Did Not Pass Their Initial Hearing Screening**  
(does not include deceased)

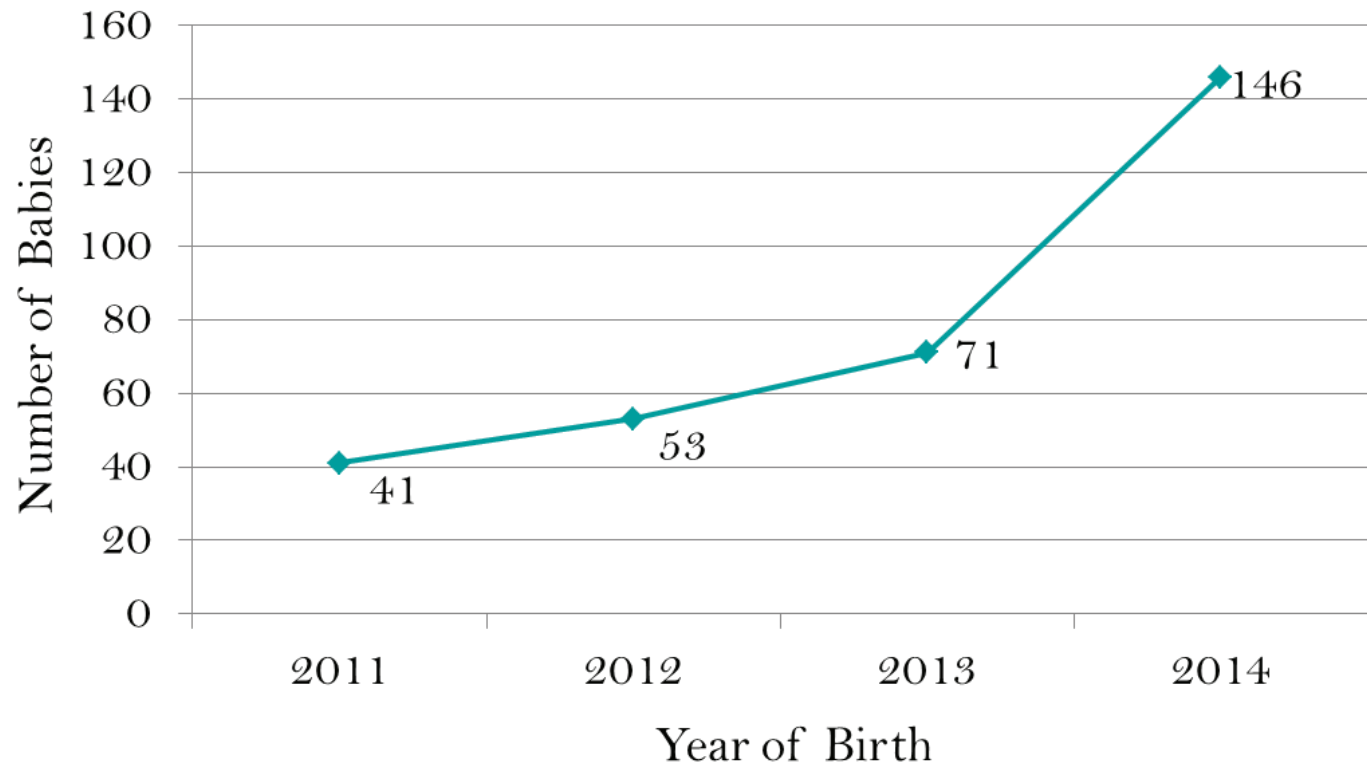


**Reasons Babies Did Not Receive Follow-Up After Baby Did Not Pass Hearing Screening**



## Providing Additional Outreach and Screening

### Number of Babies Receiving a WSB-Provided Screening\*



\*Screening provided by one of the three Regional Outreach Specialists

One of the fundamental guiding principles of the WSB program is to 'meet families where they're at.' One way WSB does this is through its three Regional Outreach Specialists (ROS). The ROS are able to provide *initial* or *follow-up* screenings for families who may be experiencing barriers to accessing traditional care.

The number of babies receiving a WSB-provided screening tripled between 2011 and 2014.

Out-of-hospital births accounted for 55% of the WSB-provided screenings in 2014 compared to 36% in 2013.

Families receiving a WSB-provided screening are at risk in some way, either at risk for LTFU after not passing their initial screening or at-risk for never being screened. WSB-provided screenings impact both Wisconsin's LTFU rate and never screened rate; this is because WSB staff are providing initial screenings (improving Wisconsin's screening rate) and follow-up screenings (reducing Wisconsin's LTFU rate).

WSB began providing screenings in 2011 and the number of babies receiving a WSB-provided screening has increased every year. The WSB-provided screening option was developed to reduce LTFU for babies who did not pass and increase screening rates for babies who would not otherwise have been screened.

WSB's three Regional Outreach Specialists screened 146 babies born in 2014. WSB's Out of Hospital Outreach Specialist screened an additional 25 babies, bringing the total number of babies receiving a WSB-provided screening to 171.

WSB's 3SFU efforts focus solely on babies born in hospitals and account for much of WSB's work. However, along with the Out of Hospital Outreach Specialist, WSB's Regional Outreach Specialists also provide screenings and support for babies not as part of 3SFU.

In fact, for the first time ever, the number of babies born out of hospital made up a larger percentage of babies receiving a WSB-provided screening than those born in a hospital. In 2014, 55% (95 of the 171) babies receiving a WSB-provided screening were born out of hospital compared to just 36% in 2013.

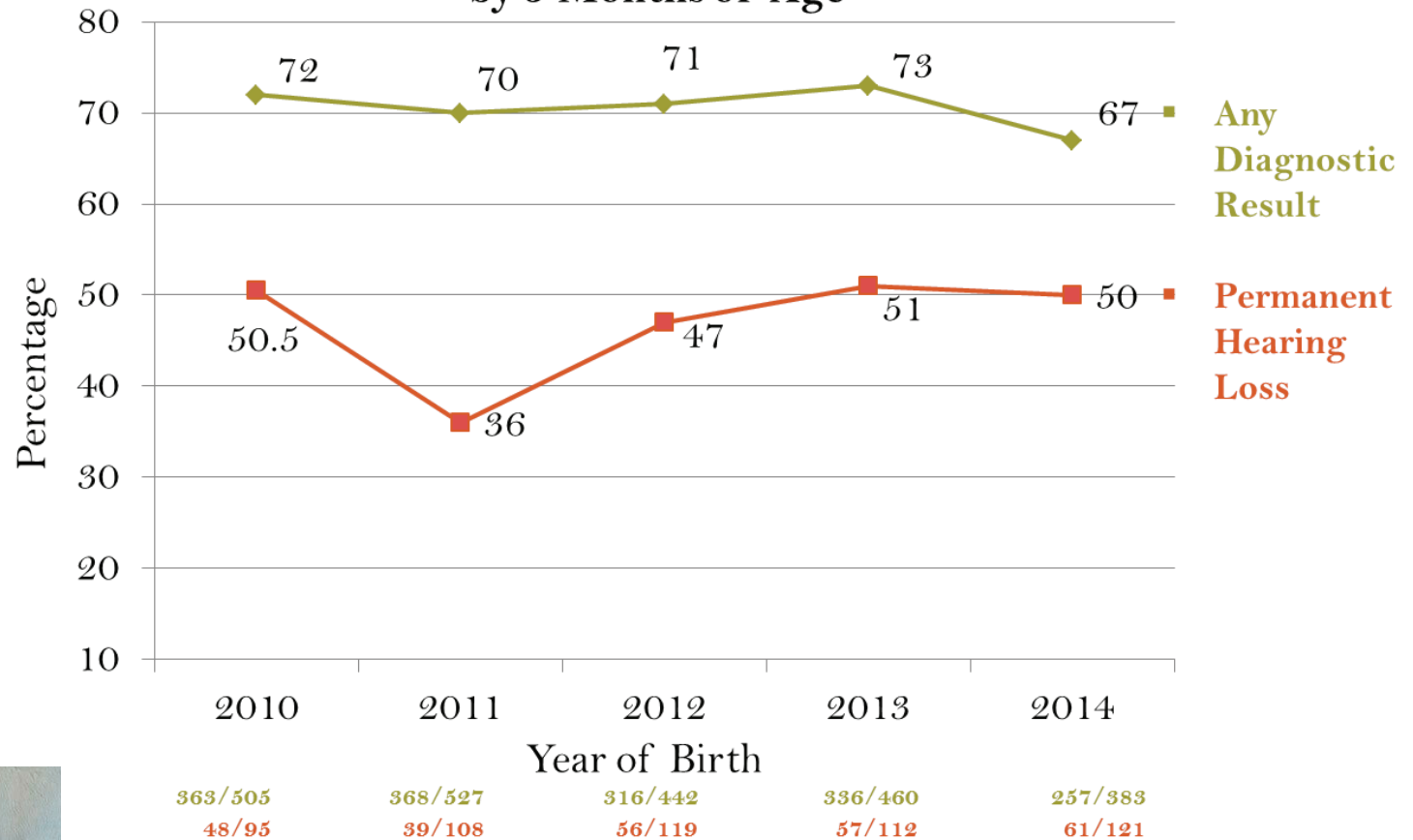


WSB Regional Outreach Specialists and Out of Hospital Outreach Specialist screened 171 babies.



# Reducing Time to Diagnosis

**Percentage of Babies Who Did Not Pass Hearing Screening Receiving Diagnostic Audiology Services by 3 Months of Age**



WSB works with providers to reduce the time to diagnosis for babies who do not pass their hearing screening. While the percentage of babies receiving diagnostic services, *regardless of diagnostic outcome* (within normal limits, permanent/transient hearing loss) by three months of age remained relatively stable for the last four years, this percentage dropped slightly to 67% (257/383) in 2014. The percentage of babies receiving a diagnosis of permanent hearing loss by three months of age remained steady in 2014 at 50% (61/121).



## Babies with Permanent Hearing Loss Referred to Early Intervention

*Average Age Between Birth and Final Diagnosis:*

106 days

*Minimum Age Between Birth and Final Diagnosis:*

7 days

*Maximum Age Between Birth and Final Diagnosis:*

597 days

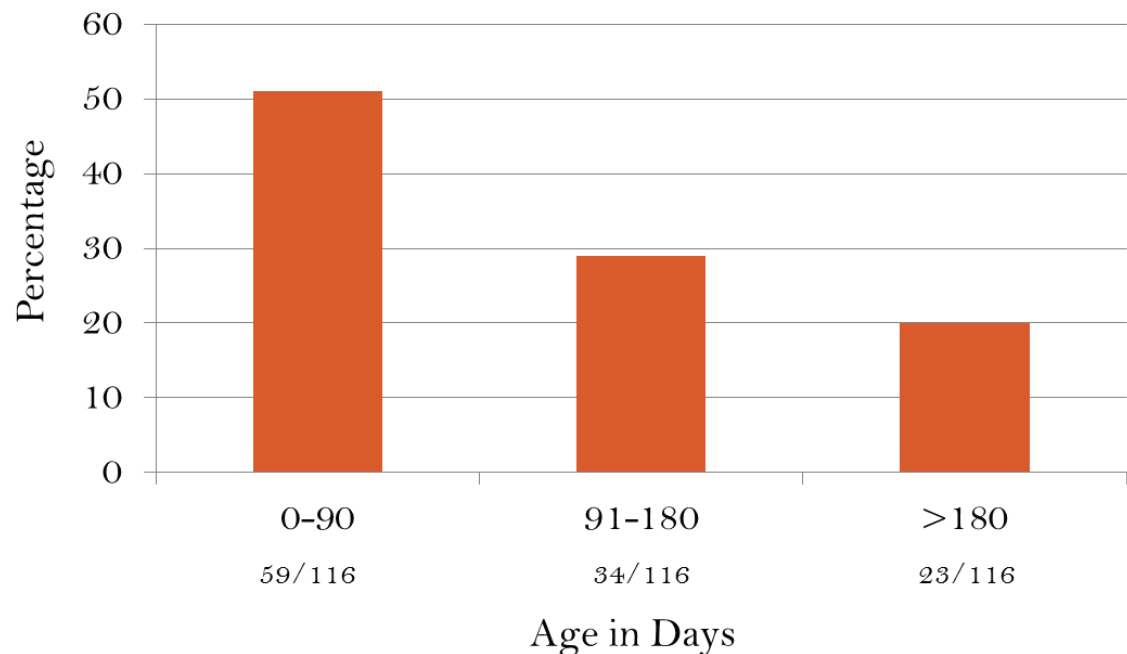


Of the 23 babies not diagnosed until they were >181 days of age, all had more than one factor impacting their later diagnosis. Issues included: multiple screenings and/or diagnostic appointments (two babies had six appointments), fluid involvement with/without tube placement, lengthy NICU stay/prematurity, appointments at more than one audiology clinic, and families cancelling or not showing up for appointments. Two babies had passing results and were later diagnosed with hearing loss.

WSB reaches out to audiology clinics to encourage accurate and timely data reporting. WSB promotes best practice as reporting information and results in WE-TRAC within one week of the child's appointment.

WSB provides quality improvement technical assistance to clinics that need or request it. Audiology clinics also can access reports through WE-TRAC to monitor their clinic's performance. As part of the 2014-2017 grant cycle, WSB focused on quality improvement in local EHDI systems. WSB identified health care systems in need of quality improvement, based on benchmarks including the number of cases requiring WSB involvement, the number of cases closed without receiving follow-up, and the number of babies diagnosed after three months of age. Those systems receiving this assistance in 2014 made improvements reflected in their data.

### Distribution of Age at Final Diagnosis for Babies with Permanent Hearing Loss and Referred to Early Intervention



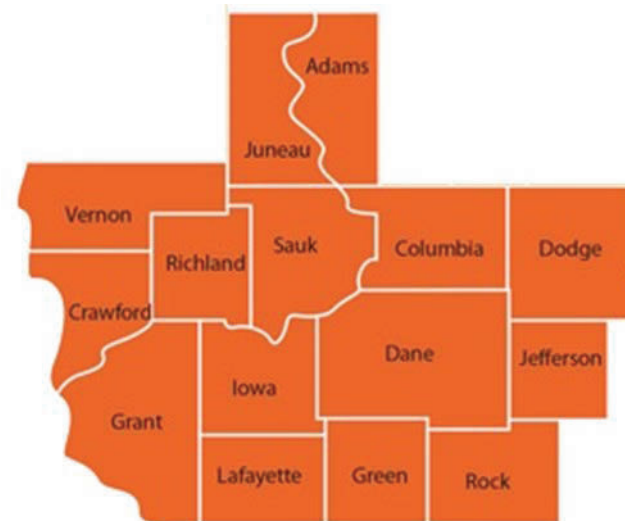
# Supporting Early Intervention and Improving Outcomes

Despite more than 90% of babies diagnosed with a permanent hearing loss being referred to the Birth to 3 Program, only half of those families enroll. To ensure access and enrollment in early intervention, WSB and the state Birth to 3 Program signed a Memorandum of Understanding (MOU) enabling WSB staff to be considered members of a child's IFSP (individualized family service plan) team; and WSB staff to work with both families and Birth to 3 Programs.

In 2014, just 54% of babies with permanent hearing loss had an IFSP documented in WE-TRAC.

In the fall of 2014, WSB launched CARES—*Coordination, Assessment, Resources and Evaluation Services* and hired its first CARES Specialist to serve the Southern Region. CARES is a resource for Birth to 3 Programs and families offering specialized knowledge and skills related to pediatric hearing loss. The CARES Specialist can participate in intake, evaluation, IFSP meetings, and joint visits with Birth to 3 Program staff and families.

Following a region-wide kick-off meeting in September 2014 with Birth to 3 Program administrators and service coordinators, the CARES Specialist met with each county program to determine how CARES could seamlessly fit into the system they had in place for enrolling a child who is deaf/hard of hearing as well as how to support any children the county was currently serving.



Of the 10 children diagnosed and referred to early intervention in the Southern Region between September and December 2014 when CARES began, 80% enrolled in their county Birth to 3 Program. CARES was involved in seven of the eight cases. Along with serving these new referrals, CARES conducted 16 IFSP meetings and/or joint visits with families who were already participating in their Birth to 3 program and became an active member of their IFSP team.



### **Assessment of Early Intervention Outcomes (AEIOu):**

Wisconsin families with children who are identified as deaf or hard of hearing and referred to the Birth to 3 Program are eligible to participate in the research project AEIOu (Assessment of Early Intervention Outcomes), part of the National Early Childhood Assessment Project (NECAP). The research goal is to analyze these children's communication, social-emotional, and general development; the early intervention they receive; and other variables that may affect their developmental outcomes.



Data is collected from participating families in two phases: Phase 1 when children are 13-20 months old and Phase 2 when children are 30-38 months old. Families complete multiple developmental questionnaires, a demographic form, and consent forms for release of audiological records and their family's Birth to 3 Program Individualized Family Service Plan.

Families are invited to participate in the study during a WSB outreach phone call or text message that takes place when children are approximately 14 months old. The outreach call offers the family an opportunity to talk with another parent and learn about resources. Resources commonly shared include: Wisconsin Families for Hands & Voices; the Guide By Your Side Program; Deaf Mentor Program; Babies and Hearing Loss Notebook; opportunities to meet other families at conferences and social events; and the Children and Youth with Special Health Care Needs Regional Centers. For families not receiving Birth to 3 Program services at the time of the call, WSB staff has provided contact information about their Birth to 3 Program and encouraged families to contact their local Birth to 3 Program and/or WSB has re-referred them to the Birth to 3 Program.

WSB began providing these calls in 2012 and has successfully spoken with 230 families to date. Of those families eligible and interested in participating in AEIOu, 84 have completed phase 1 and 41 have completed both phases to date.

Beginning in June 2015, eligibility for participation was expanded to include all families with children who are deaf/hard of hearing independent of their participation in the Birth to 3 Program.

Evaluation of AEIOu outcomes results is ongoing.



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