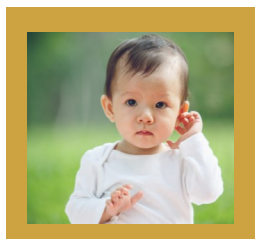
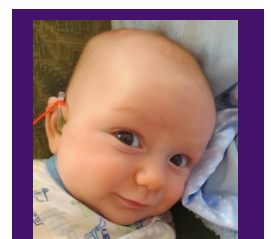
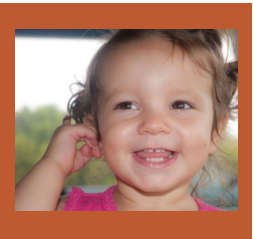


Wisconsin Sound Beginnings  
Early Hearing Detection and Intervention  
**Annual Report 2015**



# 2015 Executive Summary

Wisconsin Sound Beginnings (WSB) is the state's Early Hearing Detection and Intervention (EHDI) program. Through strategic efforts, statewide collaborations, systems building, education, outreach, direct service provision, and ongoing evaluation, WSB strives to ensure Wisconsin meets the Joint Committee on Infant Hearing recommendations that babies are **Screened by 1 Month of Age**, **Diagnosed by 3 Months of Age** and **Enrolled in Early Intervention by 6 Months of Age**. WSB and its partners have successfully increased the number of babies screened, reduced the percentage of babies lost to follow-up (LTFU), increased the percentage of babies receiving timely diagnosis of permanent hearing loss and referral to early intervention, and provided specialized support to Part C Early Intervention programs and families. WSB serves as a safety net for providers and families involved in the EHDI system. WSB and its partners continue to explore ways to strengthen

systems; increase use of proven quality improvement strategies among hospitals and clinics; increase local capacity for screening, particularly among out of hospital (OOH) populations; improve timely and accurate data entry into the WE-TRAC (Wisconsin EHDI Tracking, Referral and Coordination) data system; expand and sustain collaboration with statewide partners; and use sound data and ongoing evaluation to inform programmatic decisions. WSB's efforts are designed to create a sustainable, successful EHDI system supporting families and their children who are deaf or hard of hearing.

Wisconsin had the fewest number of babies never screened in more than five years—470 babies.

Hospitals, midwives, audiologists, WSB staff, and community partners screen 99% of babies born in Wisconsin, with 98% screened by **1 Month of Age**. This has remained constant for more than five years.

WSB and its partners reduced the number of babies lost to follow-up (LTFU) and increased the number of babies receiving complete diagnostic audiology services by **3 Months of Age**. In 2015, the highest number of babies were diagnosed with permanent hearing loss—133 babies.

WSB maintained a LTFU rate of less than 8% for five years.

WSB has two early intervention initiatives to increase enrollment in Part C Early Intervention by **6 Months of**

**Age**, support Part C Early Intervention programs, and improve developmental

outcomes for children who are deaf or hard of hearing. In partnership with the Waisman Center at UW-Madison, WSB received Centers for Disease Control and Prevention funding from the University of South Carolina Disability Research and Dissemination Center to study EHDI's Impact.

In 2015, WSB:

- ➔ Conducted 114 in-home or in-community initial screenings.
- ➔ Conducted 74 in-home or in-community follow-up screenings.
- ➔ Spoke with 81 families at risk for loss to follow-up (LTFU).
- ➔ Provided specialized support to 33 families and their Birth to 3 Program providers.
- ➔ Supported 25 counties receiving 78 new referrals for a child identified as deaf or hard of hearing.

In 2015, 52% of the babies diagnosed with permanent hearing loss were diagnosed by 3 Months of Age—the most to date.

WSB was one of two programs nationwide awarded a grant to evaluate EHDI's impact.

***Mission:*** WSB will identify 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.



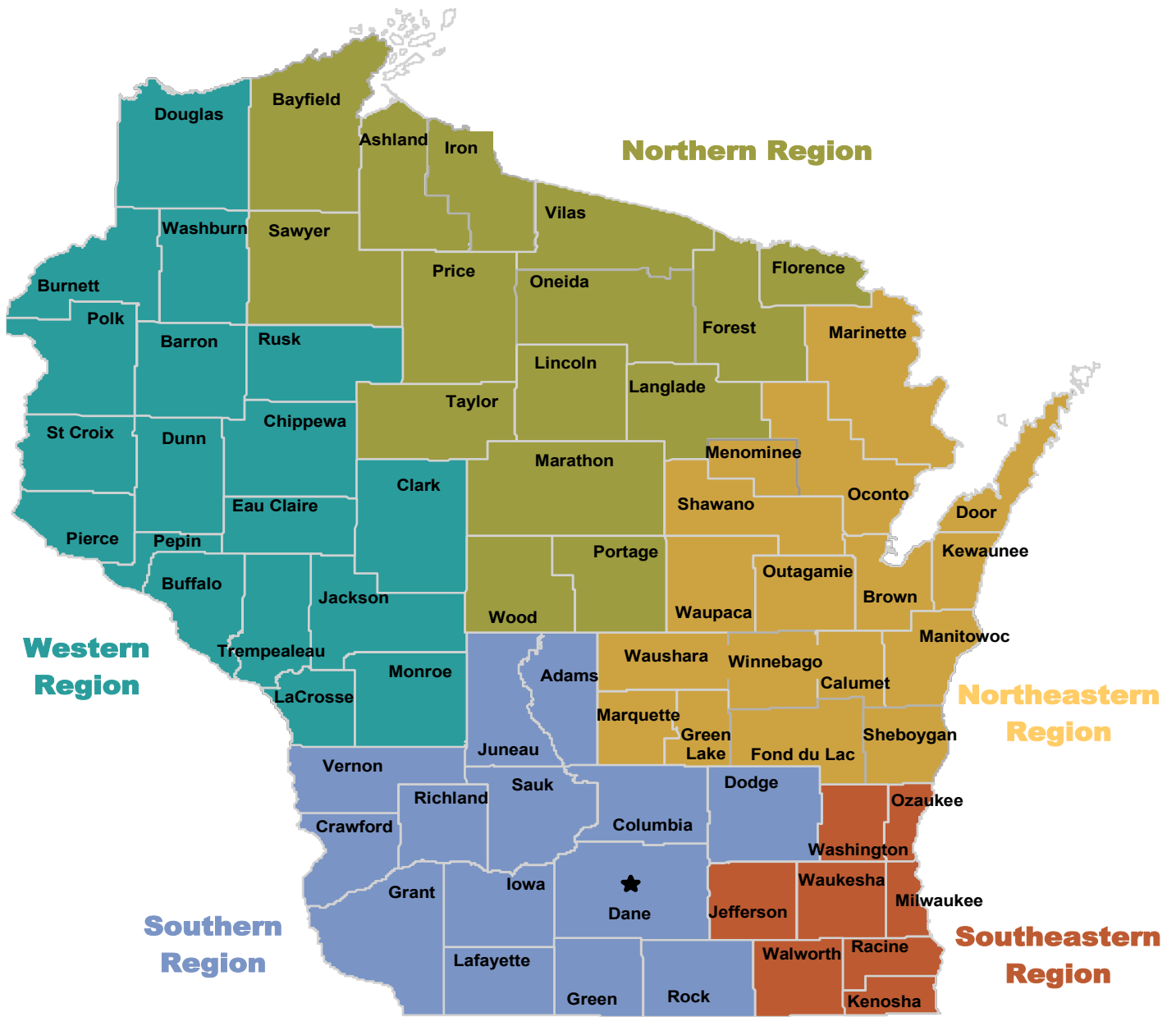
## ***Guiding Principles:***

- We meet families where they're at without judgment or bias.
- We work on behalf of the well-being of children and strive to optimize their potential.
- We drive change and decision-making with sound and valid data.
- 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 collaborations and partnerships.
- We value parent perspectives in family support, program design, and process improvement.

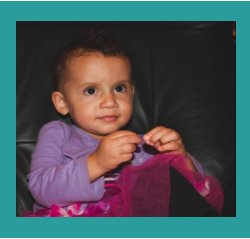
***Vision:*** All families will have equal access to a seamless system of early and continuous hearing screening, skilled and timely diagnostics, and quality interventions to enable children with hearing loss to thrive.



**The Wisconsin Sound Beginnings Team**  
Christi Hess, Jeanne Gustafson, Rebecca Martin  
Susan Picione, Elizabeth Seeliger, Connie Stevens, Gretchen Spicer  
(not pictured: Jenny Geiken and Shari Galitzer)



Wisconsin Sound Beginnings 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, Wisconsin State Laboratory of Hygiene, Chippewa County Health Department, and the City of Milwaukee Health Department.



## Table of Contents

Page 2: Executive Summary

Page 3: Mission, Vision, and Guiding Principles



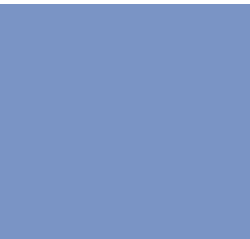
Page 4: Map of Wisconsin by Region

Page 5: Table of Contents



Page 6-7: Overview of the Screening, Diagnosis, and Early Intervention Numbers

Page 8-9: **Screened by 1 Month**



Page 10-13: **Diagnosed by 3 Months: Reducing Loss to Follow-Up for Babies Who Did Not Pass Their Hearing Screening**

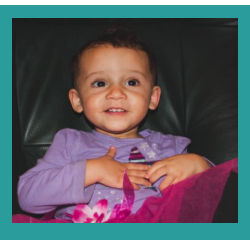


Page 14-15: **Diagnosed by 3 Months: Reducing Time to Diagnosis and Referral to Early Intervention**



Page 16-19: **Enrolled in Early Intervention by 6 Months**

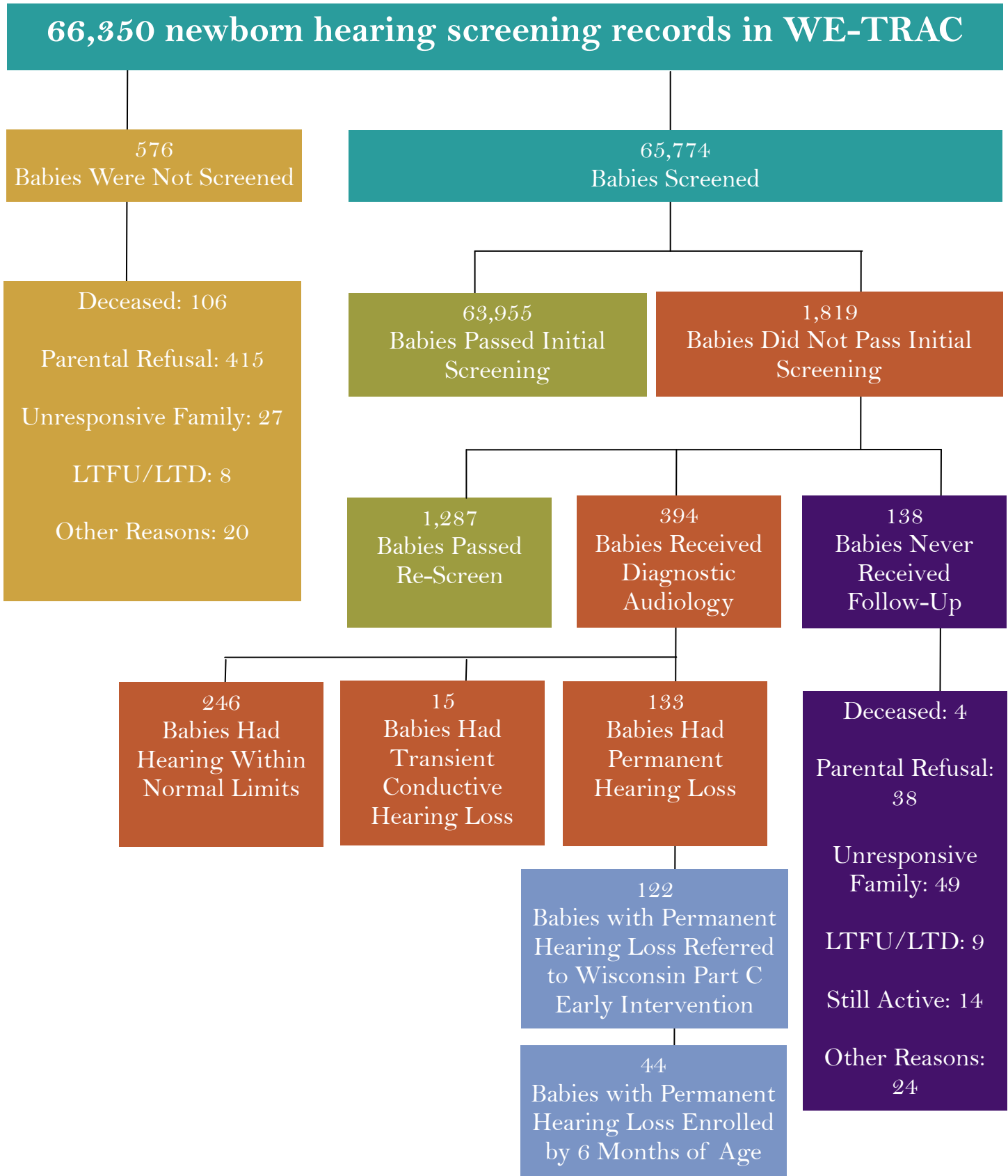
Page 20: Annual Report Definitions



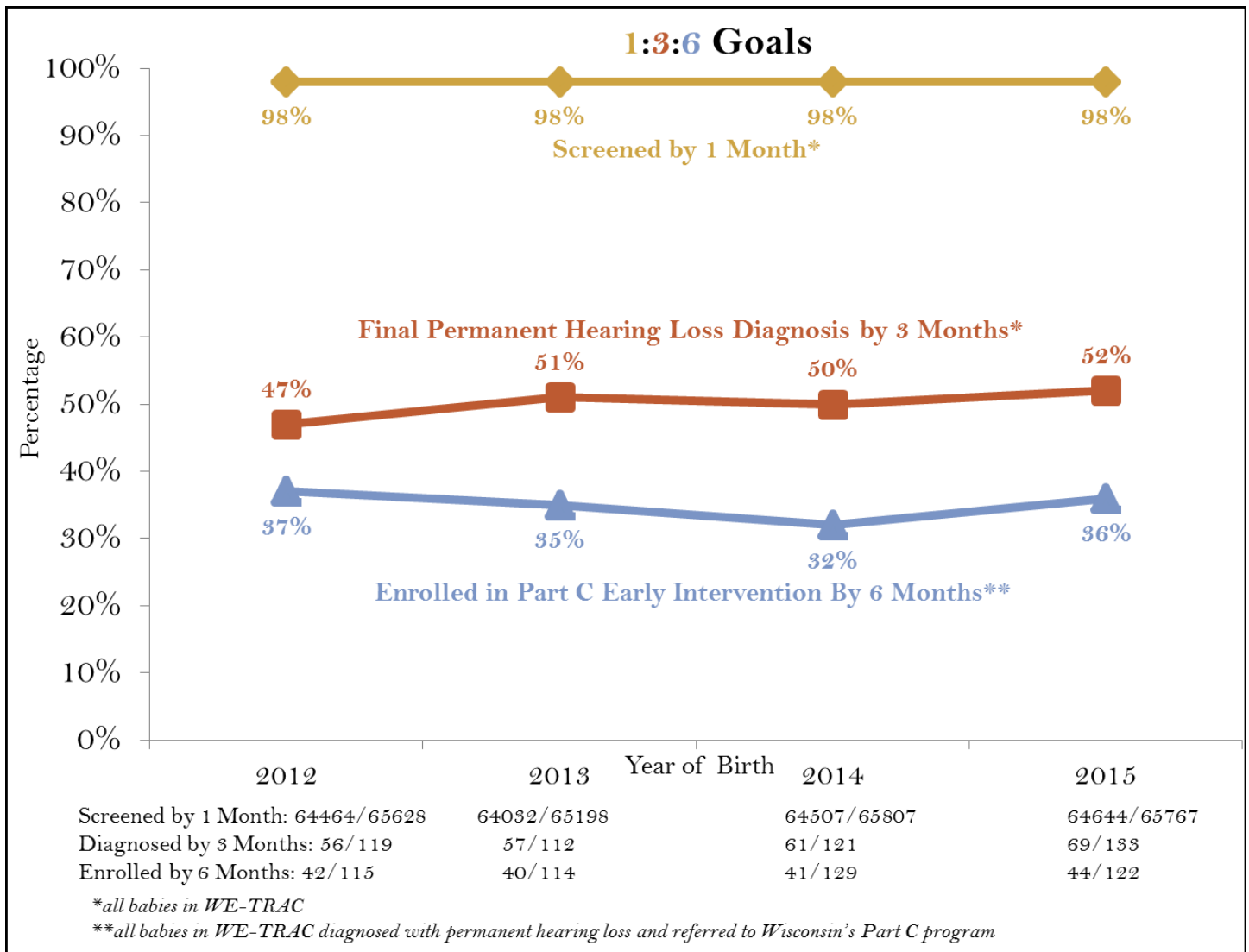
Page 21: Wisconsin Sound Beginnings Staff Contact Information

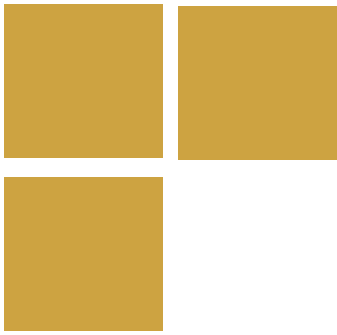


# Screening, Diagnosis, and Early Intervention 2015



Data from this report were calculated in September and October 2016. The data were generated using the WE-TRAC (Wisconsin EHDI-Tracking, Referral And Coordination) data system. WE-TRAC is Wisconsin's EHDI data system that allows Wisconsin providers to enter hearing screening, diagnostic audiology information, and early intervention referrals. WE-TRAC also receives information through an automatic process with Wisconsin Birth to 3 Program's data system, providing early intervention enrollment data. WSB monitors, manages, and measures hearing screening, loss to follow-up, diagnosis, and early intervention through WE-TRAC.

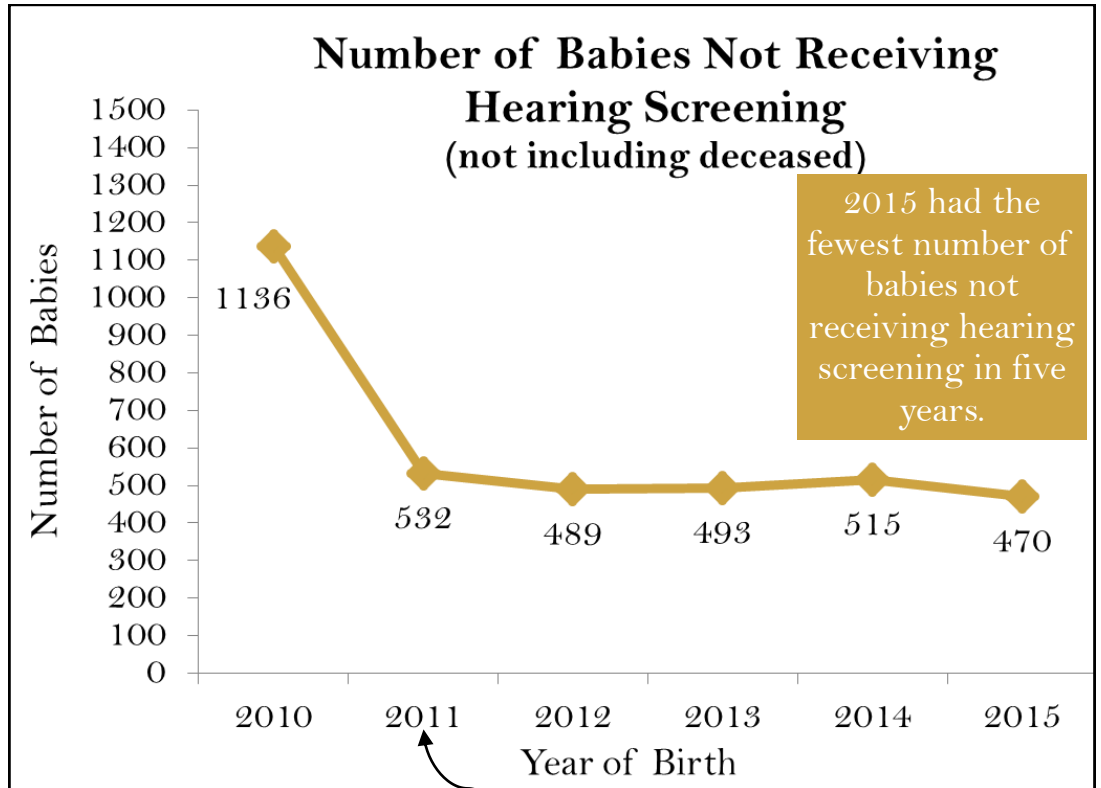




# S *creened by 1 Month*

*Reducing the Number of Babies Never Screened:* The Wisconsin EHDI system screens 99% of babies born in Wisconsin each year—98% of the babies screened receive their screening by 1 Month of Age. This has

remained constant for more than five years. In Wisconsin, the number of babies without documented newborn hearing screening has been steadily decreasing. WSB focuses its efforts to ensure newborn hearing screening by decreasing the number of babies who do not receive a newborn hearing screening (“never screened”). The majority of babies without newborn hearing screening continue to be babies who are born out of hospital (OOH) and/or members of the Plain Community (Amish/Mennonite).



WSB targeted efforts to increase screening in 2011.

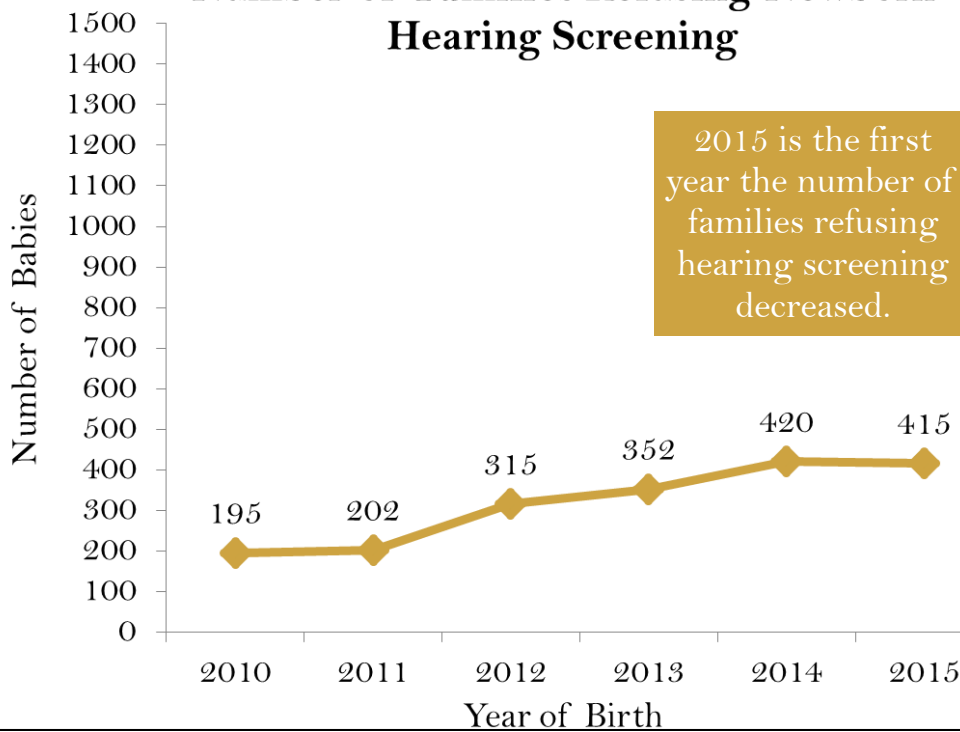
In 2015, to increase the number of babies screened, WSB:

- Held two outreach clinics, providing screening and/or diagnostic services for 13 children.
- Screened more than 100 babies born OOH.
- Provided 30 trainings/technical assistance to traditional birth attendants or midwives.
- Participated in three community meetings to establish and strengthen partnerships, educate providers and community members, and ensure access to newborn screenings.



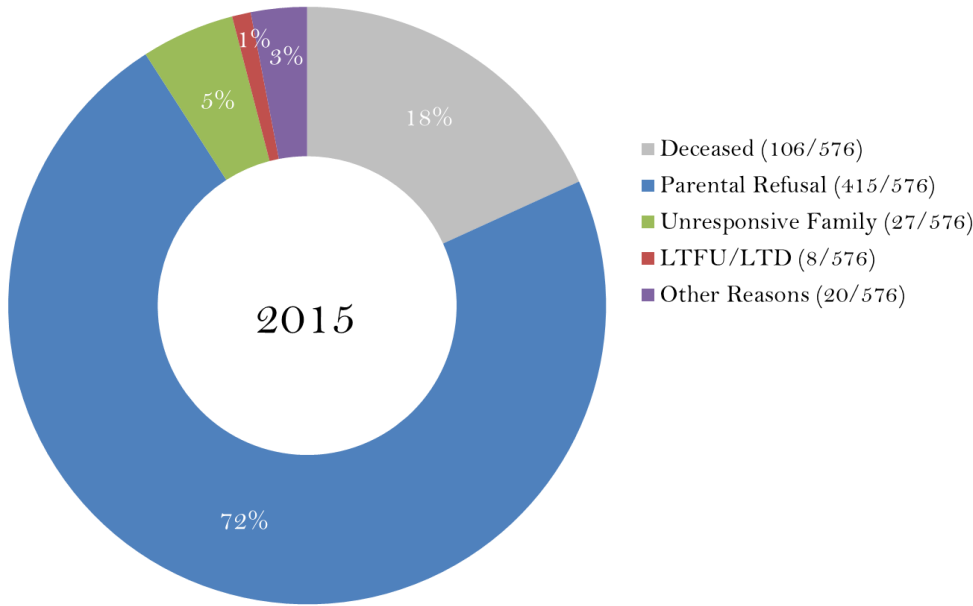


## Number of Families Refusing Newborn Hearing Screening



Via WE-TRAC, WSB monitors reasons why a baby does not receive a newborn hearing screening. The majority (72%) of babies were not screened in 2015 because of parental refusal. WSB and its partners continue their efforts to ensure that all families who want newborn hearing screening have access to it by WSB Outreach Specialists screening babies born OOH and local capacity-building to meet the needs for newborn screening. While honoring a family's right to refuse screening, Wisconsin Sound Beginnings and its partners continue to provide education and outreach about the value of newborn screening throughout key areas of Wisconsin.

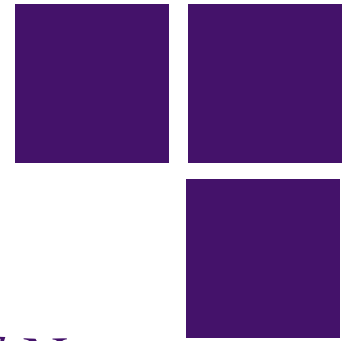
## Reasons Babies Were Never Screened for Hearing Loss



Another reason babies were not screened was LTFU/LTD (babies whose contact information/screening status is unknown), which accounted for 1% in 2015. The majority of families received some contact with providers and/or WSB, with 5% of cases closed as unresponsive family and 72% as refusal. The "other" reasons include babies on hospice or palliative care, babies who were adopted and babies who moved out of state.

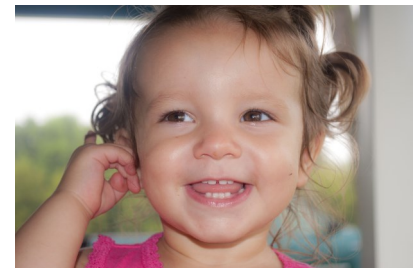


# D iagnosed by 3 Months

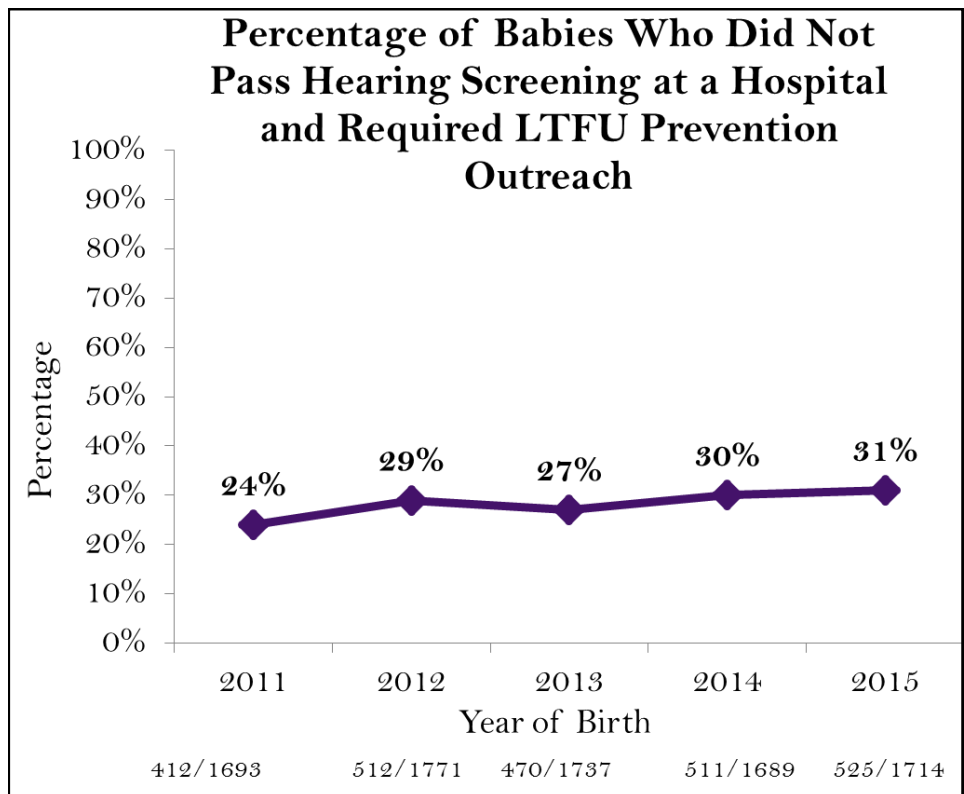


## Reducing Loss to Follow-Up for Babies Who Did Not

**Pass:** WSB's LTFU Prevention Outreach is designed to reduce Wisconsin's LTFU rate—the percentage of babies who did not pass (DNP) their hearing screening who never complete follow-up—as well as ensure that babies who do not pass receive timely follow-up. Each year, approximately 2.5% of Wisconsin babies do not pass (DNP) their initial hearing screening. WSB targets efforts to ensure babies who DNP successfully complete follow-up. WSB identifies babies who DNP their hearing screening at the hospital and do not have follow-up documented in WE-TRAC by 1 or 3 Months of Age. These babies are deemed at risk for LTFU and receive Medical Outreach, Family Outreach and/or Regional Outreach.



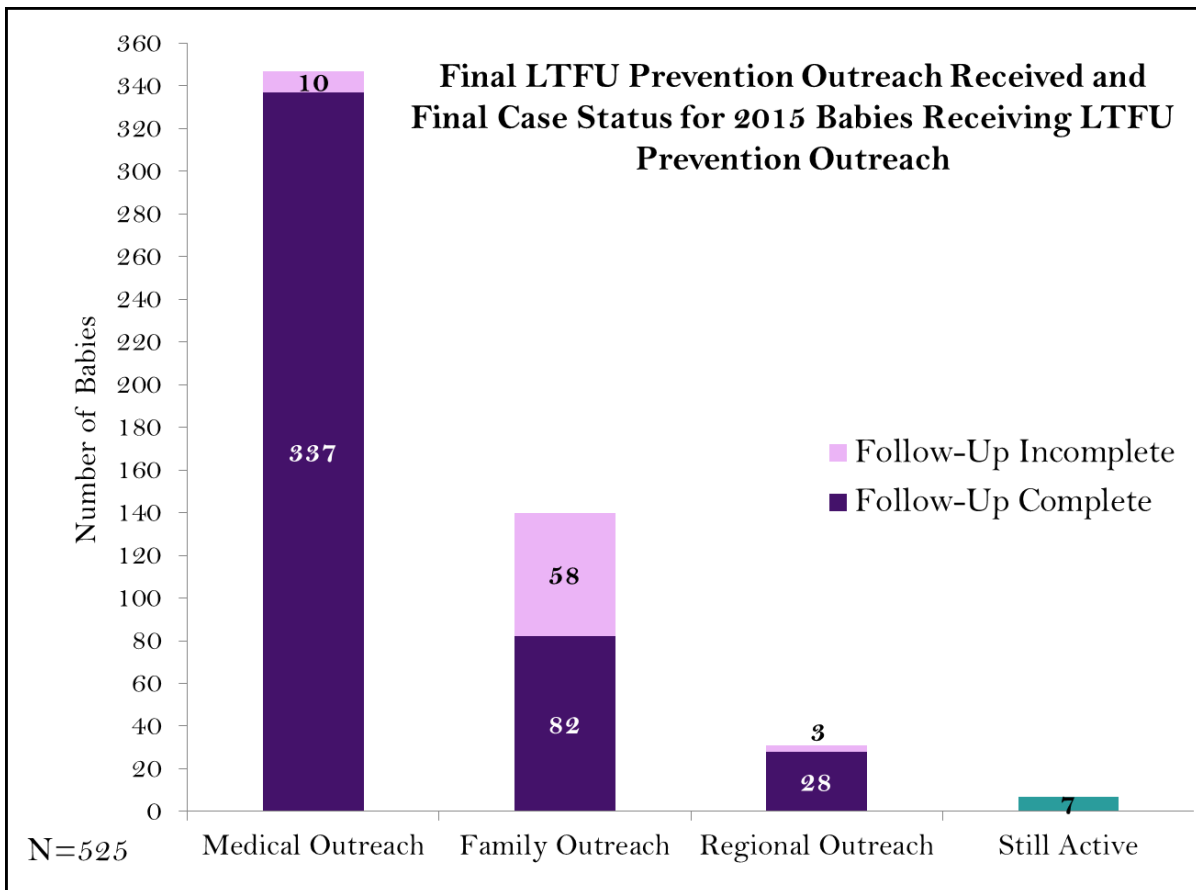
- **Medical Outreach:** The first step in the LTFU Prevention process is Medical Outreach. WSB communicates with birthing units, audiology clinics, and primary care providers to ensure the baby has received follow-up or is in the process of receiving follow-up to determine if the case needs additional support and outreach.
- **Family Outreach:** Babies whose cases are determined to need additional support receive Family Outreach. WSB contacts families to answer questions, encourage follow-up, and identify and problem-solve barriers to care.



- **Regional Outreach:** For babies whose cases need support beyond Medical and Family Outreach, WSB provides Regional Outreach. This includes a WSB-provided re-screen. WSB collaborates with local public health departments and/or community service agencies, including WIC (Special Supplemental Nutrition Program for Women, Infants and Children). Families receiving a WSB-provided re-screen are typically those most at risk for LTFU. WSB screened 28 babies as part of Regional Outreach.

WSB staff spoke with **81 families** during Family or Regional Outreach.

In 2015, 525 babies went through the LTFU Prevention Outreach process, with 85% (447/525) successfully completing follow-up. The majority (347) of the 525 babies receiving LTFU Prevention Outreach did not require support beyond Medical Outreach. For the 178 families requiring additional support beyond Medical Outreach, 62% (110/178) went on to successfully receive follow-up, 34% did not receive follow-up, and 4% remain active.



**Additional LTFU Reduction Efforts:** WSB first implemented its LTFU Prevention Outreach in 2011. Along with its LTFU Prevention Outreach (Medical, Family and Regional Outreach) WSB employs additional LTFU reduction efforts.

WSB’s additional efforts to reduce LTFU include:

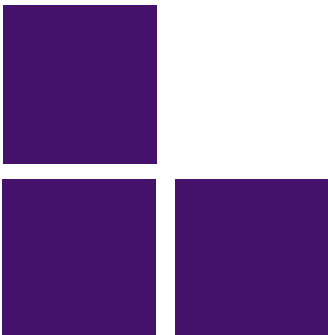
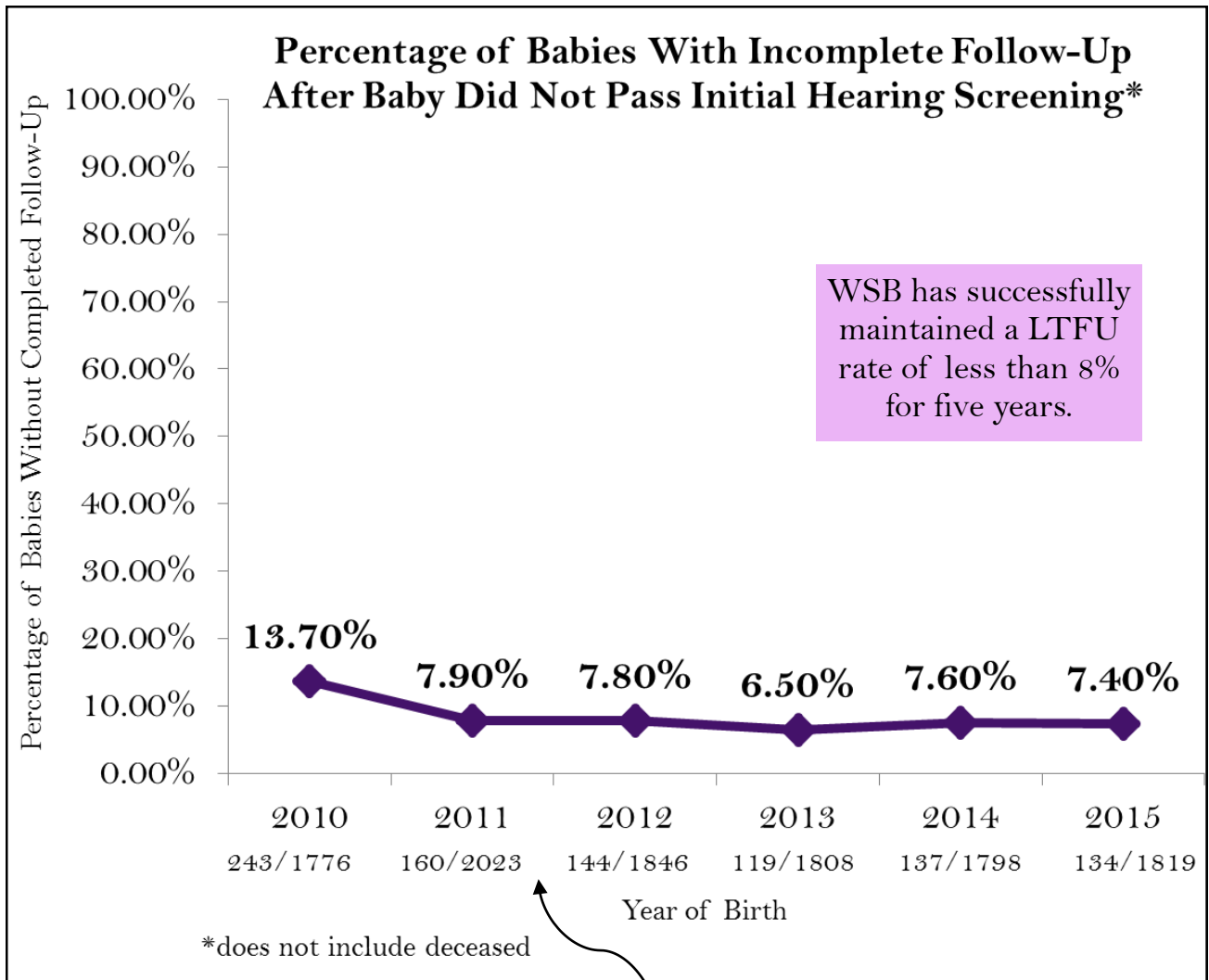
- Identifying health care systems potentially needing quality improvement (birthing units and audiology clinics), evaluating factors such as the number of cases requiring WSB involvement, the number of cases closed in WE-TRAC without completing follow-up, and the number of babies diagnosed after 3 Months of Age.
- Providing outreach to audiology clinics and hospitals to encourage accurate and timely data reporting to ensure that what is being reported in WE-TRAC reflects what occurred in the clinics
- Promoting best practice as reporting information and results in WE-TRAC within one week of the child’s appointment.
- Providing quality improvement technical assistance to organizations that need or request it.



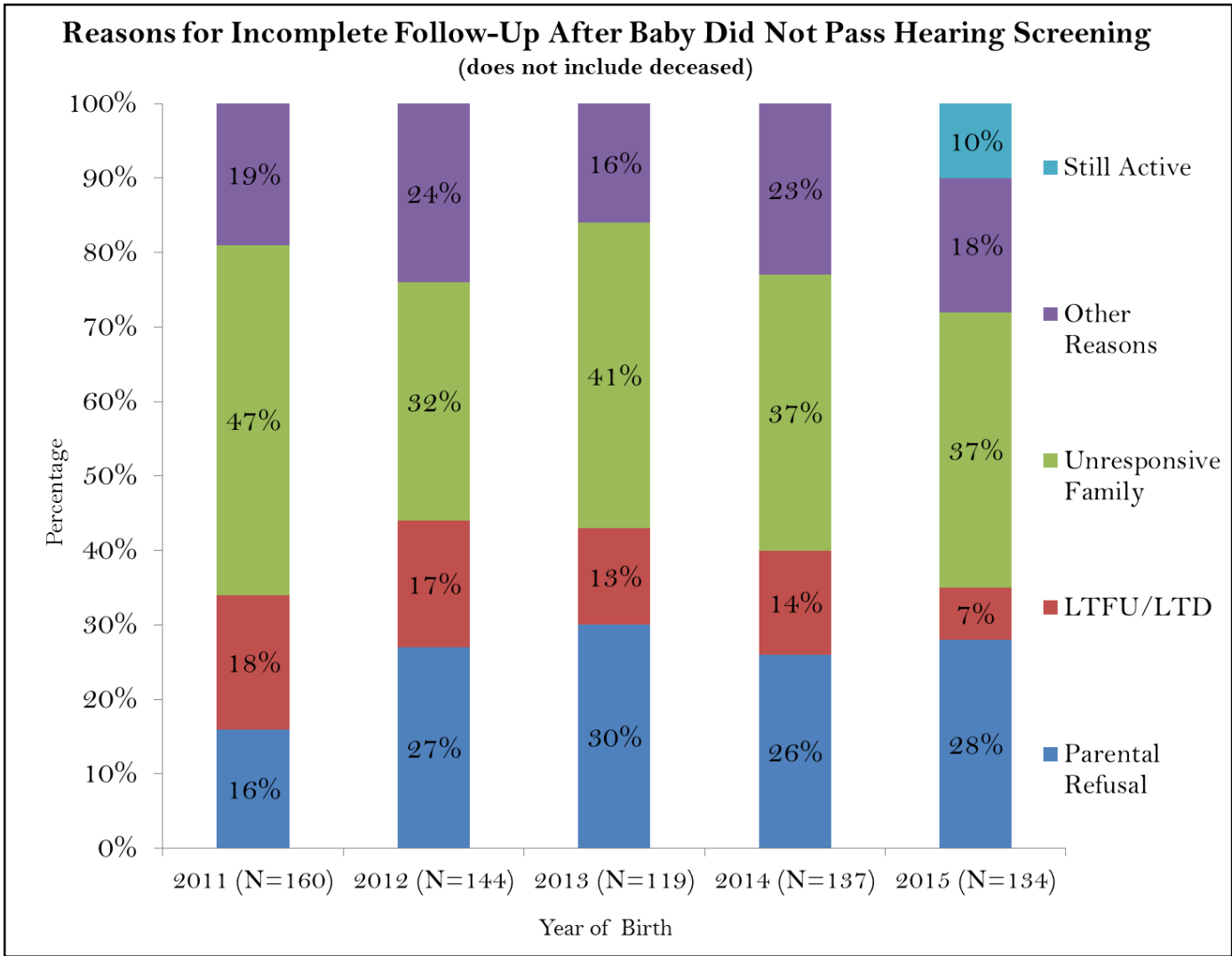


WSB's efforts, including its LTFU Prevention Outreach, to reduce the number and percentage of babies who did not receive follow-up after not passing their hearing screening have been successful.

In 2010, 13.7% (243 of the 1,776 babies) who DNP their initial hearing screening did not receive complete follow-up. One year after beginning its LTFU Prevention Outreach, the percentage of babies who did not successfully complete follow-up was 7.9% (136/1819). WSB has maintained this lowered LTFU rate of less than 8% for the last five years.



WSB began its LTFU prevention efforts in 2011.

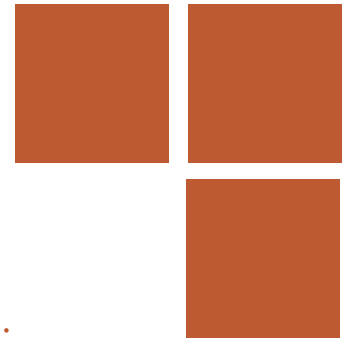


Data presented above are for babies who were screened but did not pass and did not receive complete follow-up. At time of reporting, 16 babies born in 2015 who did not pass still had open and active cases, accounting for 10% (14/134) of the babies who have not completed follow-up. The percentage of babies whose contact information or screening status remain unknown (LTFU/LTD) is 7%. The percentage of families refusing follow-up has remained relatively consistent at 28% (39/134); 18% of cases in 2015 closed as “other,” which predominantly includes babies who were on palliative care/hospice and babies who were adopted. WSB works with providers to ensure that families are receiving outreach and education about the importance of follow-up and that data reported in WE-TRAC is as accurate as it can be.



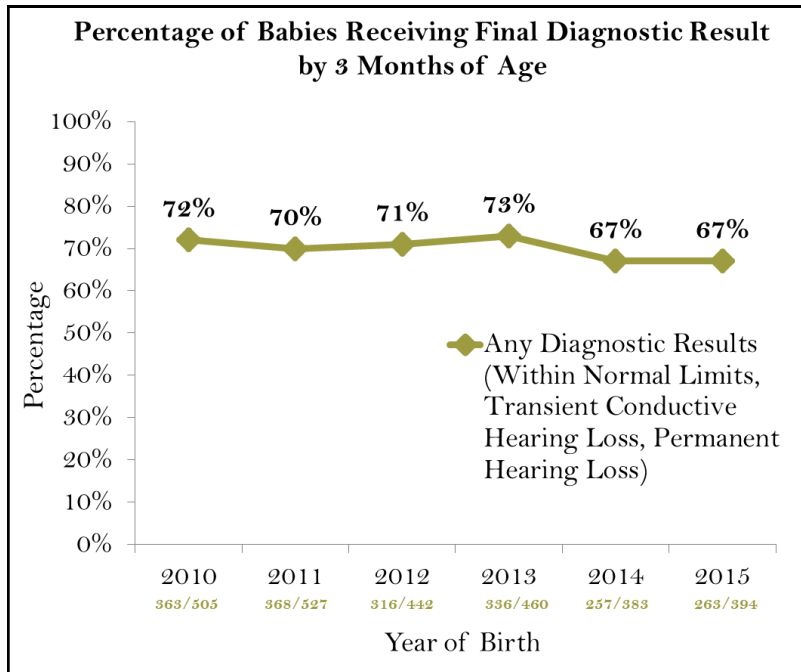


# D iagnosed by 3 Months



## Reducing Time to Diagnosis and Early Intervention

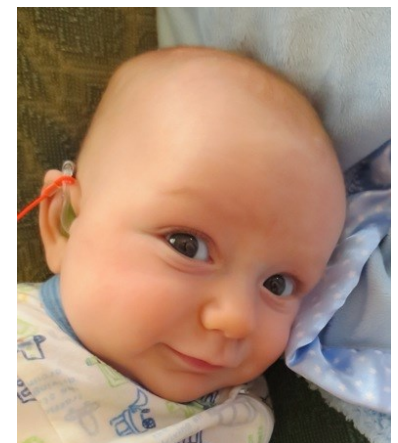
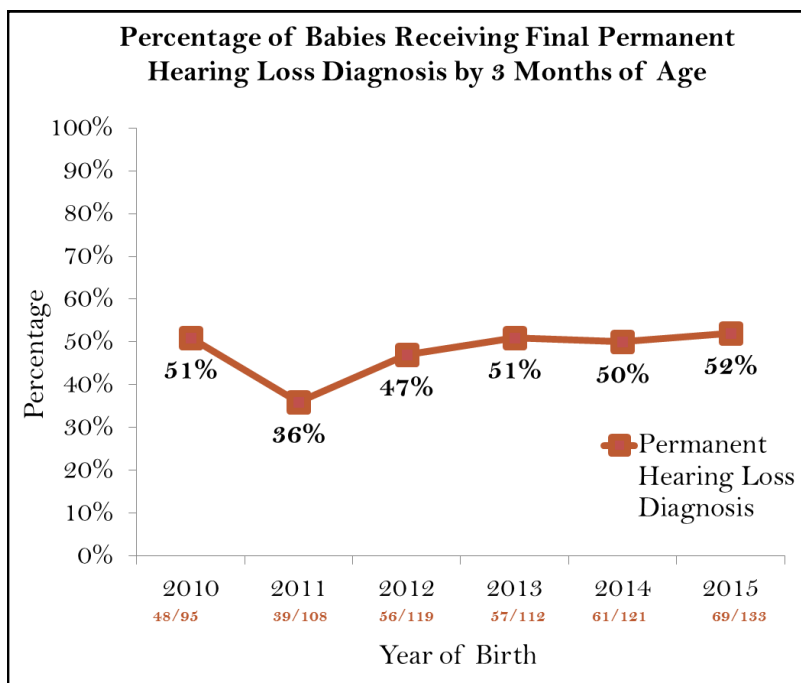
**Referral:** WSB's efforts to screen babies and reduce LTFU all contribute to the goal of ensuring babies receive diagnostic audiology services by 3 Months of Age. WSB works with health care systems and families to reduce both the time to diagnosis and the time to referral to early intervention.



The percentage of babies receiving diagnostic services, *regardless of diagnostic outcome* (within normal limits, permanent hearing loss, transient hearing loss), by 3 Months of Age remained the same between 2014 and 2015.

The national estimate of congenital permanent hearing loss (PHL) is one to three babies per 1,000 births. The number of children diagnosed with PHL in Wisconsin has hovered around 100 babies each year, less than the estimate based on Wisconsin's birth rate. In 2015, the number of babies diagnosed with PHL was 133 babies—the most to date.

52% of babies born in 2015 received their PHL diagnosis by 3 Months of Age—the highest in five years.



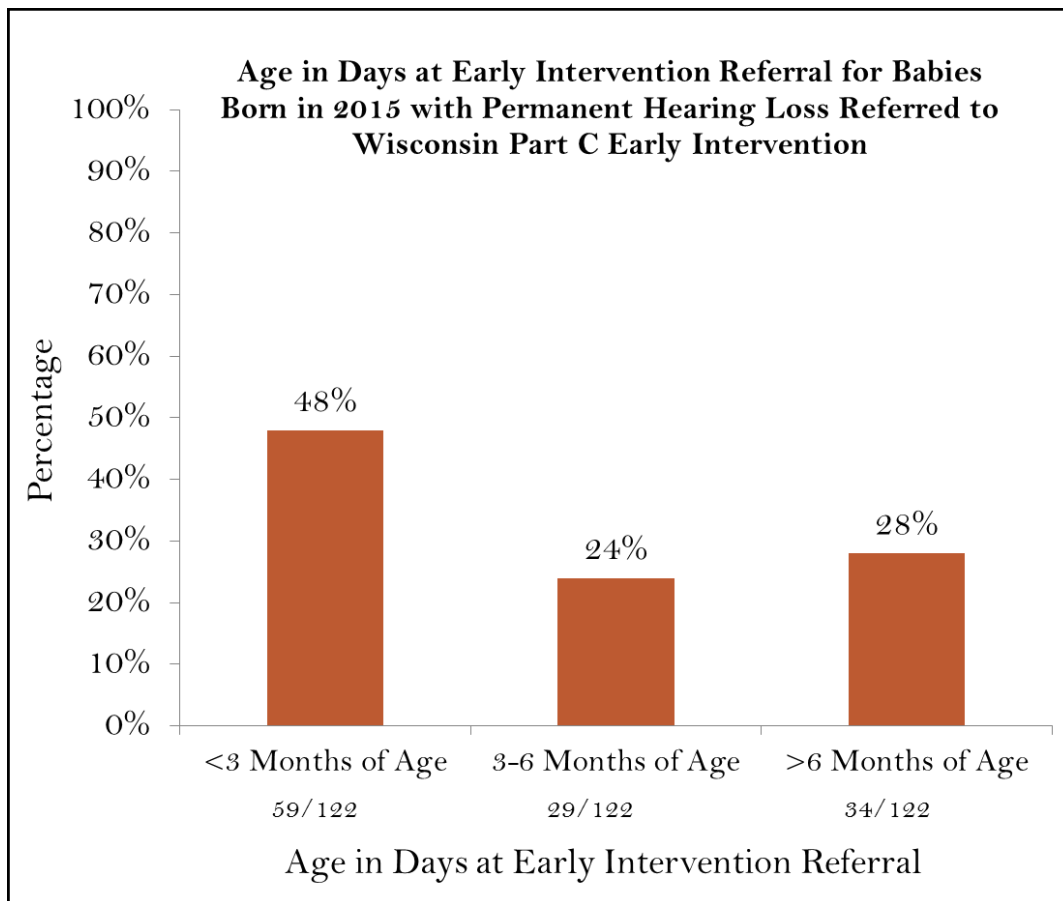


**Referral to Early Intervention:** The goal of timely diagnosis is to facilitate timely referral to Early Intervention (EI).

Of the 133 babies born in 2015 and diagnosed with PHL, 122 were referred to Wisconsin Part C Early Intervention (some babies were referred to Part C programs outside of Wisconsin). Of the 122 babies referred to Wisconsin Part C EI, 48% were referred by 3 Months of Age.



Reasons for delays in diagnosis and referral to Part C EI include a combination of factors such as: complex medical needs; multiple screenings/diagnostic appointments; middle ear fluid with or without tube placement; NICU stay/prematurity; appointments at more than one audiology clinic; and families cancelling or not showing up for appointments. Three babies passed their hearing screening and were later diagnosed with hearing loss (this is comparable to the number in 2014).



**Data Details:** The 122 babies diagnosed with PHL and referred to Wisconsin Part C EI fit into two categories—“already enrolled in EI” and “not already enrolled in EI”—at the time of their WE-TRAC referral. Enrollment is defined as having an Individualized Family Services Plan (IFSP) date documented in WE-TRAC. Already enrolled babies are babies whose IFSP date pre-dates their EI referral via WE-TRAC. Babies not already enrolled are babies who did not. In 2015, 19 of the 122 babies were already enrolled. They are not included in the EI data analysis in the following pages. Excluding the group of already enrolled babies from the data provides the opportunity to better analyze WSB’s efforts to increase enrollment and timely enrollment.

# Enrolled by 6 Months

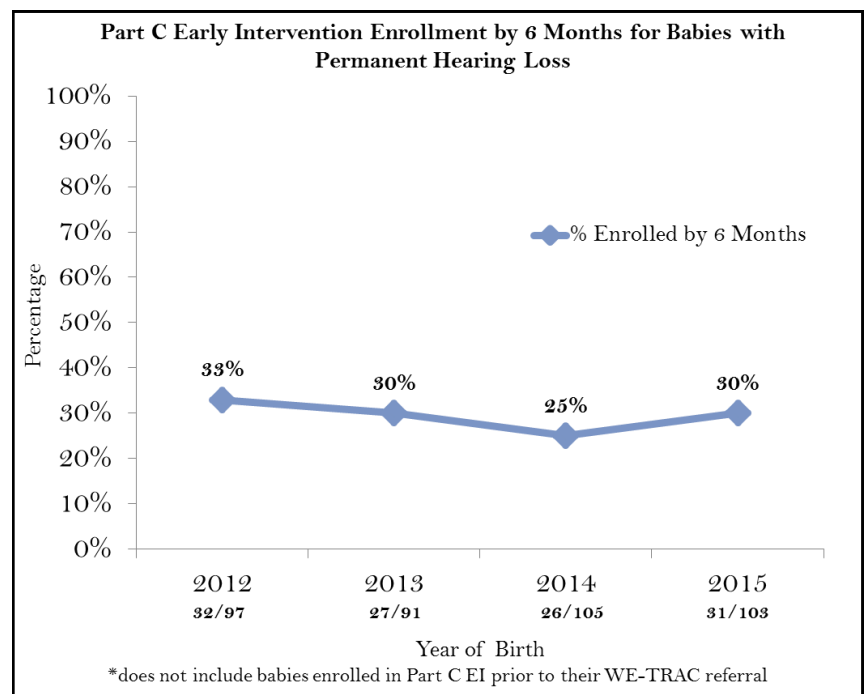
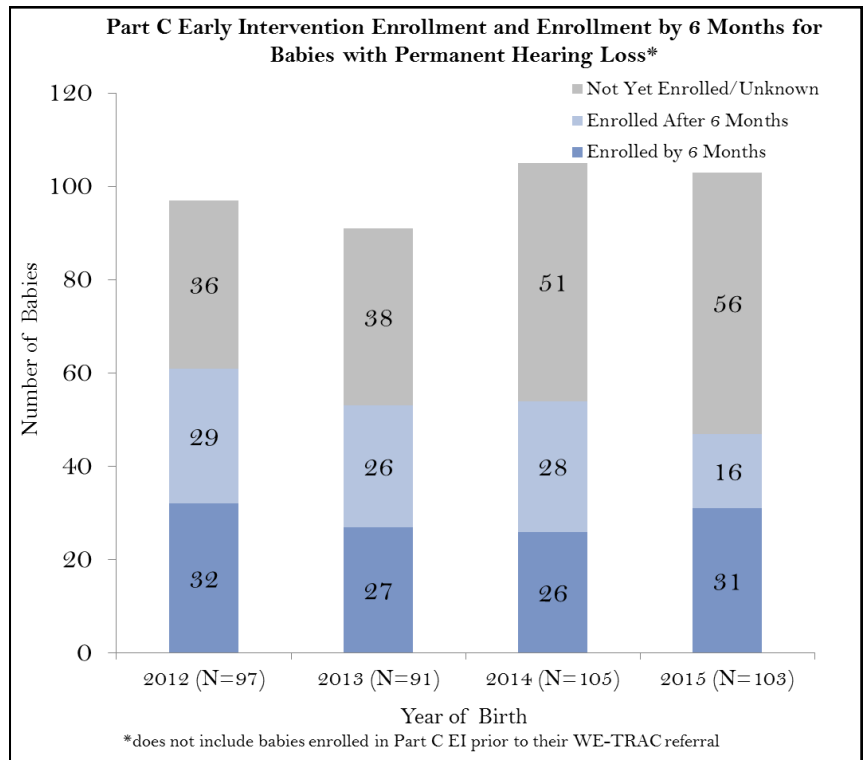
## Enrollment in Part C Early Intervention:

Through a Memorandum of Understanding, WSB and Wisconsin Part C EI (Birth to 3 Program) work together to: support local Birth to 3 Programs; support families enrolled in Part C EI; increase enrollment in EI; improve timely entry of IFSP date or non-enrollment reason into the Birth to 3 Program's data system; and improve the information exchange mechanism between WE-TRAC and the Birth to 3 Program data system.

WSB receives IFSP dates and EI case closed reasons for babies referred to EI via WE-TRAC. The child's IFSP date or Part C EI case closed reason comes directly from the Birth to 3 Program's data system. In Wisconsin, PHL is included in the list of conditions that allow children to be found eligible for Part C EI services due to diagnosis regardless of whether the child is demonstrating developmental delays at time of referral.

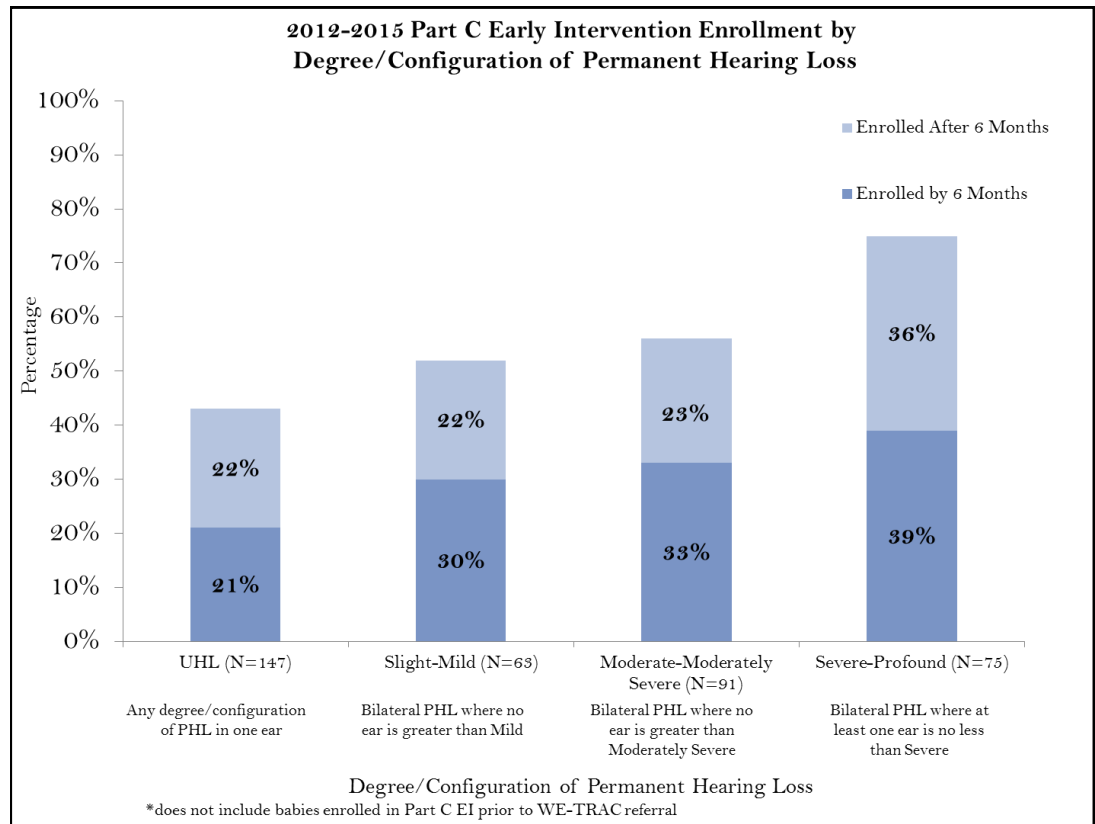
In 2015, 47 babies had a documented IFSP date in WE-TRAC; 31 enrolled by 6 Months of Age. Statewide, 54% (215/396) of all children born between 2012 and 2015 with PHL enrolled in Wisconsin

Part C EI, with 29% (116/396) enrolled by 6 Months of Age. The percentage of families enrolling and enrolling by 6 Months of Age has remained relatively consistent.



Differences emerge when comparing enrollment and enrollment by 6 months by degree/configuration of PHL.

Babies with a Unilateral Hearing Loss (UHL) had the lowest percentage of enrollment at 43% overall, with 21% of babies enrolling by 6 Months of Age and nearly equal percentage enrolling after 6 Months of Age. Children with Severe-Profound hearing loss had the highest enrollment at 75% overall, with 39% of babies enrolling by 6 Months of age and 36% enrolling after 6 Months. Babies with Slight-Mild hearing loss had 53% enrollment and babies with Moderate-Moderately Severe hearing loss had 56% enrollment.



Degree/configuration is entered into WE-TRAC by the diagnosing audiologist as a pure tone average for each ear. Babies with incomplete degree information or auditory neuropathy are excluded from the above graph.



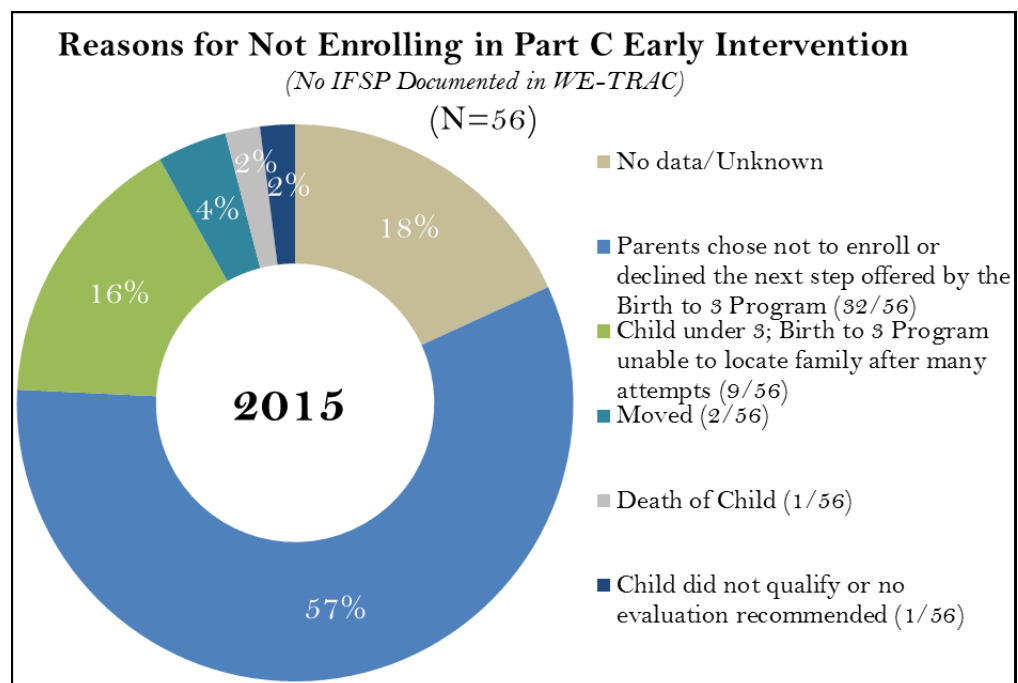
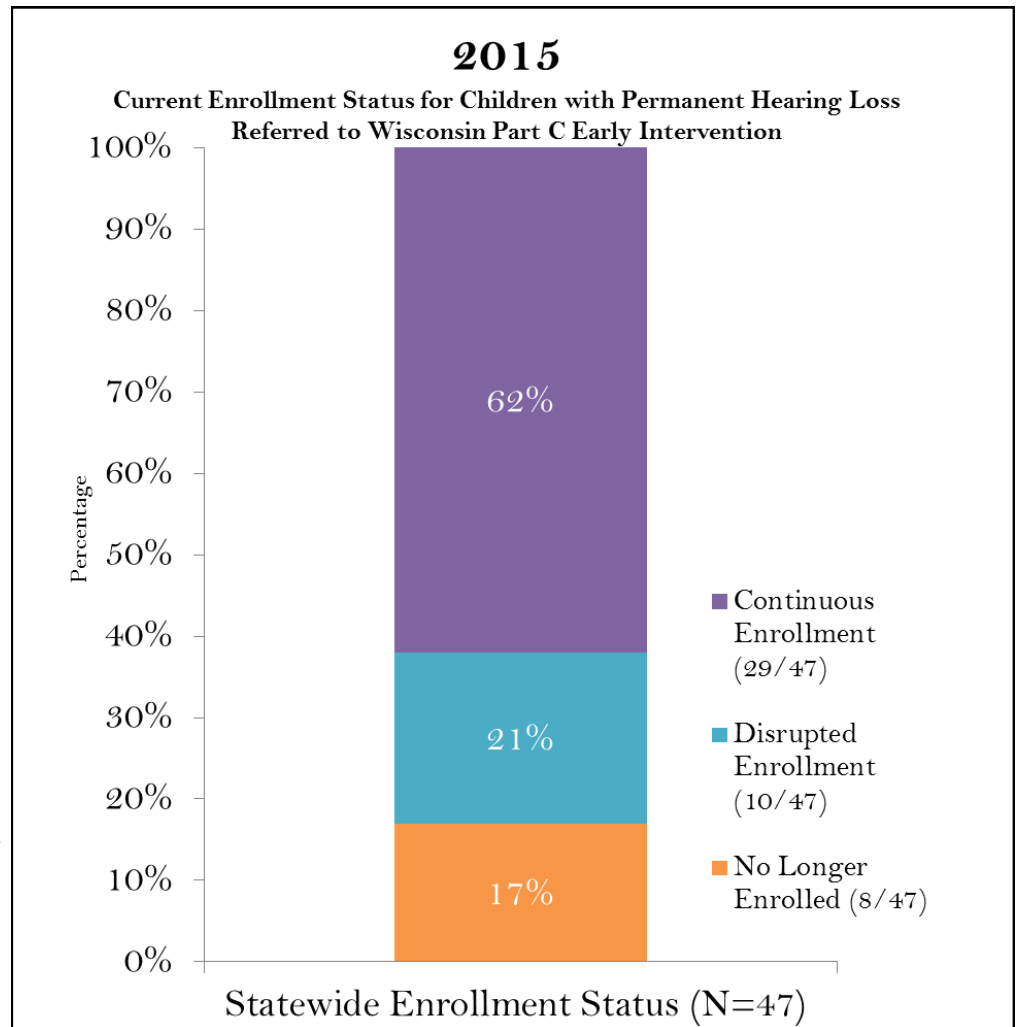
**Data Details:** Families may enroll at time of referral to Part C or at any point until the child turns three. Part C EI is a voluntary program and families consent to participate. WSB's data system provides information about a child's most current status for screening, diagnosis, and EI enrollment. For example, a child born in 2012 who did not enroll at time of diagnosis at three months but did enroll when the child was two years old is counted as "enrolled" in WSB's EI data but not "enrolled by 6 months." At the time of reporting in 2012, that same child would have been counted under "not yet enrolled." Children may be enrolling in EI later than the initial referral, but not necessarily because they were late in being diagnosed.

**Enrollment Status:** Along with evaluating enrollment and enrollment by 6 Months of Age, WSB evaluated the current enrollment status for babies born in 2015. Of the 105 babies referred to Part C EI, 48 babies enrolled.

At time of analysis, 62% (29/47) of the babies who enrolled in Part C EI had continuous enrollment; 21% (10/47) had disrupted enrollment; and 17% (8/47) were no longer enrolled. Reasons for no longer being enrolled vary.

WSB also evaluated reasons why a family hasn't yet enrolled in Part C EI. Of the 105 babies, 57 are not documented as enrolled in Part C Early Intervention.

The majority of families (57%) chose not to enroll in Part C EI services. The second highest reason for not yet enrolling was "Birth to 3 Program unable to locate the family after many attempts," accounting for 16% (9/56) of the families who did not enroll.



*Supporting Early Intervention and Improving Outcomes:* WSB has two early intervention initiatives: CARES—*Coordination, Assessment, Resources and Evaluation Services* and REIL—*Regional Early Intervention Liaison*. CARES and REIL staff work to increase enrollment, increase enrollment at the time of referral to Part C EI, increase duration of enrollment, and to improve developmental outcomes for children who are deaf or hard of hearing. Launched in late 2014, the first CARES Specialist serves Wisconsin’s Southern Region. REIL launched in the spring of 2015 to support regions without a CARES Specialist. In 2015, WSB began planning to expand CARES to an additional region. In 2016, WSB hired its second CARES Specialist to serve the Northeastern Region.

**CARES:**

- Provides specialized knowledge and skills related to pediatric hearing loss as a resource for both Birth to 3 Programs and families.
- Participates in intake, evaluation, Individualized Family Service Plan (IFSP) meetings, joint visits with Birth to 3 Program primary providers, and families and/or transition support when children turn three.
- Supports families in conjunction with the family’s Birth to 3 Program primary provider.

**REIL:**

- Provides specialized knowledge and skills related to pediatric hearing loss as a resource for Birth to 3 Programs
- Supports local Birth to 3 Programs when a baby is referred to their program.

REIL staff worked with 25 different counties for 78 babies born in 2015 with PHL and referred to Wisconsin Part C EI.

- Supports local Birth to 3 Programs currently serving children who are deaf or hard of hearing and their families.
- REIL staff do not work with families.

In 2015, the Southern Region CARES Specialist provided individualized support to Southern Region Birth to 3 Programs and families. The Southern Region CARES Specialist:

- Worked with 33 different families.
- Worked with children ranging in age from a few months old to three years.
- Attended 8 out of 12 initial intake visits for newly referred children.
- Attended 10 out of 10 of the evaluation/ IFSP meetings.
- Completed numerous joint visits with each family and their primary provider.
- Provided ongoing support for programs and all of the families enrolled in Part C EI in the Southern Region.
- Supported Birth to 3 Programs and families with transition out of Part C EI at age three.

**Assessment of Early Intervention Outcomes (AEIOu):** Wisconsin families with children who are deaf or hard of hearing are eligible to participate in the research project AEIOu, part of the National Early Childhood Assessment Project. Families participate when children are 13-20 months old and 30-38 months old. The research goal is to analyze participating children’s communication, social-emotional, and general development; the early intervention they receive; and other variables that may affect their developmental outcomes. WSB staff invite families to participate in the study during a WSB outreach call when children are 14 months old. During the outreach call, WSB provides information about resources (e.g. Wisconsin Families for Hands & Voices; Deaf Mentor Program; Babies and Hearing Loss Notebook; upcoming 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 provides Birth to 3 Program contact information and encourages families to contact their local Birth to 3 Program or WSB re-refers them to the Birth to 3 Program. Of the families eligible and interested in participating in AEIOu, 106 have completed Phase 1 and 54 have completed both Phases to date. The “EHDI Outcomes Study” in Wisconsin will increase enrollment in AEIOu with the following aims for 2015-2017: to assess the impact of receiving early intervention services on developmental outcomes; and to compare CARES and REIL support.



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EHDI Program  
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## 2015 Annual Report Definitions

Term	Definition
Baby	The term “baby” is used in the annual report to encompass all children involved in EHDI aged zero to three.
Birth to 3 Program	Wisconsin’s Part C Early Intervention program. This term is used interchangeably with Part C Early Intervention or EI in the annual report.
Complete Case	Cases where the baby has received complete follow-up. Complete follow-up includes passing a re-screen, receiving a within normal limits diagnostic result, or confirmed permanent hearing loss/early intervention referral.
DNP	Did Not Pass: babies who did not pass their hearing screening.
EHDI	Early Hearing Detection and Intervention
Enrolled in Early Intervention	Enrolled/Enrollment in Part C Early Intervention/Birth to 3 Program: a baby with an Individualized Family Service Plan (IFSP) date documented in WE-TRAC.
Incomplete case	Cases where the baby has not received necessary follow-up (reasons may vary).
LTFU/LTD	Loss or Lost to Follow-Up / Loss or Lost to Documentation This is a combined category of reasons a baby has not received follow-up. LTFU indicates that no contact information has been found for the family. LTD indicates that a family may have followed up but no documentation of follow-up has been found. LTFU in this context is a specific definition for why a baby has not received follow-up. LTFU is also a general term to indicate all babies who have not received follow-up (LTFU Rate).
LTFU Rate	The number of babies who did not pass their initial hearing screening and did not receive follow-up (not including deceased) divided by the total number of babies who did not pass their initial hearing screening. In this case LTFU encompasses all reasons a child did not receive follow-up (except for deceased) and not just those for whom no contact information has been found.
Never Screened	A baby who has not received newborn hearing screening or any type of hearing testing; has not engaged in the EHDI continuum of care.
Not Yet Enrolled in Early Intervention	A baby referred to Part C Early Intervention who does not have an IFSP date but does have a closed reason for not enrolling. Since the child has until they turn three to participate in Part C EI, they have the potential to enroll up until their third birthday.
Part C Early Intervention (EI)	Early intervention provided for children from birth to age three years old as part of the federal Individuals with Disabilities Education Act (IDEA) designed to serve infants and toddlers with disabilities, established developmental delays, and/or diagnosed conditions with a high probability of resulting in a developmental delay.
PHL	Permanent Hearing Loss; a diagnosis of hearing loss of any degree that is permanent.
Still Active Case	Cases where the baby is still in the process of receiving follow-up.
WSB	Wisconsin Sound Beginnings—Wisconsin’s Early Hearing Detection and Intervention program.
WE-TRAC	Wisconsin EHDI-Tracking Referral And Coordination: Wisconsin’s EHDI data system for hearing screening, diagnostic, and early intervention information. WSB monitors, manages, and measures Wisconsin’s hearing screening, loss to follow-up, diagnosis, and early intervention through its data system, WE-TRAC.

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