

WISCONSIN SOUND BEGINNINGS

99% of
Babies
Screened for
Hearing Loss

LTFU
Reduced by
57% since
2010

98% of Babies
Referred to
Early
Intervention

75% of Babies
Received
Diagnostic
Audiology by
Age 3 Months

80 Babies
Received In-
Home or
Community
Screening

promoting
hearing
health...one baby
at a time

2013 Annual Report

Winter 2015

TABLE OF CONTENTS

| | |
|---|-------|
| Table of Contents | 3 |
| WSB Team Contact Information | 4 |
| Mission, Vision and Guiding Principles | 5 |
| 2013 Screening and Diagnostic Numbers | 6 |
| Executive Summary | 7 |
| Ensuring Newborn Screening: Reconciliation Project | 8-9 |
| Ensuring Newborn Screening: Out of Hospital (OOH) Outreach | 10-11 |
| Reducing Loss to Follow-Up (LTFU) for Babies Who Did Not Pass their Newborn Hearing Screening | 12-13 |
| Analyzing WSB's LTFU for Babies Who Did Not Pass their Newborn Hearing Screening | 14-15 |
| WSB Outreach: In-Home Screenings | 16-17 |
| Reducing Time to Diagnosis for Babies Who Did Not Pass | 18-19 |
| Reducing Loss to Follow-Up and Improving Outcomes for Babies Referred to Early Intervention | 20-21 |
| Wisconsin State Map with Regions Defined | 23 |

CONTACT INFORMATION

Central Office

Fax: 608-267-3824

Christi Hess, PhD, CCC-SLP

CARES Outreach Specialist

Southern Region

Christi.Hess@wi.gov

Rebecca Martin, MPH, IMH-E® (II)

Outreach Specialist Coordinator

Southern/Northeastern Regional Outreach Specialist

608-261-7654

Rebecca.Martin@wi.gov

Elizabeth Seeliger, Au.D

Program Director

608-267-9191

Elizabeth.Seeliger@wi.gov

Gretchen Spicer, CPM, LM

Out-of-Hospital Outreach Specialist

608-532-6464

Gretchen.Spicer@wi.gov

Connie Stevens, MA

Guide By Your Side Follow-Through Coordinator

608-266-0917

1-888-405-2724

Connie.Stevens@wi.gov

WE-TRAC Project Manager

vacant

Northern and Western Region

Jeanne Gustafson

Regional Outreach Specialist

715-726-7900, ext. 2131

jgustafson@co.chippewa.wi.us

Southeastern Region

Susan Picione, BSN, RN

Regional Outreach Nurse Specialist

414-286-6618

spicio@milwaukee.gov

WISCONSIN SOUND BEGINNINGS

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

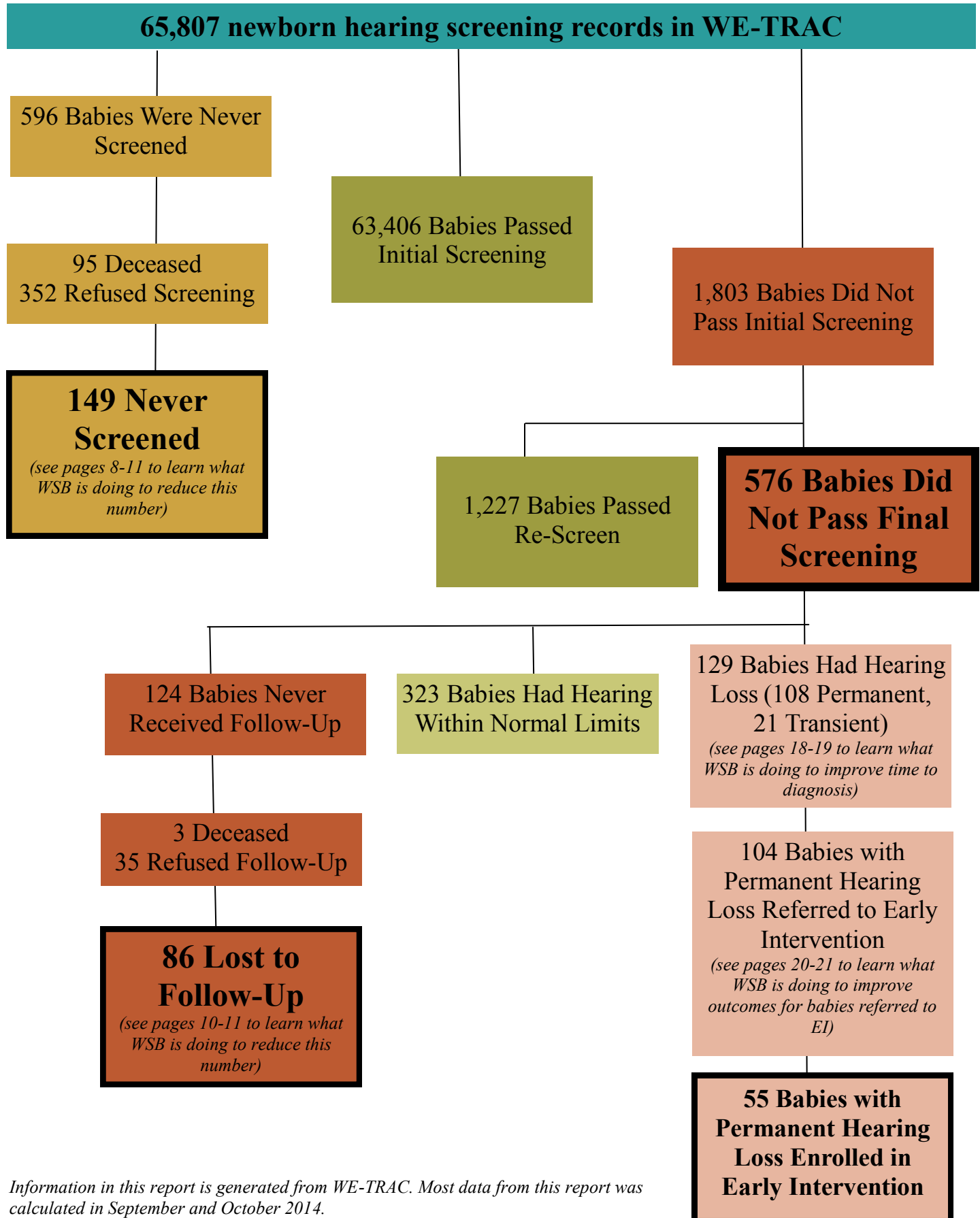
- ♦ We meet families where they're at without judgment or bias.
- ♦ We drive change and decision-making through the use of sound and valid data collection.
- ♦ We work on behalf of the well-being of children and strive to optimize their potential.
- ♦ We are dedicated to innovative development and sustainable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

Christi Hess, Jeanne Gustafson, Rebecca Martin
Susan Picione, Elizabeth Seeliger, Connie Stevens, Gretchen Spicer

2013 Screening and Diagnostic Numbers



Information in this report is generated from WE-TRAC. Most data from this report was calculated in September and October 2014.

WISCONSIN SOUND BEGINNINGS

Executive Summary

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 receive quality early intervention. 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 the web-based data system, **WE-TRAC**. WSB is administered collaboratively through contracts between the Department of Health Services and the University of Wisconsin-Madison State Laboratory of Hygiene and Waisman Center University Center for Excellence in Developmental Disabilities.

Wisconsin Sound Beginnings works to:

Ensure All Babies Are Screened or Have Documented Refusal

Hospitals and midwives continue to screen 99 percent of babies born in Wisconsin. WSB, along with its newborn screening partners, have embarked on a project to analyze whether all babies born in Wisconsin received or have documented refusal of one or more newborn screenings.

The majority of babies who do not receive a hearing screening continue to be those who are born at home or a free-standing birth center, not hospitals. To increase the number of babies screened, WSB provides outreach, education and support to midwives and traditional birth attendants who serve babies born out-of-hospital (OOH) and their families. WSB provides direct services to families and community partners to provide hearing screening to families choosing an OOH birth.

Reduce Loss to Follow-Up (LTFU) for Babies Who Did Not Pass their Newborn Hearing Screening

WSB continues to systematically reduce LTFU through its 3-Step-Follow-Up process for babies who *did not pass* their newborn hearing screening. WSB works with hospitals, medical homes, families and local partners to help ensure accurate documentation in WE-TRAC, encourage audiological follow-up for those families who need it and provides in-home or in-community re-screens.

Reduce the Time to Diagnosis for Babies Who Need Diagnostic Services

WSB collaborates with audiologists and health care systems to decrease the age at diagnosis and provide case-specific and quality improvement support as needed or requested.

Reduce Loss to Follow-Up and Improve Outcomes for Babies Referred to Early Intervention

WSB created CARES —Coordination, Assistance, Resources and Evaluation Services—for children who are deaf or hard of hearing. Currently, a CARES Specialist supports both families and Birth to 3 early intervention providers serving children who are deaf or hard of hearing in the Southern Region.

WSB also conducts the Assessment of Early Intervention Outcomes (AEIOu) study that tracks developmental outcomes of early-diagnosed children who are deaf or hard of hearing in the areas of general, communication and social-emotional development; the early intervention they receive; and the variables that affect positive outcomes.

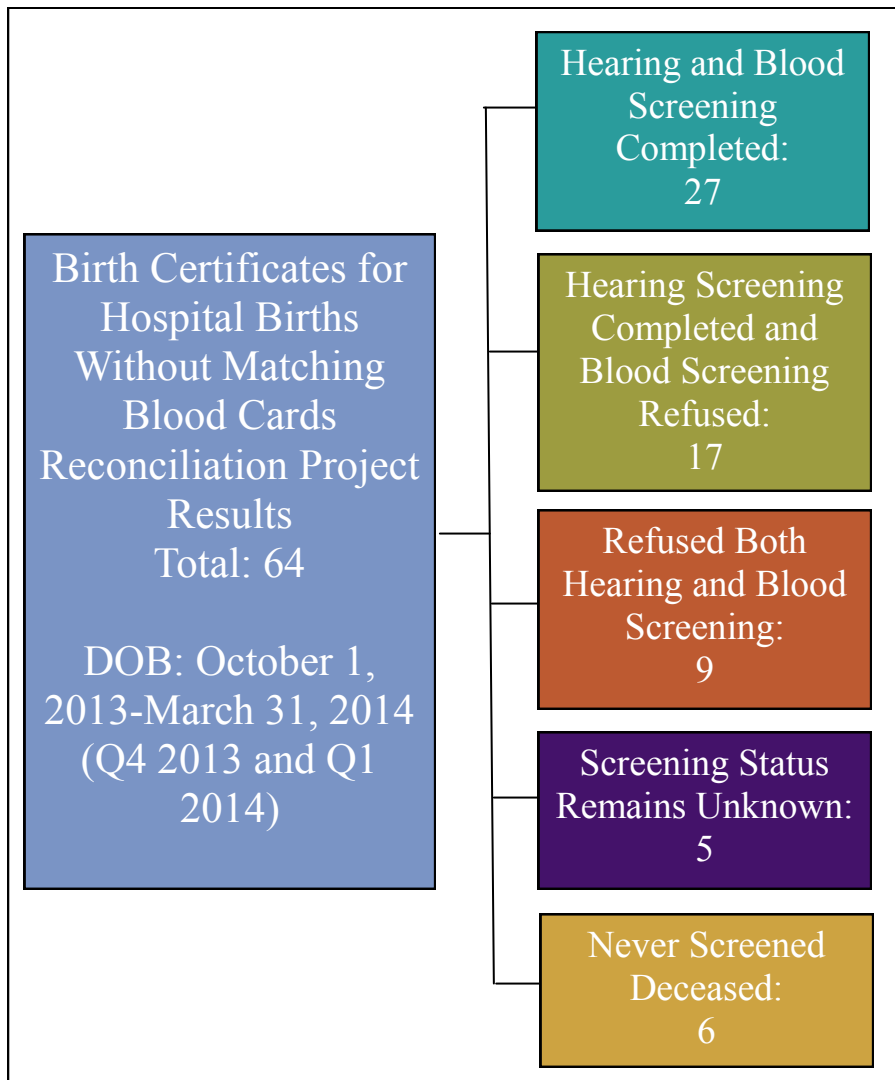
ENSURING BABIES ARE SCREENED

Blood Card-Birth Certificate Reconciliation Project

WSB and the State Vital Records Office (SVRO) created a data exchange mechanism between WE-TRAC and the SVRO birth certificate database. This allows WSB to match newborn screening blood cards with birth certificate records—*providing for the first time ever, the opportunity to evaluate whether the number of babies born (via birth certificates) and the number of babies screened (via WE-TRAC records) match.* This blood card-birth certificate reconciliation project is part of an overarching quality assurance project for the newborn screening program to document that all babies born in Wisconsin receive newborn screening or have documented refusal.

WSB and its partners have reconciled records for the last quarter of 2013 and the first quarter of 2014. For Hospital Births, the focus has been on documenting refusal and ensuring accurate data transmission from birth hospitals to the State Laboratory of Hygiene (SLH) and from SLH to WE-TRAC. In the two quarters that have been reconciled, 64 cases were hospital births and 127 cases were home births. More than half of the OOH births (62 percent) appear to be from the Plain community (Amish or Mennonite).

For the hospital birth cases that went through the reconciliation process, *83 percent of the 64 cases were successfully reconciled* by documenting results or refusals.



One key finding from the reconciliation project is that many of the babies who had a Wisconsin birth certificate but no Wisconsin screening information were born in Wisconsin but transferred immediately out of state, usually to a Neonatal Intensive Care Unit. Most of these babies received newborn screening while at the out-of-state hospital.

The other key finding is that while a family might refuse the blood screening, that didn't mean they refused all screening. But hospitals did not know they could or should report hearing screening only results to WSB.

This reconciliation project also has served an important role in developing procedures to ensure that hospitals and midwives are able to accurately report information to the newborn screening programs.

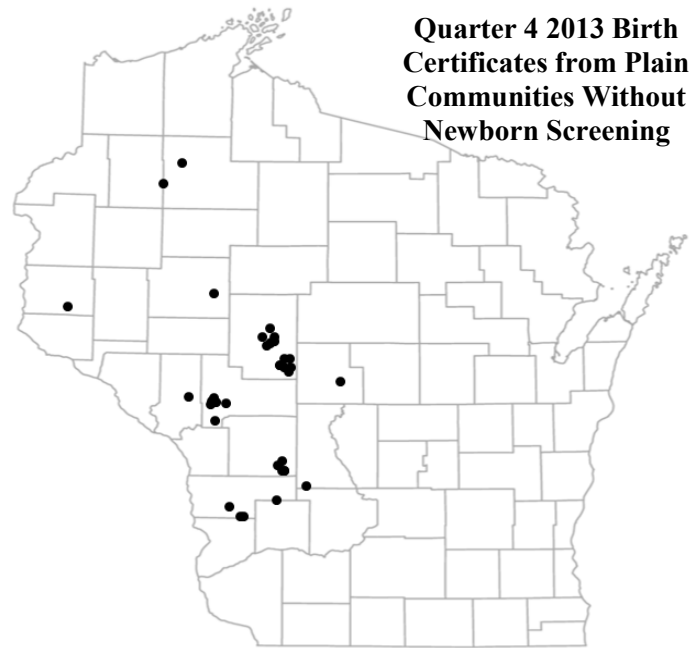
ENSURING BABIES ARE SCREENED

Blood Card-Birth Certificate Reconciliation Project

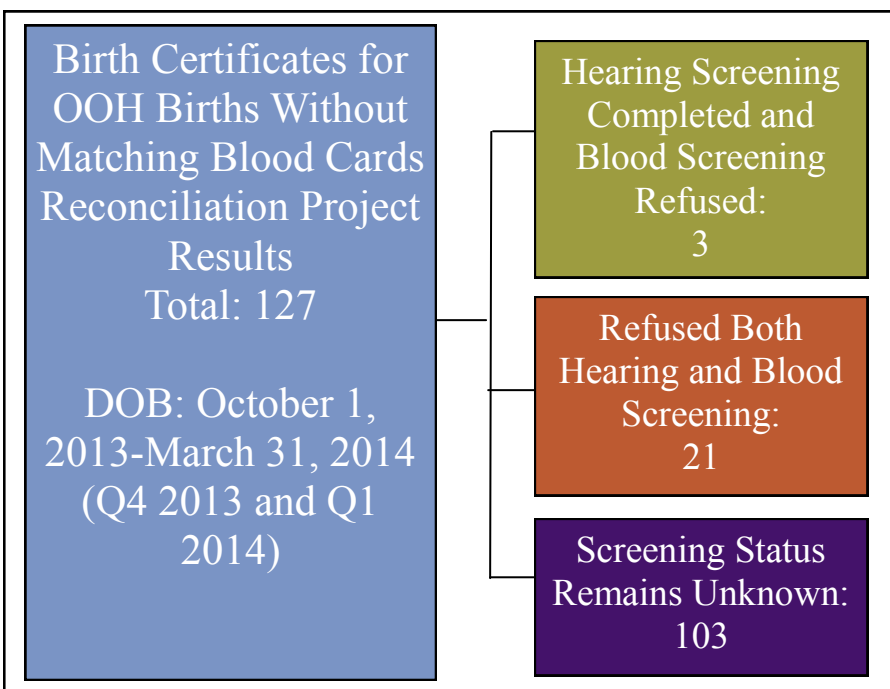
The preliminary data analysis from the Reconciliation Project for out-of-hospital (OOH) births has focused on identifying areas with high-density OOH births with low screening rates (typically births attended to by traditional Amish or Mennonite birth attendants). Identifying geographic trends has informed targeted efforts to train birth attendants and develop screening and diagnostic clinics or other options for families in these areas.

WSB continues working to document screening refusals for the OOH births, similarly to the hospital births, but many of the OOH birth certificates without a matching blood card are for Amish or Mennonite babies whose births were attended by traditional birth attendants. Typically neither the family nor the birth attendant have phones, making the reconciliation process (confirming refusal, documenting results or identifying possible issues the birth attendant may have had with screening) more lengthy.

The preliminary results are that the majority of families refused one or more of the screenings. Similarly to the hospital births, midwives were not aware of how to report hearing screening results to WSB if the family had only refused the blood screening.



Data and lessons learned from the reconciliation project have been key to changes being made to newborn screening reporting in Wisconsin. Upcoming changes to the newborn screening program include the following: providers will now submit a blood card for every baby born; blood cards have been modified to include information for all three newborn screenings, including refusal; and WE-TRAC is being modified to accommodate direct entry of screening results from the 2014-mandated Critical Congenital Heart Disease Pulse Oximetry screening into WE-TRAC.



ENSURING BABIES ARE SCREENED

Out of Hospital Outreach

In 2013, the majority of not screened babies (66 percent) were born out of hospital (OOH) and/or to members of the Plain community. WSB continues to target its efforts to improve hearing screening in the OOH/Plain community by:

- Providing culturally appropriate screening materials, training and support to birth attendants and providers serving OOH and Plain communities.

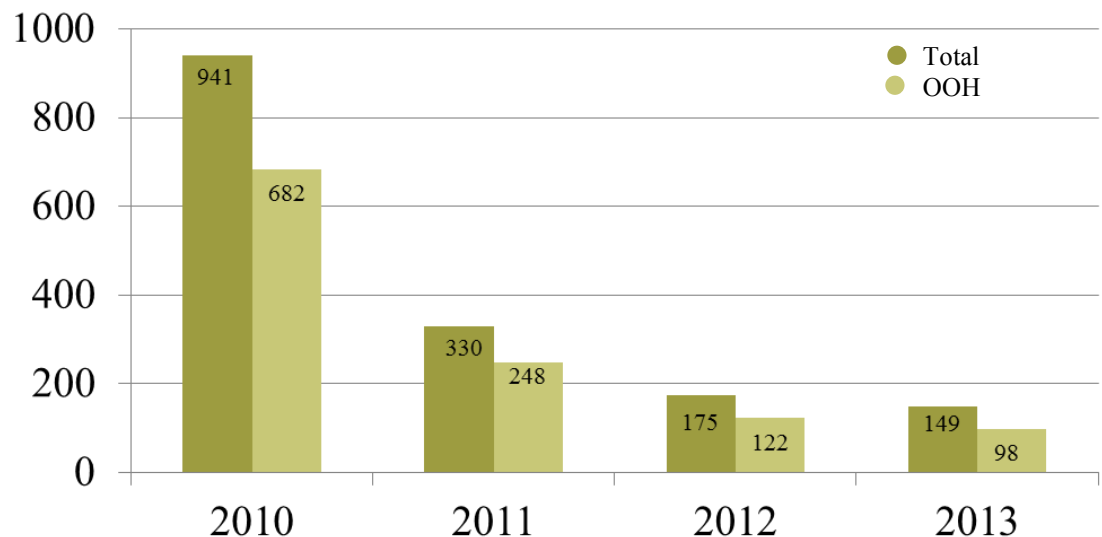
- Holding outreach clinics in key areas of the state: WSB held six screening and diagnostic clinics in conjunction with local public health

Thanks to OOH screening clinics, 44 babies were screened and one child was diagnosed with bilateral permanent hearing loss.

departments and traditional birth attendants in the Athens and Augusta areas in northwestern Wisconsin. WSB staff, University of Wisconsin-Madison and Waisman Center audiology staff and students screened 44 babies and diagnosed one with bilateral permanent hearing loss. (Staff also screened 87 children and 47 adults.)

- Providing in-home screenings to OOH families: WSB has three Regional Outreach Specialists (ROS) and an OOH Outreach Specialist. For babies born in 2013, ROS screened 25 OOH babies. The OOH Outreach Specialist screened an additional 10 babies. OOH babies accounted for half of all the hearing screenings WSB staff provided in 2013.
- Establishing referral networks for Amish midwives not performing hearing screening: WSB met with Amish midwives, licensed midwives and public health department staff from two counties to build partnerships to ensure that every baby in the area has access to affordable and culturally appropriate hearing screening services.

Number of Babies Never Screened by Total and OOH (does not include refused/deceased)



ENSURING BABIES ARE SCREENED

Out of Hospital Outreach

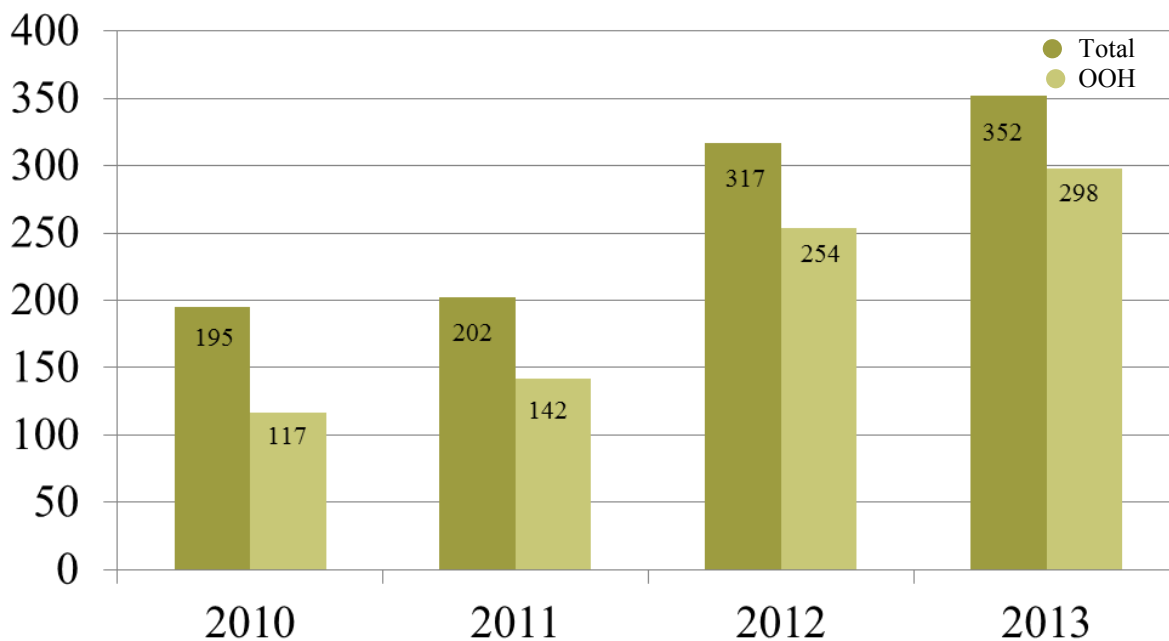
- Providing targeted outreach to the OOH community: WSB held two trainings for Amish midwives, one at the end of a community meeting with six Amish midwives. The second was a day-long training at an Amish family's home with 33 Amish midwives and included a hearing screening demonstration, discussion about the impact of undiagnosed hearing loss on children and the importance of communication in developing attachment between mother and baby. The Amish midwives contributed many insights to the discussion on how to promote hearing screening in their communities.

While all of these efforts increased the number of babies screened, 352 families in 2013 still refused the newborn hearing screening (as documented in WE-TRAC). Of those, 85 percent were born out of hospital (and 63 percent were likely members of the Plain community).

Therefore, community outreach and building local providers' competence and support for newborn screening has been a key component in WSB's work. As WSB improved screening access and reporting, as anticipated, the number of refusals has risen. With the addition of the reconciliation project to identify babies born in Wisconsin and document their screening results or refusals, WSB anticipates that the number of refusals may be even higher in the coming years due to increased reporting of both OOH/Plain community births and screening refusals. WSB continues to build rapport, support and screening capacity among these communities in an effort to increase screening and decrease refusals among the OOH and Plain communities.

In 2013, 85% of the babies whose family refused the hearing screening were born out-of-hospital .

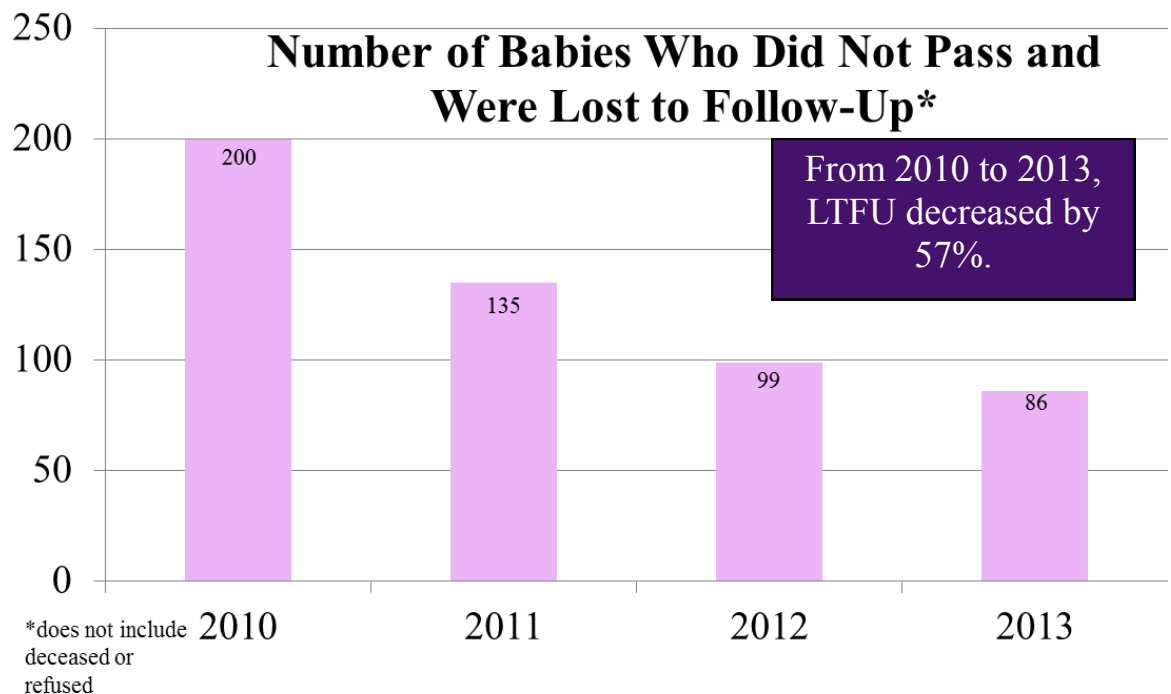
Number of Babies Whose Family Refused Hearing Screening by Total and OOH



REDUCING LOSS TO FOLLOW-UP

For Babies Who Did Not Pass their Hearing Screening

WSB continues to systematically reduce LTFU for babies who did not pass their hearing screening through the 3-Step-Follow-Up (3SFU) process. Based on the 1-3-6 goals, WSB identifies babies who did not pass their newborn screening and have not received follow-up in WE-TRAC by one month of age. These babies are deemed at-risk for LTFU and go through the 3SFU process.



In 2013, 384 babies out of the 1,803 who did not pass their initial screening went through 3SFU—21 percent. In 2012, it was also 21 percent. ***So while WSB's 3SFU and other efforts successfully reduced Wisconsin's LTFU rate, the percentage of babies identified as potentially at risk and requiring 3SFU remained the same.***

STEP 1 Medical Outreach: WSB reaches out to birth units, medical homes and audiology clinics to determine if the child has received follow-up. WSB informs primary care providers of the child's hearing screening results and the need for follow-up. WSB monitors the case to ensure follow-up or determines if the case needs additional LTFU prevention intervention. Many cases at Step 1 are at risk for being *lost to documentation*. The child may have been referred for follow-up or may have already received follow-up but it has not been documented accordingly in WE-TRAC—***64 percent of the successfully resolved cases in 2013 were resolved at Step 1.*** If the family has not received follow-up and does not have follow-up scheduled, has not seen the primary care provider or has missed multiple appointments, the case moves on to Step 2.

STEP 2 Regional and Family Outreach: WSB provides direct outreach to families to encourage follow-up, address concerns and answer questions. WSB contacts families by phone or letter and is available to support parents as they move through the EHDI continuum of care. If WSB can't reach a family or the family cannot or will not access traditional healthcare, the case moves on to Step 3.



REDUCING LOSS TO FOLLOW-UP

For Babies Who Did Not Pass their Hearing Screening

STEP 3 In-Home/In-Community Screening: WSB provides in-home or in-community rescreens for those families experiencing barriers (cultural, linguistic, logistical, economic, etc) 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 whose cases require Step 3 intervention are usually the most at-risk for LTFU, with families confronting many barriers to follow-up. In fact, 19 of the 38 cases (**50 percent**) successfully resolved at Step 3 received a WSB-conducted re-screen.

As part of the 3SFU process, WSB collaborates with its partners at WIC (Special Supplemental Nutrition Program for Women, Infants and Children) to help reach families at-risk for LTFU. At Step 1, WSB staff determines which families require additional follow-up and whether they are also participating in WIC. Families at-risk for LTFU and in WIC receive an alert in their WIC file requesting WIC staff provide the family with a letter encouraging follow-up or to contact WSB to coordinate care.

In 2013, 384 babies' cases required 3SFU intervention. More than 60 percent of those that entered 3SFU did not move beyond Step 1 and never qualified for the WIC alert project. Of the 155 that did move beyond Step 1, 33 percent (51) received WIC alerts. This is *less* than the state average of approximately 50 percent of babies born in Wisconsin participating in WIC. However, of those that required the more intense WSB intervention and went to Step 3, 66 percent were WIC participants.

In 2013, 71 percent of non-WIC participant babies in 3SFU received follow-up, while slightly more—80 percent—of babies with WIC alerts received follow-up. Because the WIC alert project is wholly integrated into the 3SFU process, it has been difficult to ascertain the alert's impact on the baby receiving follow-up. To better document WIC's responses to the alert, starting in 2014, WIC provides direct feedback to WSB regarding WIC's efforts. Also in 2014, families who receive a WIC alert are asked to fill out a three-question survey so that WSB can also evaluate the family's response to the alert.

The WIC alert project is conducted in partnership with the Waisman Center and is funded in part by a grant from the Centers for Disease Control and Prevention.

384 Babies Entered 3SFU

(341 received follow-up; 2 remain in progress; 41 were still LTFU)

221 Successfully Received Follow-Up While at Step 1

82 Successfully Received Follow-Up
While at Step 2

38 Successfully Received
Follow-Up While at Step 3

ANALYZING WSB'S LTFU

For Babies Who Did Not Pass their Hearing Screening

Wisconsin defines its LTFU as the number of babies who did not pass their final hearing screening and did not receive follow-up care but excludes babies who are deceased or whose families refused follow-up. In 2013 this LTFU number was 86.

To analyze trends among those LTFU, WSB looked more closely at these 86 cases. First, WSB removed those LTFU because the baby was on hospice, receiving palliative care or whose medical condition precluded testing and those in which a baby was placed for adoption. WSB wanted to focus our LTFU analysis on the population of babies who did not pass their hearing screening and did not receive follow-up care, but who could be impacted by WSB's current or future efforts (i.e. not those who were deceased, on hospice, adopted or whose family refused). **This left 75 LTFU.**

Of the 75 LTFU, 85 percent ended up in the WSB safety net, with WSB trying to reduce LTFU in some way—72 percent (54) went through 3SFU and an additional 10 babies had other kinds of WSB involvement. All of the LTFU cases had notes written in them from either the audiology clinic or the birth unit staff documenting their efforts to assist the family to receive follow-up. No cases appear to have simply 'fallen through the cracks.'

WSB looked at several aspects of these LTFU cases to identify trends, including birth hospital, mother's race/ethnicity and mother's education level.

Of the 39 birth hospitals represented by the 75 babies LTFU, Hospitals C and G are receiving targeted quality improvement from WSB. Others will be involved in quality improvement efforts in the next years of the WSB grant.

WSB examined mother's race/ethnicity represented among the babies who were LTFU. There is a greater percentage of Hmong, Black and Native Americans represented among the LTFU cases than there are compared to the overall population who gave birth in 2012*—Hmong (2 percent of births compared to 9 percent LTFU), Black (9 percent of births compared to 16 percent LTFU) and Native Americans (1 percent of births compared to 5 percent LTFU).

Additionally, WSB looked at the breakdown of mother's education represented among babies who were LTFU. There are some differences between the education levels of cases LTFU compared to the overall population who gave birth in 2012*. For example, women who had less than a high school education were only 9 percent of the general population versus 26 percent of those LTFU. Fewer women had Bachelor's degrees among those LTFU (13 percent of LTFU compared to 22 percent of the total population), Associate Degrees (5 percent LTFU compared to 11 percent) or Master's Degrees (1 percent LTFU compared to 8 percent).

For babies LTFU, WSB also looked at the age of mothers at delivery and found that the average age was 28, the minimum age was 18 and the maximum age was 43. The mean and median age was 23.

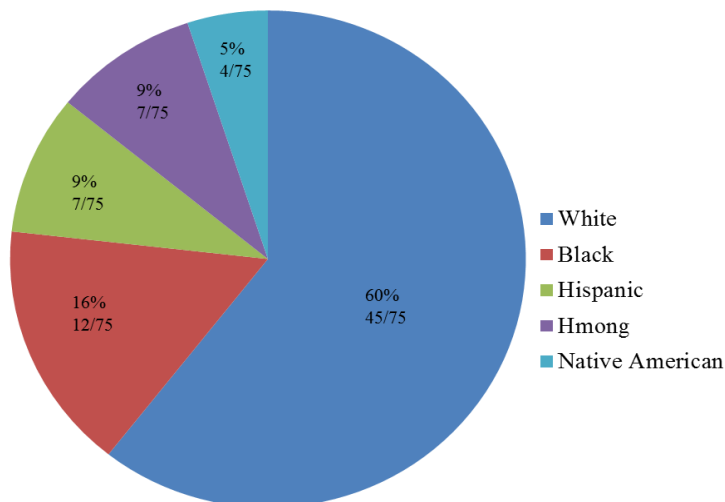
| Hospital | Percentage of LTFU Cases | Number of Births (per WE-TRAC) |
|----------|--------------------------|--------------------------------|
| A | 10% (8/75) | >3,000 |
| B | 7% (5/75) | 2,000-2,500 |
| C | 5% (4/75) | 500-1,000 |
| D | 4% (3/75) | 1,500-2,000 |
| E | 4% (3/75) | 1,000-1,500 |
| F | 4% (3/75) | >3,000 |
| G | 4% (3/75) | 500-1,000 |
| H | 4% (3/75) | <500 |
| I | 4% (3/75) | 2,500-3,000 |

*<http://www.dhs.wisconsin.gov/births/wisbirthsreport2012.htm>

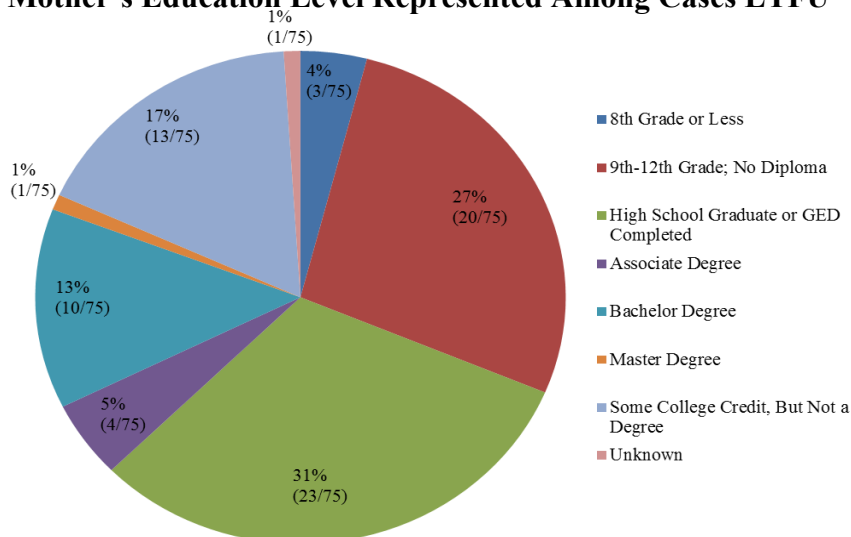
ANALYZING WSB'S LTFU

For Babies Who Did Not Pass their Hearing Screening

Mother's Race/Ethnicity Represented Among Cases LTFU



Mother's Education Level Represented Among Cases LTFU



Potential factors that may be impacting LTFU include: whether the parent received prenatal education about newborn screening; what messages parents receive at the time of screening; whether follow-up appointments were scheduled prior to hospital discharge; whether parents and primary care providers are informed of the screening results and need for follow-up; the presence of risk factors such as transportation barriers, insurance issues, workplace flexibility, education level, language or literacy levels, socioeconomic issues, disparities and more.

WSB continues to work to address these issues through our quality improvement, in-home screening, parent outreach and other targeted efforts, which have steadily been reducing LTFU in Wisconsin.

WSB OUTREACH

WSB-Provided Hearing Screenings

Similarly to WSB’s analysis of its LTFU population, WSB is looking more closely at another key aspect of our work—in-home or in-community hearing screenings.

One of the fundamental tenets of the WSB program is ‘meeting 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

| WSB Provided Screenings for Babies Born in 2013 | WSB-Provided Screening Total N=70 | WSB Region*: Southeastern N=44 | WSB Region: Northern Western N=18 | WSB Region: Southern Northeastern N=8 |
|---|-----------------------------------|--------------------------------|-----------------------------------|---------------------------------------|
| Hospital Births | 64% (45/70) | 77% (34/44) | 28% (5/18) | 75% (6/8) |
| OOH Births | 36% (25/70) | 23% (10/44) | 72% (13/18) | 25% (2/8) |

barriers to accessing traditional care. 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 Wisconsin’s never screened rate.

ROS receive referrals for families in need of an in-home screening as part of Step 3 of 3SFU, as a direct referral (from a hospital or an out-of-hospital midwife) or through other WE-TRAC data clean-up (ie-re-opening a case that was inappropriately closed).

| WSB Provided Screenings for Babies Born in 2013 | WSB-Provided Screening Total N=70 | WSB Region*: Southeastern N=44 | WSB Region: Northern Western N=18 | WSB Region: Southern Northeastern N=8 |
|---|-----------------------------------|--------------------------------|-----------------------------------|---------------------------------------|
| Initial Screening | 33% (23/70) | 25% (11/44) | 66% (12/18) | 0 |
| Follow-Up Screening | 67% (47/70) | 75% (33/44) | 33% (6/18) | 100% (8/8) |

WSB began providing screenings at the end of 2011 and the number of babies receiving an in-home screening has increased every year (56 in 2012 to 70 in 2013). The WSB-provided screening option was developed as a way to address barriers families may be experiencing to accessing traditional care to reduce

LTFU for babies who did not pass and increase screening rates for babies who were not screened.

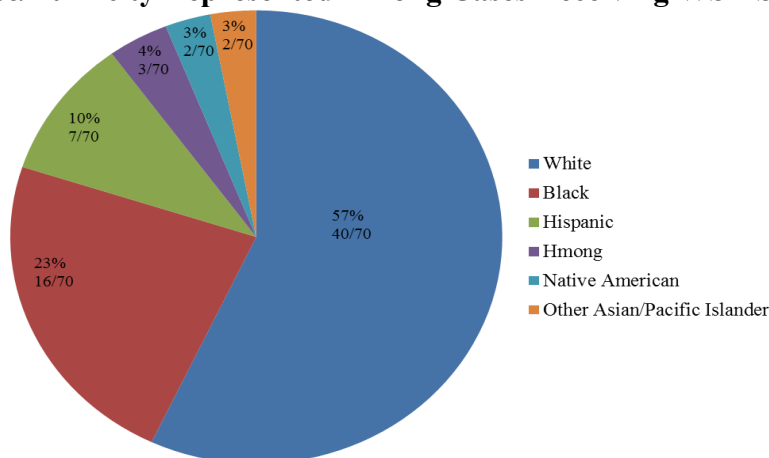
In 2013, 70 families received a WSB-provided screening. Of these, 25 were provided to out-of-hospital families. Twenty hospitals are represented in the other 45 cases receiving a WSB screen. WSB examined mother’s race/ethnicity and mother’s education represented among babies receiving a WSB-provided screening. WSB also examined mother’s age at delivery for babies receiving a WSB-provided screening. The average age was 29, the minimum age was 17 (one mother) and the maximum age was 45 (one mother). Similarly to the cases LTFU, there is a higher percentage of some racial/ethnic groups represented among the cases receiving a WSB screening than in the general birth population as well as differences among mothers’ education level.

**While ROS regions are based on the Department of Health Services regional designations (see map on page 23), WSB staff follow-up on babies based on region or who is geographically closer (ie-Sheboygan is in the Northeastern Region but the Southeastern ROS is closer. Families also move in and out of regions. The cases reported here are included in the region for the ROS who provided the screening.*

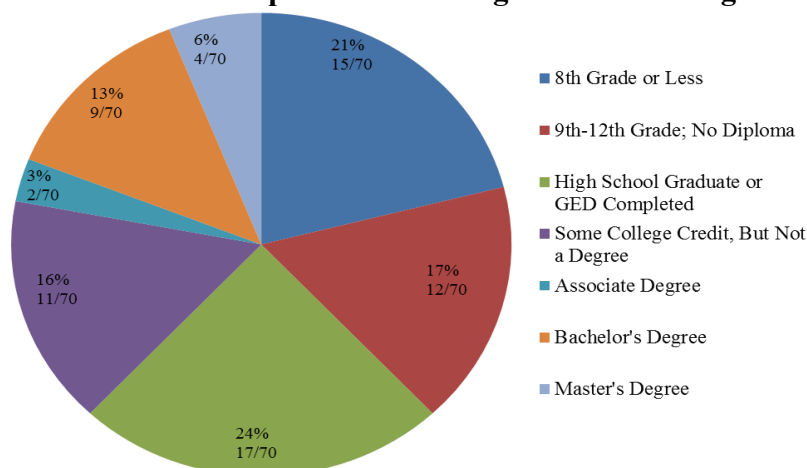
WSB OUTREACH

WSB-Provided Hearing Screenings

Mother's Race/Ethnicity Represented Among Cases Receiving WSB Screening



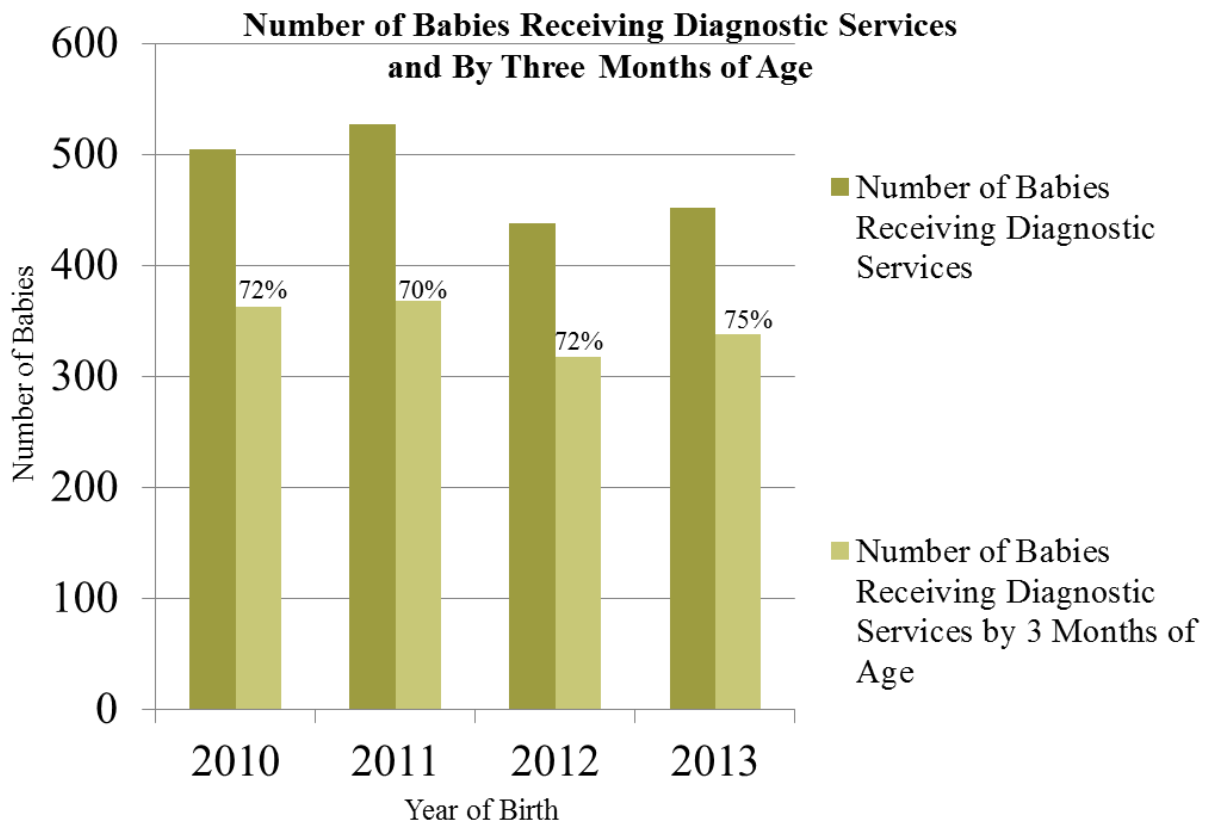
Mother's Education Level Represented Among Cases Receiving WSB Screening



Perhaps the most important information to emerge from this analysis is that of those babies who received, but did not pass, their WSB-provided screening, *most were still LTFU* and they never received additional screenings or diagnostic evaluation. In fact, of the 12 babies who did not pass their WSB-provided screening, only two cases were successfully resolved—one with diagnosed hearing loss. The other cases were closed as unresponsive families or the families refused additional follow-up. This is despite WSB outreach, case management, support and in-person visits with the families. WSB's in-home/in-community screening outreach reduced the number of babies lost to follow-up and increased the number of babies being screened. However, for those babies who still did not pass after the WSB-provided screening, the factors that impacted the family initially may still be impacting their follow-up. Of more importance might be the combination of risk factors that those families who don't pass and are subsequently LTFU might be experiencing. WSB will continue to analyze its outreach efforts and adhering to its guiding principle of meeting families where they're at.

REDUCING TIME TO DIAGNOSIS

For Babies Who Did Not Pass their Hearing Screening



WSB works to reduce the time to diagnosis for those babies who do not pass their hearing screening and receive diagnostic services. While the percentage of babies receiving diagnostic services, *regardless of diagnostic outcome* (within normal limits, permanent/transient hearing loss) by three months of age, did **increase slightly for 2013**, this percentage has not changed much over the last four years.



WSB reaches out to audiology clinics to encourage accurate and timely data reporting to 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 provides quality improvement technical assistance to clinics that need or request it. Audiology clinics also can access reports through WE-TRAC so they can monitor their own clinic's performance.

As part of the 2014-2017 grant cycle, WSB is focusing on quality improvement in EHDI systems. To identify health care systems (birthing units and audiology clinics), WSB looked at factors such as 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.

REDUCING TIME TO DIAGNOSIS

For Babies Who Did Not Pass their Hearing Screening

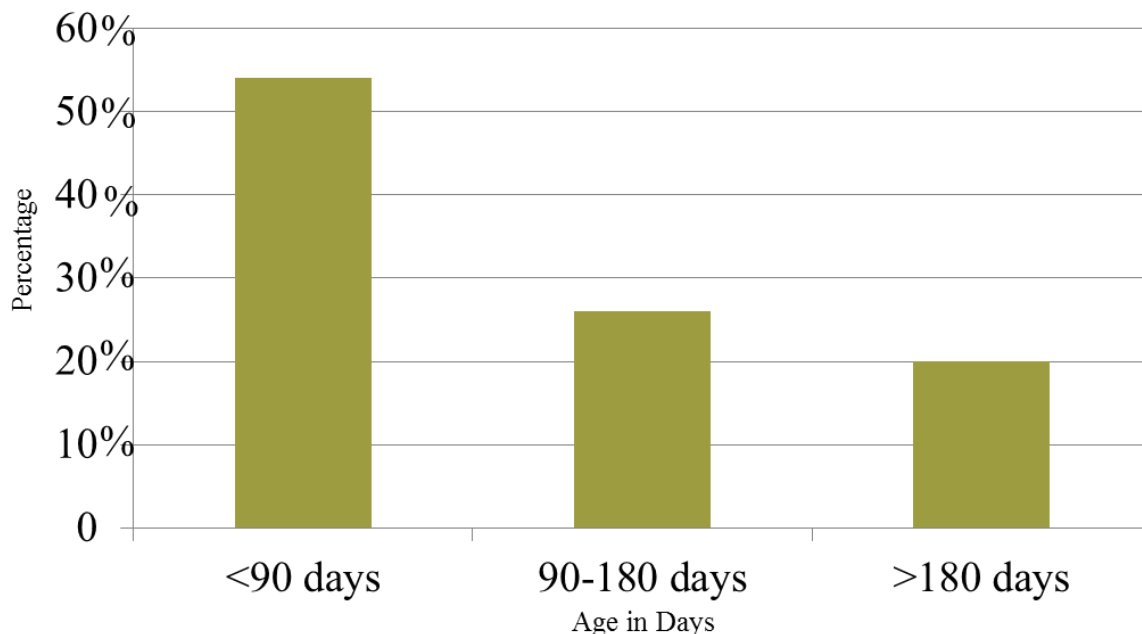
While the percentage of babies receiving diagnostic services, regardless of outcome, by three months of age in 2013 was 75 percent, the percentage of babies *diagnosed with a permanent hearing loss* (and referred to Early Intervention) by three months of age was much smaller. For babies diagnosed with a hearing loss, the percentage who received their diagnosis by three months of age was just **51 percent**. While this is better than in 2012 when it was 48 percent and even better than 2011 when it was just 37 percent, there remains room for improvement.

Although most of the children born in 2013 were diagnosed less than 90 days from birth, a handful of babies weren't diagnosed until they were more than a year old.

Factors associated with delayed diagnosis include: multiple rescreens; deviations from best practice follow-up protocols; repeated rescreens due to suspected middle ear issues; multiple appointments to confirm diagnosis; and children with complex medical needs.

In 2013, only 51% of babies with permanent hearing loss were diagnosed by 3 months of age.

Age at Hearing Loss Diagnosis (in Days) for Babies Born in 2013, Diagnosed with Permanent Hearing Loss and Referred to Early Intervention



In 2013:

- ⇒ Average number of days from birth to final hearing loss diagnosis: 66 (*down from 116 in 2012*)
- ⇒ Median number of days: 72
- ⇒ Minimum number of days: 12
- ⇒ Maximum number of days: 383

REDUCING LOSS TO FOLLOW-UP AND IMPROVING OUTCOMES

For Babies Referred to Early Intervention

Despite more than 90 percent of babies diagnosed with a hearing loss being referred to the Birth to 3 Program in 2012 and 2013, **only half** actually enrolled. To improve follow-up and ensure access and enrollment in early intervention, WSB and the State Birth to 3 Program (the state's early intervention Part C program) signed a Memorandum of Understanding (MOU). This MOU enables WSB to be a participating Birth to 3 provider, allowing: WSB and Birth to 3 to exchange child-specific information; 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.

While WSB and the Birth to 3 Program's MOU is new, WSB, Birth to 3 and other partners have been engaged in a reimagining of the system of care for children who are diagnosed as deaf or hard of hearing since 2008. At that time, families and service providers identified a need to redesign the service delivery model for Wisconsin children who were deaf or hard of hearing to ensure access to quality, family-centered services and supports. This need remains six years later.

Our goal is that “the unique identity of the family, and the child’s place within it, is honored and supported as it develops. Families receive systems and supports that are—accessible, equitable, high-quality, collaborative, empowering and sustainable—that allows for multiple possibilities as part of the journey of raising their child.”

Wisconsin Dreams to Design Participants, 2009

<http://www.wesp-dhh.wi.gov/wesp/out-birth-six-redesign.cfm>

While 90% of babies diagnosed with hearing loss were referred to Early Intervention in 2013, only half enrolled.

Therefore, WSB developed CARES—*Coordination, Assessment, Resources and Evaluation Services*. Starting in 2014, a Wisconsin Sound Beginnings CARES Specialist works closely with families and state and local Birth to 3 Programs in the Southern Region of Wisconsin.

The CARES Specialist is a resource for Birth to 3 programs and families, offering specialized knowledge and skills in issues related to pediatric hearing loss to every IFSP team in the Southern Region. The CARES Specialist can participate in intake, evaluation, IFSP meetings and joint visits with Birth to 3 staff and can be called in to consult and support families and providers at other points in time.

| | Southern | | Western | | Northern | | Northeastern | | Southeastern | | TOTAL | |
|---|----------|------|---------|------|----------|------|--------------|------|--------------|------|-------|---|
| | 2012 | 2013 | 2012 | 2013 | 2012 | 2013 | 2012 | 2013 | 2012 | 2013 | 2012 | 2013 |
| Babies Referred to EI via WE-TRAC | 22 | 26 | 15 | 13 | 6 | 5 | 24 | 21 | 43 | 40 | 110 | 102* (*2 were referred to EI out of state) |
| Number of Children with IFSP via WE-TRAC reporting | 13 | 11 | 7 | 6 | 3 | 3 | 18 | 9 | 30 | 26 | 71 | 55 |
| Percentage of Children with IFSP | 59% | 42% | 47% | 46% | 50% | 60% | 75% | 43% | 70% | 65% | 65% | 54% |

REDUCING LOSS TO FOLLOW-UP AND IMPROVING OUTCOMES

For Babies Referred to Early Intervention

CARES works with Birth to 3 and families to increase enrollment and duration in Birth to 3; improve developmental outcomes of children who are deaf and hard-of-hearing; improve Birth to 3 providers' confidence and competence in serving children in their programs through IFSP participation, trainings, joint visits and one-on-one support; address family satisfaction and confidence in parenting their child by connecting families with community programs, resources and services; collaborate with organizations serving children who are deaf or hard of hearing; and more.

As part of the 'A' in CARES, the CARES Specialist will assist with WSB's ongoing Assessment of Early Intervention Outcomes (AEIOu) research project. AEIOu includes assessments, demographic and audiological information completed by participating Wisconsin families. AEIOu is part of the National Early Childhood Assessment Project (NECAP). NECAP's goal is to analyze language and other developmental outcomes of children with hearing loss. Wisconsin collects data from participating families in two phases—phase 1, when children are between 14 and 20 months old and phase 2, when children are 30 and 38 months old.

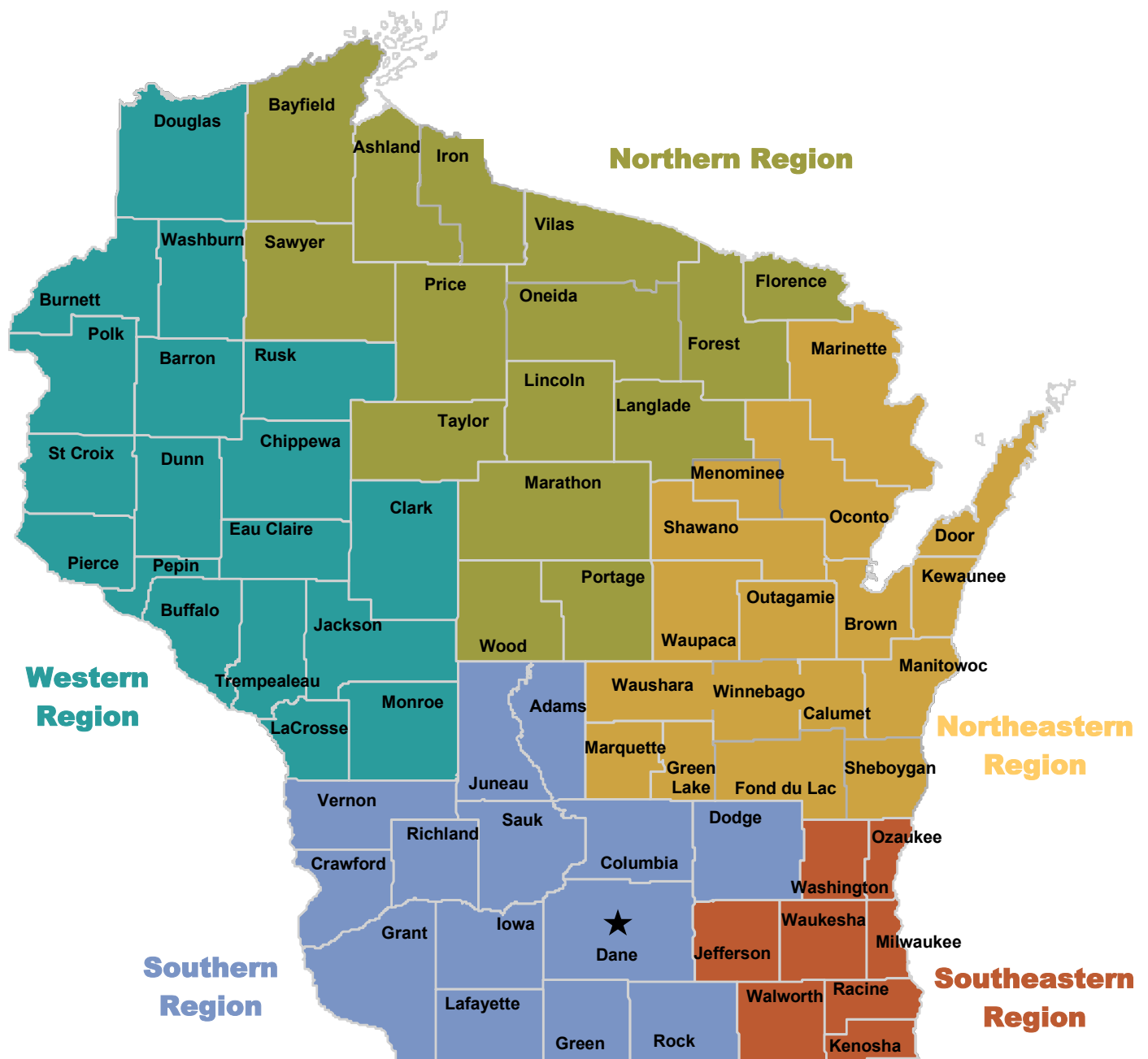
Wisconsin's AEIOu project includes not only the NECAP assessments, but also a social-emotional and a parent-child relationship assessment.

When a child who has been diagnosed as deaf or hard-of-hearing turns 14 months old, WSB staff provides an outreach phone call to the family, offering support and information about resources in the state (such as Wisconsin Families for Hands & Voices, Guide By Your Side, Deaf Mentor Program and conferences, trainings and upcoming activities in their area) and invites them to participate in AEIOu. For families not receiving Birth to 3 services at the time of the outreach phone call, WSB staff has provided information about Birth to 3, encouraged families to contact their local Birth to 3 Program and/or WSB has re-referred them to Birth to 3.

WSB began providing outreach phone calls in 2012 and has successfully spoken with 181 families to date. Of those families eligible and interested in participating in AEIOu, 66 have completed phase 1 and 38 have completed both phases. Additionally, 20 families have participated in the parent-child relationship assessment to date. Evaluation of AEIOu outcomes results is ongoing.

“Now that newborn hearing screening is well-established, our focus turns to the responsibility of early intervention programs to assure children attain the positive outcomes that are promised by early identification.”
Arlene Stredler-Brown,
2006





This program is funded in part by grants from the Maternal & Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

Wisconsin Department of Health Services Program for Children & Youth with Special Health Care Needs
Wisconsin Sound Beginnings
P-00606
(2/2015)