

## Early Hearing Detection and Intervention Advisory Committee Minutes

Thursday, October 7, 2010

10:00-3:00 p.m.

**Location:** Altoona Public Library, 700 8th St SW, Altoona, IA

**Committee Members:** Emily Andrews, Grace Bargstadt, Amanda Carr, Cathy Coppes, Valerie Caputo, Barb Khal, Dennis Konkell, Valerie Lynch, Suzy Mannella, Don Miksell, Shannon Sullivan, Jeffrey Hoffman and Debra Waldron

**Staff:** Susan Hagarty, Vicki Hunting, Tammy O'Hollearn, Peggy Swails, and Jen Thorud

### Introductions & Announcements

- **CDC iEHD grant award.** The EHD program was recently awarded a two year Centers for Disease Control and Prevention (CDC) iEHD pilot database grant. The purpose of this grant is to collect individual-level de-identified data from two states. This data will allow the CDC EHD team to complete additional data analysis on hearing outcomes and answer questions that they were unable to answer with the aggregated data collected through the annual CDC Survey. This opportunity would allow the Iowa EHD program to provide feedback to CDC regarding newborn hearing screening and follow up surveillance. Iowa EHD will be completing a data match between EHD and vital records data that will be submitted starting in March 2011.
- **HRSA/CDC competitive grant.** The EHD program will be writing for both the Health Resources Services Administration (HRSA) follow up and CDC surveillance grants this winter. Both of these grants will be for new competitive grant cycles. Iowa EHD will be in competition with all states and US districts for these grants. These two grants help build needed infrastructure across the state in the absence of state funding or other resources. The HRSA guidance came out last week of September and is due Dec 3, 2010. The current HRSA EHD grant ends March 31, 2011. It is anticipated that the CDC grant will be out the end of 2010/beginning of 2011 and will be due the end of February/beginning of March 2011. As EHD program staff begins working on these applications, we will be sending emails to the advisory committee to get feedback or suggestions for the application, as needed.

Details of the HRSA grant: Grant period begins April 1, 2011 through March 31, 2014. The HRSA/MCHB grant is to improve loss to follow-up infants who

did not pass a physiologic newborn hearing screening examination prior to discharge from the newborn nursery by utilizing specifically targeted and measurable interventions. The funding opportunity will also focus efforts to improve the loss to documentation/loss to follow-up by utilizing specific interventions to achieve measurable improvement in the numbers of infants who receive appropriate and timely follow-up. The HRSA grant also asks that Iowa EHDI speak about collaborative relationships with other agencies- Part C Early ACCESS and the home visiting needs assessment program, as well as others. A number of activities from NICHQ project are included in this grant. We hope to look at the data soon specific to our pilot sites to see what impact the NICHQ work made in reducing the number of children loss to follow up or documentation. HRSA EHDI staff will also request letters of support, letters of agreement, and descriptions of existing contracts to include with the application.

Both grants continue to work towards national 1-3-6 goals. Activities of both grants focus on meeting these guidelines. We hope that various strategies currently being implemented throughout the program will bring us closer to meeting those goals.

HRSA will provide 38 grant awards with over 50 applicants anticipated. Vicki reported that this means the EHDI program needs to come with good ideas and strategies. The CDC grant will be similar, but the focus is more on surveillance, program evaluation and quality assurance. Tammy reported that Iowa has been very fortunate over the last ten years with receiving both grants.

### **Iowa Symposium on Hearing Loss: Impact on Children & Their Families (Emily)**

Symposium was held September 17 and 18<sup>th</sup> at the Marriott in Ankeny. The Center for Disabilities and Development received approximately \$15- 20,000 from a CDC grant to help fund the symposium. CHSC's EHDI also applied for technical assistance money from HRSA Maternal and Child Health Bureau to pay for the costs of one national level speaker. The EHDI program has been successful in obtaining technical assistance money to pay for one speaker the last three symposiums.

CDC sent a representative to the symposium, Eric Cahill. Eric attended the conference and reported that he was impressed with the symposium and speakers. Lenore asked Eric if grant money would be available again in the future. Eric put a call into CDC, but received no word by the end of the symposium.

Overall, Emily reported the comments about the symposium were positive. Many surveys were collected and Tammy and other committee members also received e-mails or comments in person saying it was a great conference; better than previous years. Participant comments indicated they were much happier with the location in Ankeny at the hotel versus the Scheman Center in Ames. Many participants stayed in the hotel which made it convenient. Tammy and Emily both reported positive comments from both parents and professionals about the opportunities for parents and professionals to interact. Participants liked the variety of content speakers as evidenced by the high marks. Tammy noted that a thank you will be sent to hospital administration for letting a nurse who manages the hospital EHDI program attend the symposium. She said that a strategy they may use to increase attendance at the next symposium would be to call an administrator at the hospital.

One area of concern noted was that CEU's were not given out in even increments; some were 0.8. Emily stated that the committee would ensure even numbers at the next symposium. A second area of concern was about the symposium being held on a Fri/Sat. Emily noted that the symposium was changed from Thursday/Friday to Friday/Saturday about four years ago to accommodate parents as we had gotten some feedback that families could do more on Saturday's because of child care, work schedules, etc. In the future, the committee may send out a survey to past participants to assess which days would work better for participants, including parents. It was noted that attendance by the various entities has not changed much from year to year. Emily reported that participants made comments indicating that there was too much emphasis on deaf children/adults and not enough on children/adults who are hard of hearing. The final comment was that there were often times when there were two good sessions that fell at the same time making it hard for participants to choose. In the future, the committee will look at offering some sessions more than once so participants can go to both.

The next symposium will be in the fall of 2012 if the EHDI program receives funding. Emily noted that symposium attendees and committee members feel there is a definite need for this type of learning and networking opportunity. The committee will work to increase attendance of a variety of providers, including nurses and parents. This year's speakers were national level speakers which were high level CEUs for the price. Emily noted audiologists have a hard time getting CEUs without going to a national conference. Emily noted that a number of the sessions were good for both educational and private audiologists.

After feedback Lenore received from audiologists, she feels that the next conference will have a big emphasis on hearing aid fitting, especially with some of the

information gathered through their research. There was discussion that we may want to consider adding an audiology workshop the day before the conference. Many decisions rely on whether the EHDI program receives funding from CDC.

### **Medical Home (Dr. Sullivan/Dr. Waldron)**

Dr. Waldron introduced Dr. Sullivan as the new EHDI Chapter Champion. She stated that Dr. Sullivan would be working with pediatricians in Iowa to educate them about the EHDI program and management of children who are deaf or hard of hearing. She will collaborate with Dr. Hoffman to engage the family practice physicians, as well.

Dr. Sullivan provided an overview of the medical home concept and how the medical home is an important partner in coordinating care for a child who is deaf or hard of hearing. Dr. Sullivan explained the concept of a medical home is to have a primary care provider (this can be a nurse practitioner, family physician, pediatrician, physician's assistant) who works in partnership with a child and a child's family to assure all medical and non medical needs are met. It means that specialists, such as audiologists, communicate with the medical home so they know what referrals need to be made or resources shared.

Dr. Waldron noted that in Iowa, there are over 2-3000 medical providers that may care for children in this capacity. She stated that it is the EHDI programs responsibility to assist the medical home in knowing best practices related to newborn hearing screening and follow up as well as provide them with a list of resources to ensure they can assist the family. It does not mean that the medical home provides all care. It means that the healthcare provider or practice personnel assists the family in making necessary referrals, coordinates care and provides information or resources to parents.

Rev. Konkel inquired if the medical home provides information to parents in an unbiased way? Susan Hagarty spoke up and said that is where the Guide By Your Side program can serve in partnership with medical home to provide unbiased information for families. The medical home does not always know what all the communication options are that are available for families so they could refer the family to the GBYS program. Susan reminded the committee that the guides have all of the information available to them about the various communication options, ongoing care (e.g. ophthalmology, genetics, etc, as well as resources. The guides are all parents, trained to provide unbiased support, as well as emotional support. Many of the guides have been on a similar journey. For example, they may assist parents in

developing a list of questions for the medical home, specialty providers or early interventionists.

Activities or goals surrounding medical home is stressed in both the grant guidance for both HRSA and CDC grants. Child Health Specialty Clinics will take the lead on medical home initiatives for the EHDI program.

Dr. Hoffman provided the rural and family practice perspective related to medical home. Dr. Hoffman stated that they have been using the model for a while. He said the AAP medical home concept is good and family practice is working to make sure kids don't fall through the cracks by working in partnership with parents and providers serving the family. All physicians and committee members agreed there will be great benefits for families and ongoing growing pains, but support is growing for this type of approach. Dr. Sullivan stated she would love to hear what ideas other committee members may have to engage the medical home. Contact her through e-mail or by phone.

### ***Follow up questions/discussion on medical home***

Who is responsible for getting resources and GBYS program info to parents? Susan stated that it is currently given to families most often by the audiologist and sometimes when they are connected to early intervention in Iowa, Early ACCESS (EA). Susan shared that referrals to the GBYS is not where they want it to be right now, but it is improving. Susan shared that in other states, the GBYS program contacts families when infants have not passed two screenings before diagnosis to help answer questions. In Iowa, the GBYS program often becomes involved following diagnosis. Susan would like to see the program get involved sooner. They are currently spreading the word about the GBYS program to providers throughout the state.

Dr. Hoffman said that in Iowa, there are about 1200 family physicians and approximately 1100 belong to the academy. Dr. Hoffman said that they may want to see about writing an article for the e-newsletter or their magazine. Tammy shared that they had written an article about a year to two years ago regarding risk factors for hearing loss, their role in assisting parents, etc. Dr. Hoffman said to contact Katie Cox with the central office of the Iowa Academy of Family Practice for assistance with information about writing an article. He said that the program may also want to consider presenting at their annual conference (can contact Katie for assistance) or visit residency programs and present on EHDI. Dr. Hoffman said that flyers often do not work because physicians get so much information in the mail and

don't have time to read it all. Katie Cox at Academy is lead for e-newsletter and in charge of conferences.

If a child is deaf or hard of hearing, are the PCP/medical home giving parents all the options and resources or referring them to be implanted or get fitted with hearing aids? Tammy explained that the parents have the right to choose what works best for their family based on information from a variety of entities; not just the PCP/medical home. Debra reinforced that it is important that parents know all the options available to them.

### **Children with Hearing Loss; 2007-2009 Data Analysis (Amanda Carr)**

Amanda Carr, an audiology student, at the University of Iowa presented her analysis of kids with hearing loss. Amanda's presentation will be included as a pdf at the end of the meeting minutes. Amanda noted that the numbers related to children with hearing loss (SNHL, conductive, auditory neuropathy) are broken out by ear whereas the unilateral and bilateral numbers are by kid, so the numbers differ. A summary of this data and the findings will also be included in the spring EHDI newsletter. If any committee member has additional questions, please direct them to Tammy O'Hollern and she will contact Amanda and send an e-mail to all committee members.

### **EHDI Data Request FUP (Jen)**

Jen presented data for the additional data items that were requested during the April Advisory Committee meeting. The data items included the following:

- Newborn hearing screening and follow up goals
- Performance indicator target goals
- EHDI comparison across states
- OP hearing screen providers
- Demographics breakdown
- Metabolic and EHDI refusals comparison
- Impact of Amish outreach
- Hearing outcomes and refusals by risk factor status
- Hearing outcomes by nursery
- Improvements after hospital site visits

Jen presented the seven CDC EHDI goals and five HRSA/MCHB Discretionary Grant Performance Measures. These goals and performance measures help guide the work of the two grants. The Healthy People 2020 goal related to EHDI is the national 1-3-6 goals of newborns who are screened for hearing loss by no later than age 1 month,

have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months. Target goals for the CDC performance indicators are currently being developed by the members of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA). These targets were meant to let states know how they are doing. Tammy noted that it may also give states the opportunity to compare the 1-3-6 data throughout the US. The results were not meant to be published at this time due to the discrepancies between data sets. Tammy shared that discussions are continuing regarding the purpose of these state reports and what they should look like.

Jen stated that a survey was sent to birthing hospitals in 2009 asking about their EHDI contact(s), screening equipment, implementation of best practices, including follow-up practices for children missed or who did not pass and need another screen. This survey will be repeated in 2010/2011. That will allow for a comparison to see how many additional hospitals are now bringing back infants for an outpatient screen now compared to 2009. Results will be presented to the Advisory Committee at that time.

The EHDI demographics data shows that our data is similar to vital records data for 2009. In EHDI and through vital records electronic birth certificate reporting, more than one race can be selected. In the EHDI database, the same individual may be counted multiple times if more than one race is selected. Vital records bridges their single and multiple race fields so these numbers sum to the occurrent births. The one thing to note for the 2009 EHDI race/ethnicity data is that 13,000+ records did not report a race/ethnicity. This shows some of the discrepancy between EHDI data and vital records. This issue will be addressed through future training. Most of the unknown sex fields are due to not previously collecting this variable from vital records and not being able to add it to our home birth kids. This has been changed and the EHDI program will be able to collect infant sex in the future.

A comparison of the refusals in the Metabolic database compared to the EHDI data shows that 70% of the metabolic refusals refused the hearing screen and an additional 11% of the metabolic refusals were marked as 'lost' in the EHDI database. Surprisingly, 19% of the metabolic refusals were screened and results indicated normal hearing. Fifty-four percent of metabolic refusals were home births vs. 75% of the hearing refusals.

Outreach to two Amish communities by the EHDI program resulted in 72 families being screened that would not have been screened otherwise. Grant Wood AEA has screened children in 32 families during 6 visits. Great Prairie AEA has screened approximately 40 families. Tammy contacted the elders she worked with in both of

the communities to request the contact information of the elders in two additional Amish communities in the state to explore their interest in setting up screening programs in their communities. Tammy will work with the AEAs in those communities to set up screening programs.

Data analysis of 2009 kids with and without risk factors shows that among kids with risk factors, 91% received a birth screen by 1 month of age and 60% received an outpatient screen by 1 month of age. Of those kids with risk factors, 91% passed their birth screen and 73% passed their outpatient screen or audiological assessment. This is compared to 91% who passed their birth screen and 89% who passed their outpatient screen or audiological assessment among kids without risk factors. The percentage of kids with risk factors with normal hearing is 94% compared to 96% of kids with risk factors who have normal hearing. The percentage of kids with risk factors diagnosed with hearing loss was 2% compared to 0.3% without risk factors diagnosed with hearing loss.

Comparing screening rates and outcomes of kids based on their nursery shows that 86% of NICU kids were screened by 1 month of age. Ninety-three percent of kids in the NICU passed their birth screen and 77% passed their outpatient screen or audiological assessment. Ninety-one percent of well baby kids passed their birth screen and 88% passed their outpatient screen or audiological assessment. Ninety-five percent of kids in the NICU have normal hearing compared to 96% of kids in well baby. Among those kids in the NICU, 1% was diagnosed with a hearing loss compared to 0.4% of well baby kids.

The refer (did not pass) and miss rates were compared at the 33 hospitals who have had a site visit since 2009. The number of hospitals who improved their refer rates following a site visit went from 42% in 2009 to 52% in 2010. The number of hospitals who improved their miss rates went from 82% in 2009 to 79% in 2010. As the year goes on, the miss rates will most likely improve because of missing data at the time this report was reviewed. For example, there is a delay since there are still NICU babies who show up as a miss until they get screened prior to discharge.

Following Jen's presentation, a request was made to provide a breakdown by risk factor to see if there are certain risk factors that lead to more cases of hearing loss. Analysis of late onset hearing loss was also requested. Jen will provide this information at meetings in the future.

## Program Evaluation (Jen)

- **Surveillance survey – preliminary results.** The survey was sent to birthing hospitals and AEAs to complete between September 10 and October 1, 2010. 114 completed surveys were returned. Seventy percent of respondents were from birthing facilities and 27% were from AEAs. A majority of respondents entered screening results (70%) and 29% entered both screening and diagnostic assessment results. Ease of use for the eSP functions ranged from easy to average with only a few selecting them as difficult. Overall, 80% of respondents strongly agreed or agreed that eSP was easy to use. Forty-seven percent of new employees are trained by facility staff and 82% would participate in additional training, preferably by EHDI staff.

Additional analysis will be completed among all respondents and also by facility type. The EHDI team will also talk with the data base vendor to identify suggestions that could be incorporated into eSP. Some comments within the survey highlighted the need for additional trainings. EHDI staff will explore the possibility of having regional trainings across Iowa to retrain facility staff.

- **Family & Provider processes and perceptions survey.** The IDPH EHDI team is continuing to meet with CDC epidemiologists to develop a survey that will go out to families this winter. The survey will get parent's perceptions of newborn hearing screening and follow up. An additional survey will be developed that will go out to providers to assess their knowledge of the EHDI program and the processes they employ to assist families with timely follow up and in reporting hearing screening or diagnostic assessment results to IDPH. The EHDI program hopes to identify areas when improvements can be made and strengths that can be built on or spread to other locations within the state. It will also give us an idea of the variability of the EHDI processes across the state.

## Guide By Your Side (Susan)

There are currently 9 guides with the GBYS program. One of new guides is an EA service coordinator. Another guide has a child with multiple issues. Susan noted that they have guides with a diverse range of experience. Guides are located in Des Moines, Cedar Rapids, Iowa City, Atlantic, Sioux City, Mason City, and Council Bluffs. Geographically, additional guides are needed in the southeast and west. Seven guides attended the symposium and training.

Susan stated that she plans to hold online training with the guides each month. Susan also asked the committee for any resources you want to share with guides, people they should know, and events they should know about. Susan will share this information with her guides. E-mail or call Susan to share your ideas.

Susan reported 3 referrals in last few weeks. She stated that they are getting more referrals now than before and will continue their efforts to get more. NCHAM's Investing in Family Support conference will be held in Kansas City the week of October 11<sup>th</sup>. There will be 3 individuals from CHSC's EHDI program attending.

If you know of a Hispanic/Latino individual interested in being a guide, contact Susan. They are also in need of deaf and hard of hearing individuals to serve as role models. Suzy Manella agreed to include this request in the Office of Deaf Services electronic newsletter.

### **EHDI Administrative Rules (Tammy)**

Tammy sent out an email in September outlining the proposed administrative rule changes. She noted the need to change the way hospitals can communicate with physicians with the push towards electronic health records. In addition, there were requests from two larger facilities to communicate through electronic medical records instead of letters being faxed, etc. The Assistant Attorney General for IDPH met with Tammy to identify ways that this could be done. Hospitals must ensure the following to allow this type of communication with primary care providers: all physicians are trained to use the medical records and the records must be able to reach all physicians (including providers not in that hospital system). If these processes are not in place, the hospital will need to communicate results in writing. The language in the rules will reflect these changes as electronic medical records continue to increase in use.

There is currently a difference in the requirements for hospitals and birthing centers. Birthing centers currently do not have to report results back to the PCP or help to schedule appointments. We want to make sure it is consistent with the hospitals requirements.

There is a different time frame for screening children born at home – currently by 3 months of age. The rules currently conflict with the national 1-3-6 goals. IDPH wants to change it to be consistent with hospital births and national goals-screened by 1 month of age. A committee member inquired where families could take their infants to be screened. Tammy shared that some hospitals provide outpatient hearing screens, private audiologists will perform the screen for infants with medical insurance and AEAs will screen all kids free of charge.

Tammy explained that some questions, issues have lead to the need to tighten up the citizenship and residency requirements for the Hearing Aids and Audiological Services funding. Are there any suggestions?

- Resident of Iowa or their primary legal residence. This is true especially along the borders.
- Proof of residency for a certain period of time.
- Using the requirements included on the state tax forms.
- For FEMA, there are 3 different forms that can be used to prove residency including utility bills (name and home address).
- Using the same eligibility rules for kids on Medicaid. Cathy wasn't sure about these requirements. Tammy will talk with Sally Nadolsky for Medicaid eligibility rules related to citizenship and residency.

There is a need to firm up the language on who is eligible to do outpatient screens. For hospitals, it is very specific. Tammy shared that in the past she thinks that most people thought audiologists would be doing the screening, but there are additional professions, providers or individuals actually performing the screens at this time. She reinforced the need for consistency and policy that reflects best practice. Barb said that Dr. Waldron suggested making it so that anyone under the supervision of a physician could provide the screen. Discussion ensued. Currently there are a number of providers who provide the hearing screens that are not under the supervision of a physician. There were also questions about billing if that were implemented, timely referrals, etc. Most likely this section will be modeled after the birthing hospital section. Barb suggested we also look at the diagnostic assessment section to make sure there is consistency in all sections. Again, it was noted that assessments are different than screenings and should be conducted by a licensed audiologist. Tammy will explore this further with the Assistant Attorney General for IDPH, licensing restrictions, etc.

Tammy shared that there is currently an exception for reporting assessment results. Transient conductive losses lasting less than 90 days do not need to be reported to EHDI. These would be kids with fluid, ear infections, etc. Tammy stated that they are finding that the kids that remain in process in the EHDI system are kids with conductive hearing loss. We are trying to close the loop with these kids, but if it is not lasting over 90 days, providers don't always report. Initially when the law first went into effect, there was concern about the number of kids that providers would be required to report on. However, not reporting also creates issues as children remain in limbo and not all children are being re-screened for a hearing loss once the fluid clears. Tammy shared that by reporting all of these results; it would be fewer kids we would have to follow up on and a record of the ongoing care. We also want to know if

kids don't show up-so we know follow up appointments were made, but the parent failed to show. We want to avoid infants and children falling through the cracks because no one is following up. Valerie Lynch said that for a busy clinic, it is just easier to fill one out a reporting form on each kid than remember they don't need one for this kid, but do need one for this kid.

Tammy reported that they would like to make these changes either before or after the legislative session because of the number of meetings and the increase in requests during the legislative session. In addition, she said that she would also like to get comments so she can make adjustments ahead of time and avoid major changes during the process. Changes will need to go before the Board of Health. The legislative rules committee will also need to sign off and a public hearing held. Doing Tammy and Cathy noted that the entire process takes almost 6 months after the initial draft is ready to go. Tammy will send out the draft to get comments from people on this committee. In addition, if there are other areas to clarify, tighten up-let Tammy know so we can do it all at once.

### **Healthy Iowans (Tammy)**

The Healthy Iowans steering committee is working with IDPH advisory committees and boards to solicit feedback regarding goals and objectives for Iowa to be included in the Healthy Iowans plan! Tammy explained that our task as an Advisory Committee is to come up with 3 recommendations or goals we think we need to work towards in our state related to newborn hearing screening and follow-up, keeping in mind they want to make sure it is something we can move forward or make a difference in. The recommendations will then go to the Healthy Iowans subcommittee for final approval. It is possible that not all recommendations will be accepted. Tammy will draft possible recommendations based on the work we do or will continue to do. She will then send it out to advisory committee members to rank with the top three being submitted to the steering committee. This information will be due towards the end of December.

### **Sharing**

- **CDC Smart Tool.** Moved to January meeting.

### **Wrap up**

- **Agenda items for January.** There was a discussion to identify other alternatives to ICNs such as online webinars for future January meetings. Rev. Konkol and Suzy Manella were asked if there are interpretive services that will help you participate over the internet. Would captioning be enough? I-visual is one option, but it can only work for up to 8 people at the same time. Rev. Konkol was not sure if it would work with this type of



meeting. Vicki said that the EHDI team will explore other options for future January meetings.

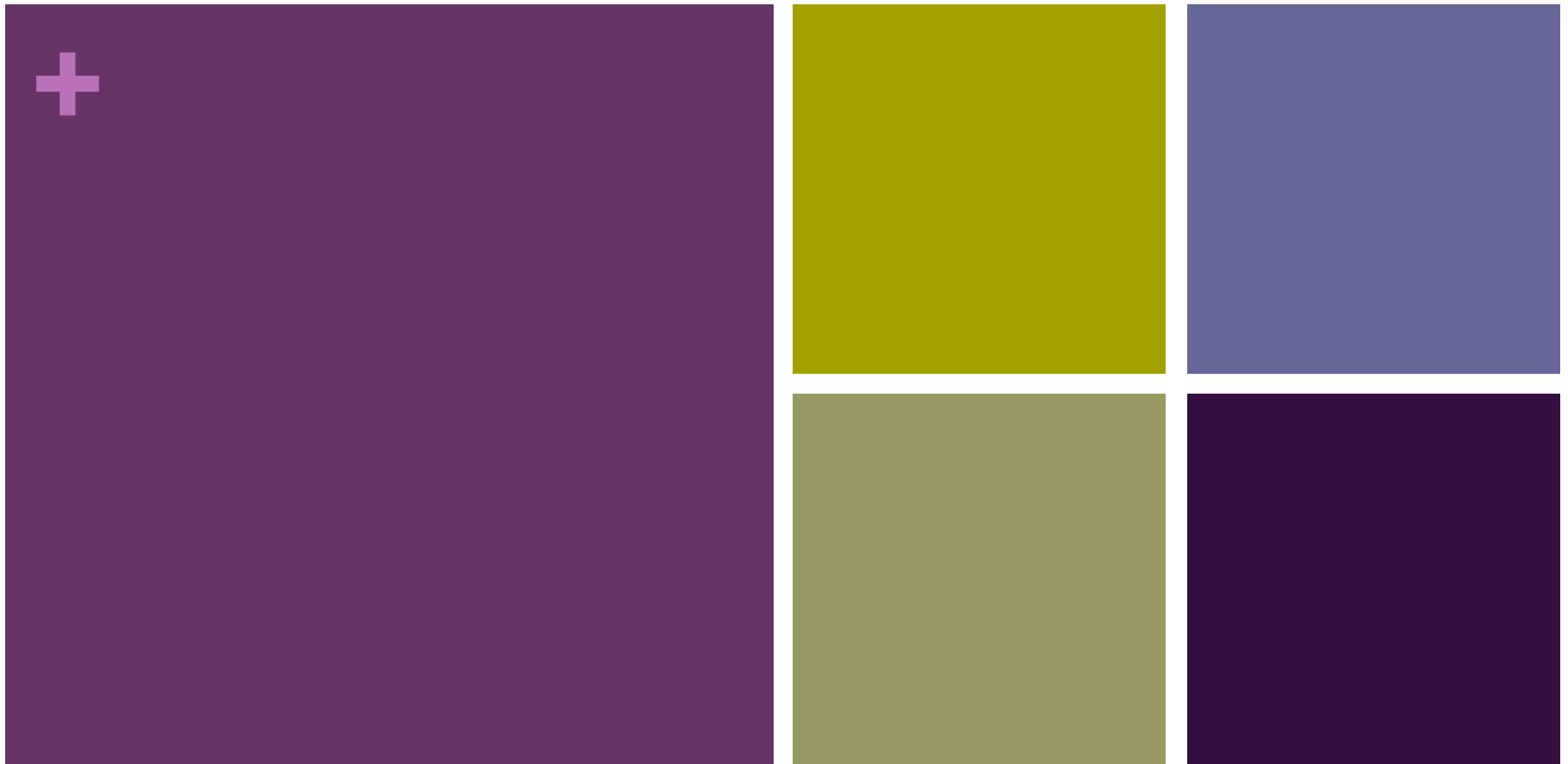
### **Next EHDI Advisory Committee Meetings**

January 6, 2011 – 9 to 12 Noon (ICN locations to be announced at later date)

April 7, 2011 – 10 to 3 p.m.

July 7, 2011 – 10 to 3 p.m.

October 6, 2011 – 10 to 3 p.m.

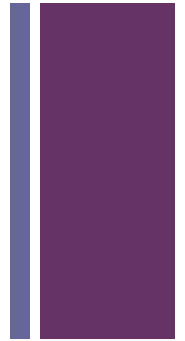


**EHDI Data:  
Children with Hearing Loss  
2007-2009**

Amanda Carr, MA  
October 7, 2010



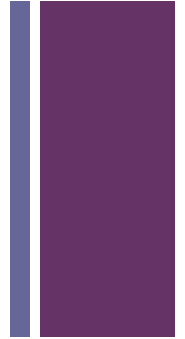
# Children born in 2007



- Children with permanent hearing loss: 53
  - 12 unilateral
  - 41 bilateral
- Type of hearing loss
  - 47 SNHL
  - 3 Conductive
  - 3 Mixed
  - 1 Auditory Neuropathy



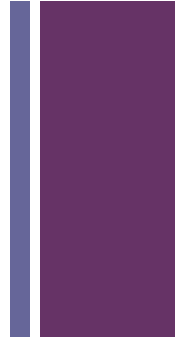
# Children born in 2007



- Average age of identification: 10.3 months
  - Standard deviation: 11
  - Range: 0-36 months
  - N=52
- Average age of early intervention referral: 13 months
  - Standard deviation: 13
  - Range: 1-36 months
  - N=12



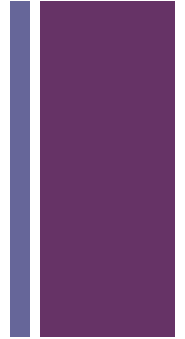
# Children born in 2007



- Average age of hearing aid fitting: 9.3 months
  - Standard deviation: 9.9
  - Range: 1-37 months
  - N=18



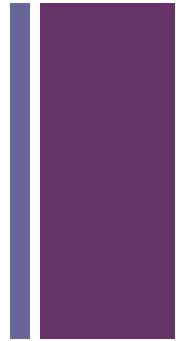
# Children born in 2007



- Reasons for late ID
  - Passed NBHS
  - Meningitis
  - Middle ear dysfunction
  - Scheduling issues
  - Non compliant parents
  - Other major health concerns
  - Passed other hearing screenings
  - Born out of the country
  - Chemotherapy



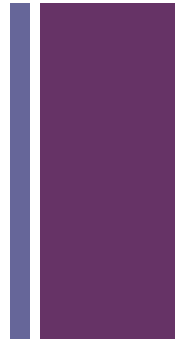
# Children born in 2008



- Children with permanent hearing loss: 67
  - 16 unilateral
  - 51 bilateral
- Type of hearing loss
  - 62 SNHL
  - 2 Conductive
  - 4 Mixed
  - 0 Auditory Neuropathy



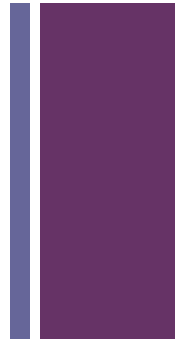
# Children born in 2008



- Average age of identification: 6.4 months
  - Standard deviation: 6
  - Range: 0-26 months
  - N=65
- Average age of early intervention referral: 2.4 months
  - Standard deviation: 2
  - Range: 0-10 months
  - N=32



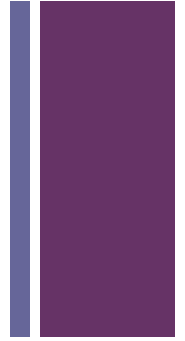
# Children born in 2008



- Average age of hearing aid fitting: 4.25 months
  - Standard deviation: 3.7
  - Range: 1-14 months
  - N=12



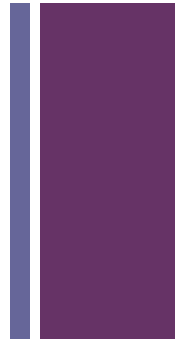
# Children born in 2008



- Reasons for late ID
  - Passed NBHS
  - Meningitis
  - Middle ear dysfunction
  - Scheduling issues
  - Non compliant parents
  - Other major health concerns
  - Passed other hearing screenings
  - Refusals



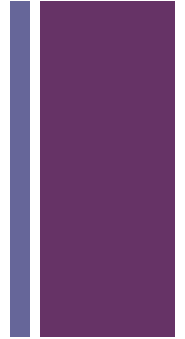
# Children born in 2009



- Children with permanent hearing loss: 56
  - 20 unilateral
  - 36 bilateral
- Type of hearing loss
  - 51 SNHL
  - 3 Conductive
  - 1 Mixed
  - 1 Auditory Neuropathy



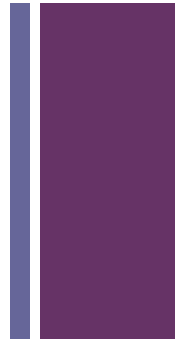
# Children born in 2009



- Average age of identification: 4.4 months
  - Standard deviation: 4.25
  - Range: 0-16 months
  - N=56
- Average age of early intervention referral: 5 months
  - Standard deviation: 5
  - Range: 0-18 months
  - N=28



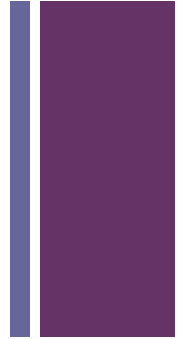
# Children born in 2009



- Average age of hearing aid fitting: 4.6 months
  - Standard deviation: 4.6
  - Range: 1-14 months
  - N=10



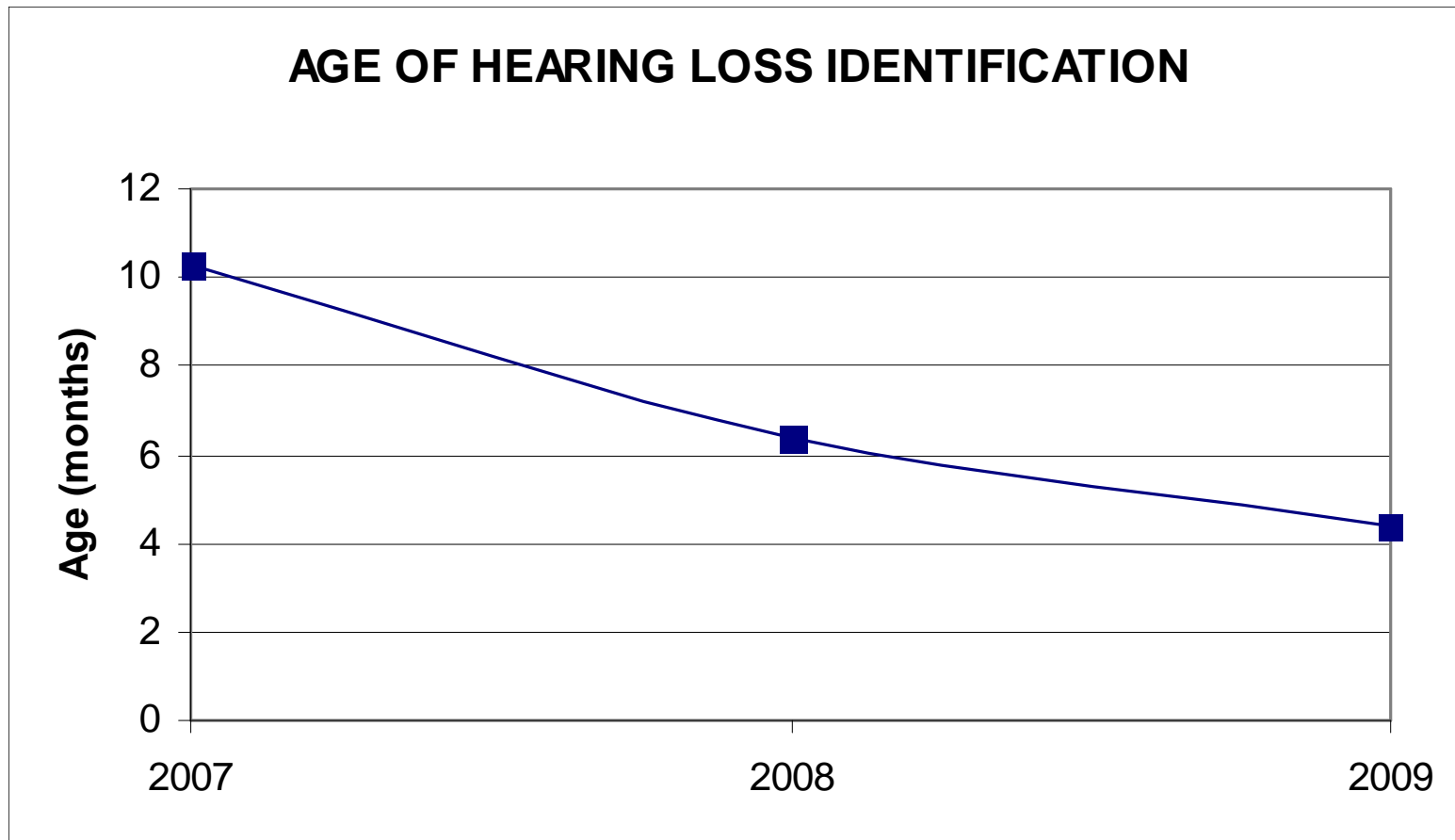
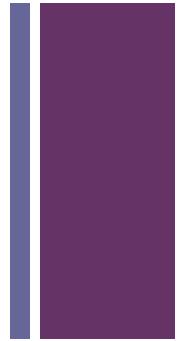
# Children born in 2009



- Reasons for late ID
  - Passed NBHS
  - Middle ear dysfunction
  - Passed other hearing screenings or evaluations
  - Incorrect dates in eSP?

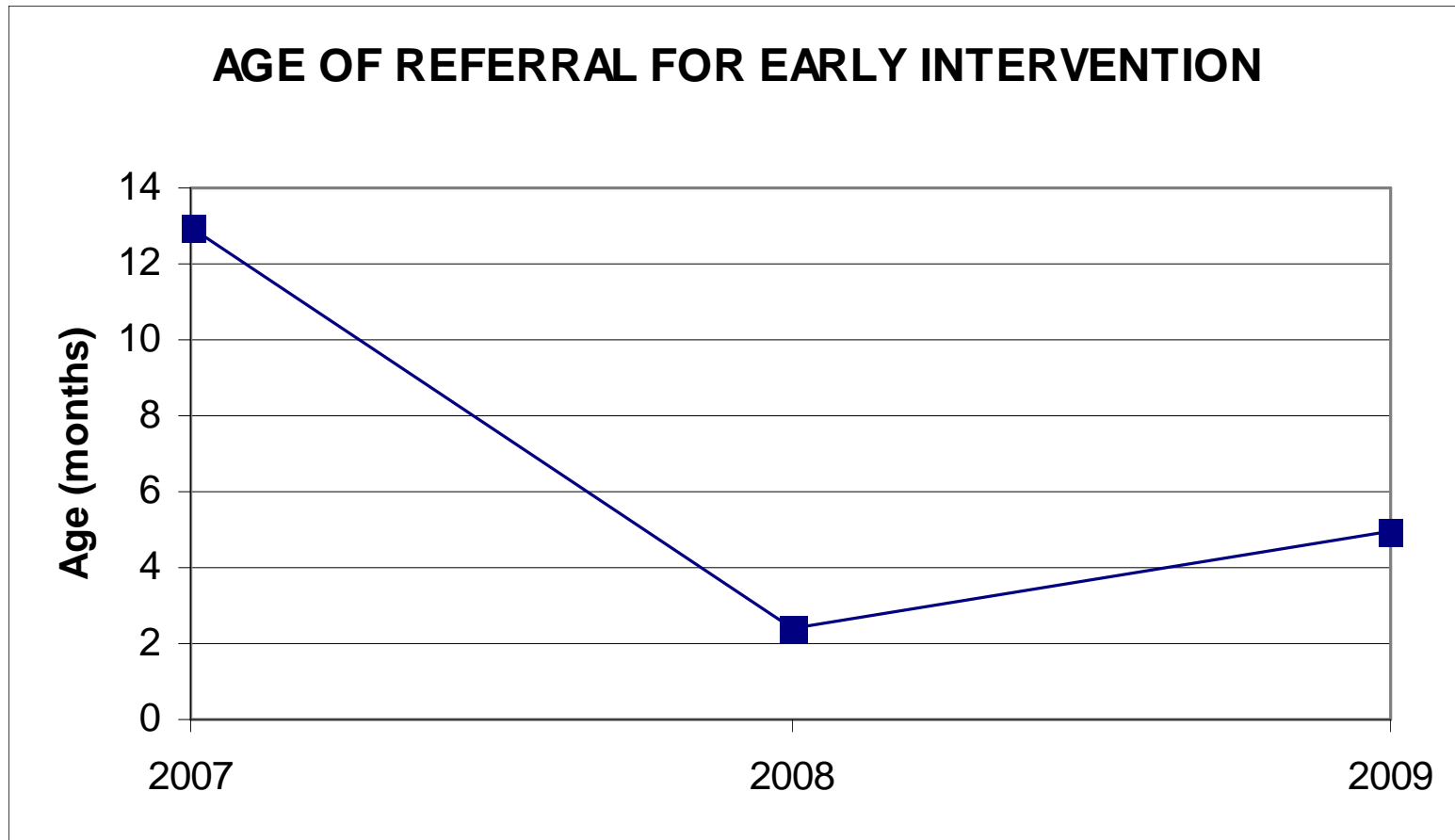
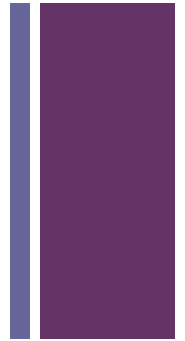


# Trends over time



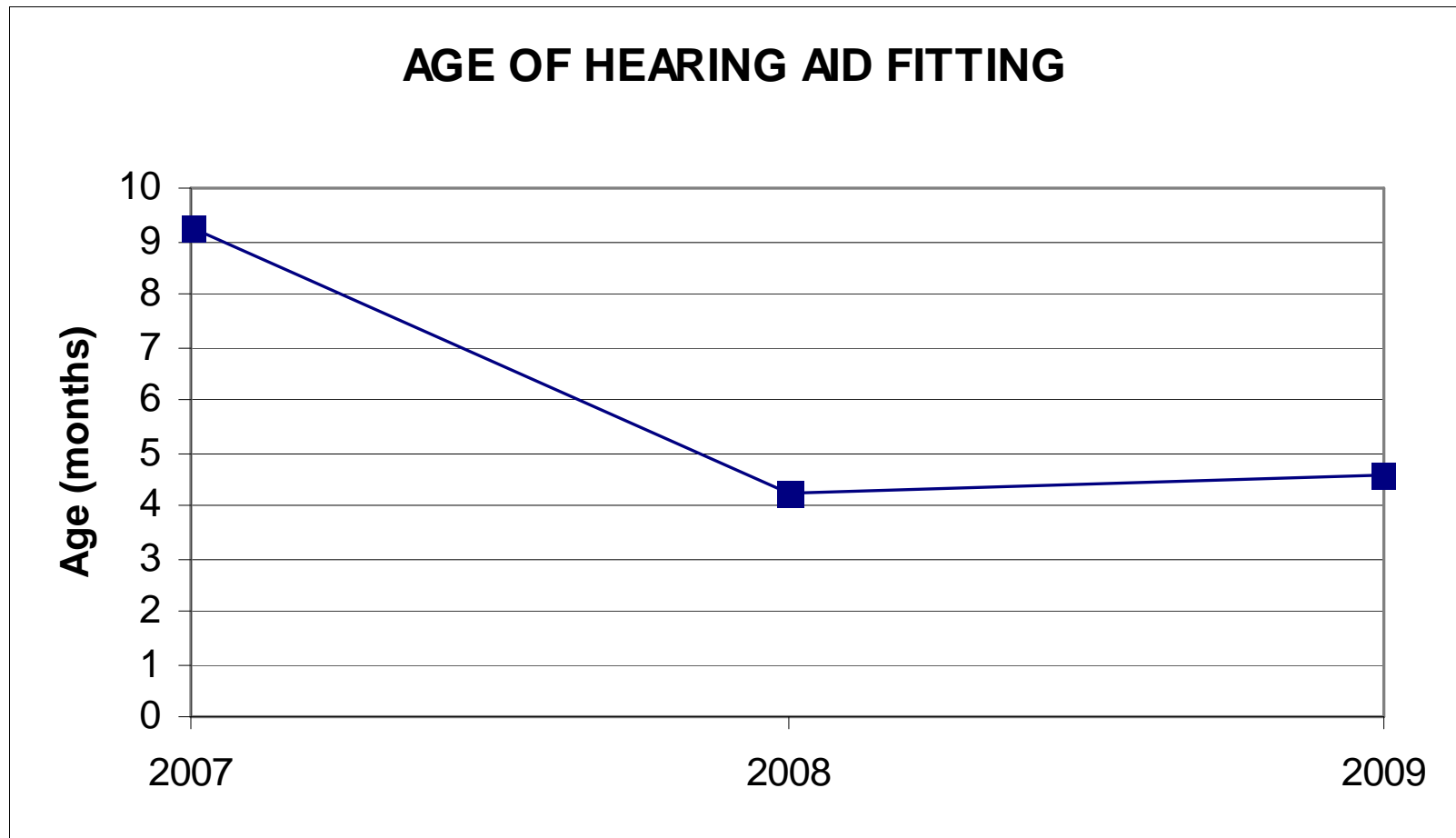
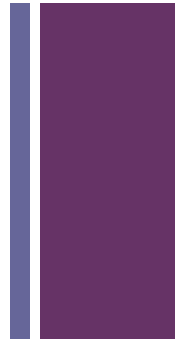


# Trends over time





# Trends over time



# EHDI Data Requests

EHDI Advisory Committee Meeting  
October 7, 2010



# Overview

- Newborn hearing screening and follow up goals
- Performance indicator target goals
- EHDI comparison across states
- OP hearing screen providers
- Demographics breakdown
- Metabolic and EHDI refusals comparison
- Impact of Amish outreach
- Hearing outcomes and refusals by risk factor status
- Hearing outcomes by nursery
- Improvements after hospital site visits

# Newborn Hearing Screening and Follow Up Goals

- CDC
  - Goal 1: All newborns will be screened for hearing loss before one month of age, preferably before hospital discharge.
  - Goal 2: All infants who screen positive will have a diagnostic evaluation before 3 months of age.
  - Goal 3: All infants identified with a hearing loss will receive appropriate early intervention services before 6 months of age.

# Newborn Hearing Screening and Follow Up Goals

- CDC

- Goal 4: All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.
- Goal 5: All infants with hearing loss will have a medical home.
- Goal 6: Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow up.
- Goal 7: Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives.

# Newborn Hearing Screening and Follow Up Goals

- HRSA
  - MCHB Discretionary Grant Performance Measures
    - PM #3: The percent of completed MCHB projects publishing findings in peer-reviewed journals.
    - PM#7: The degree to which MCHB supported programs ensure family participation in program and policy activities
    - PM# 10: The degree to which MCHB supported programs have incorporated cultural competence elements into their policies, guidelines, contracts and training.

# Newborn Hearing Screening and Follow Up Goals

- HRSA
  - MCHB Discretionary Grant Performance Measures
    - PM# 23: The degree to which grantees have assisted States in increasing the percentage of children who are screened early and continuously for special health care needs and linked to medical homes, appropriate follow-up and early intervention.
    - PM#31: The degree to which grantees have assisted States in organizing community-based service systems so that families of children with special health care needs can use them easily.

# Newborn Hearing Screening and Follow Up Goals

- Healthy People 2020
  - Objectives Retained But Modified From Healthy People 2010
    - ENT-VSL HP2020-8: Increase the proportion of newborns who are screened for hearing loss by no later than age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months.

# Performance indicators target goals

- CDC/DSHPSHWA Annual Report
  - Target goals developed at 2010 National EHDI Conference
  - Reports are being created as a tool for states to use in comparison with other states
  - Reports not meant to be published
  - The purpose of these reports is still being discussed

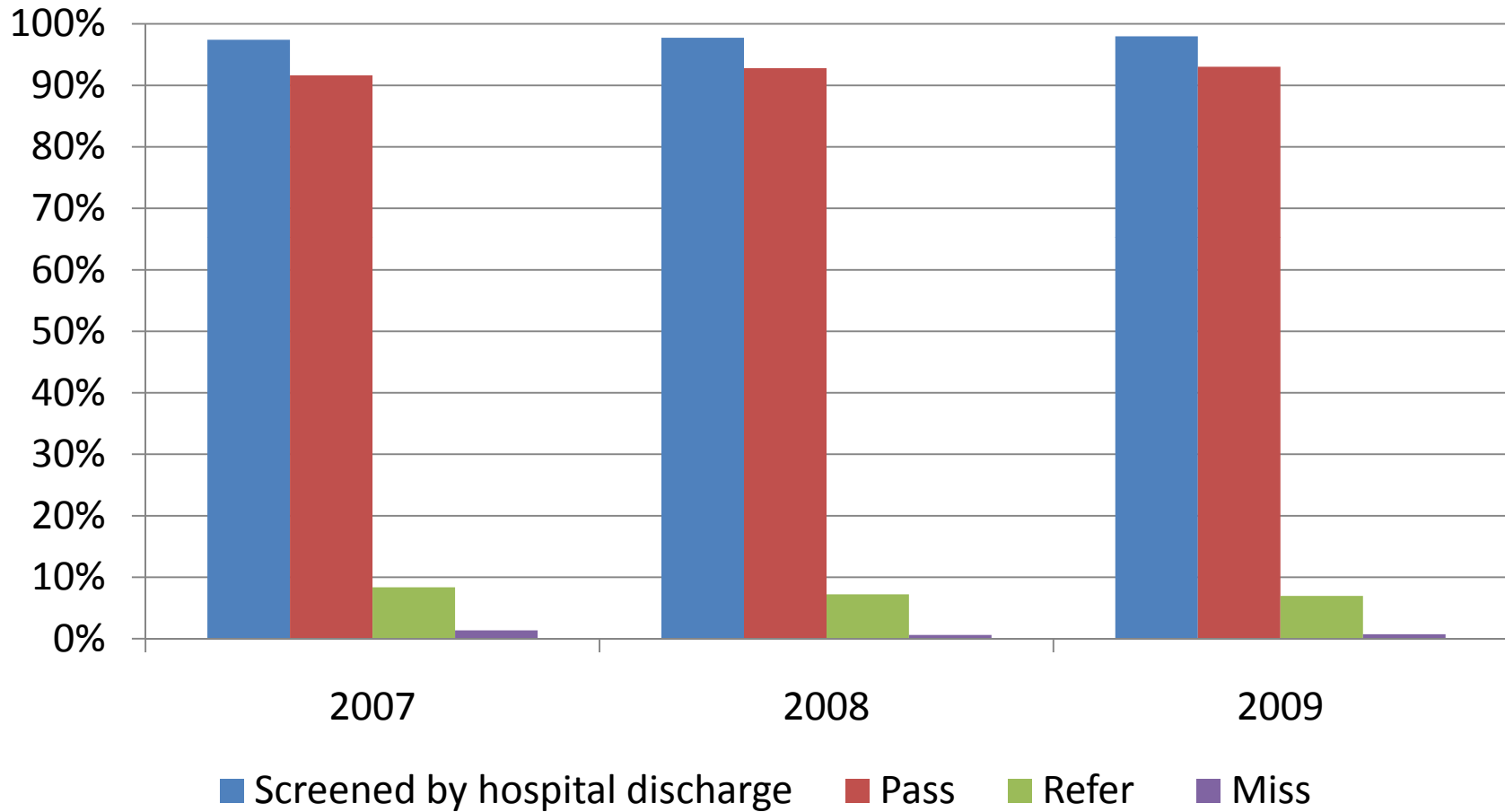
# EHDI comparison across states

- Brief overview of CDC report comparing state results
  - Future activity
    - Currently, there is no way to compare outcomes across states
    - CDC iEHDI project data might help move this forward

# Outpatient screening providers

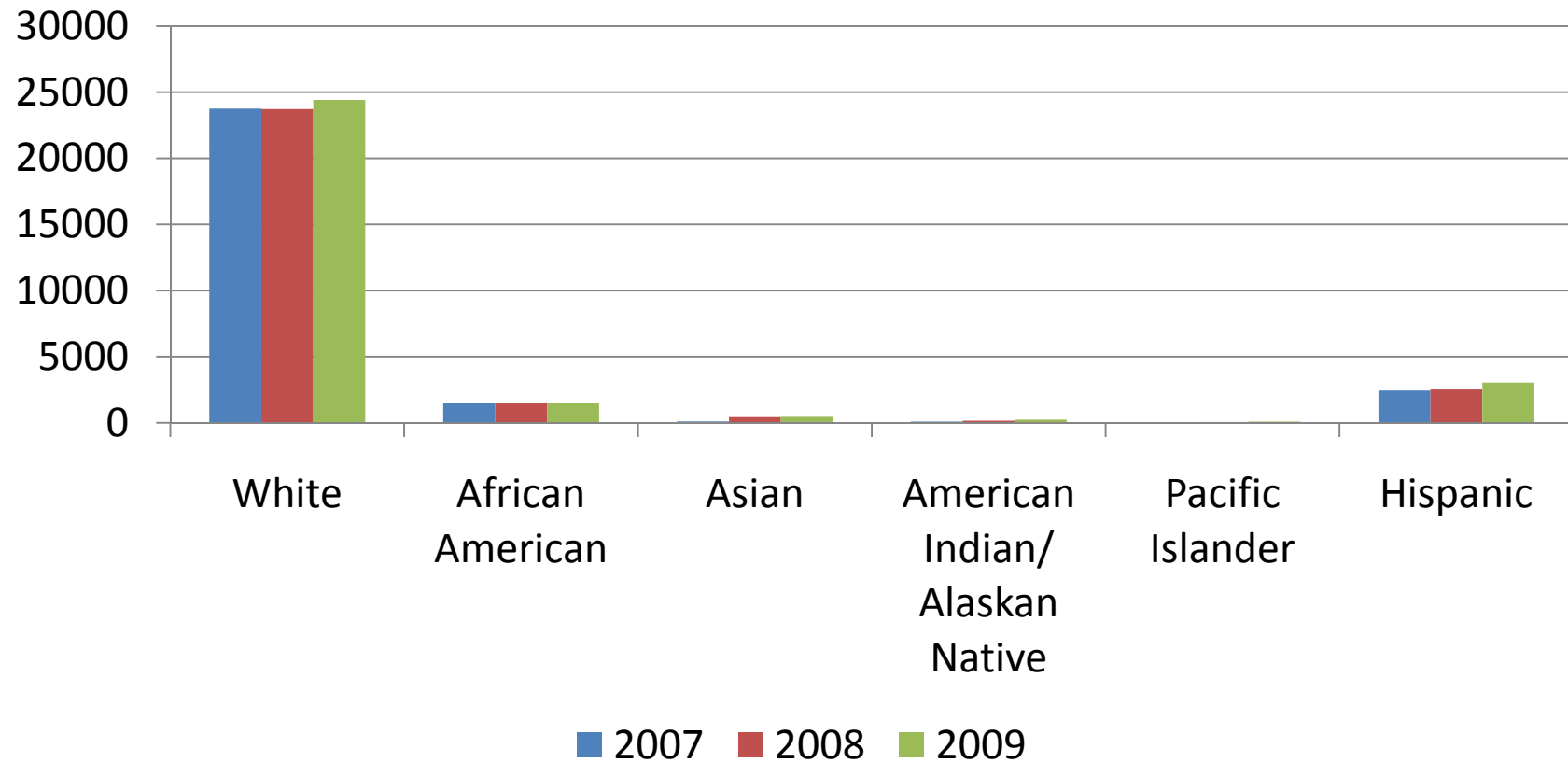
- How many providers are now providing outpatient hearing screens that weren't previously?
  - Future activity
    - Birthing Hospital Survey sent out in 2009 regarding contact(s), screening results and follow-up practices
    - Another survey will be sent out in 2010/2011

# Overall screening rates



# EHDI Demographics

Race/Ethnicity



# 2009 Race/ethnicity comparison

## **EHDI numbers**

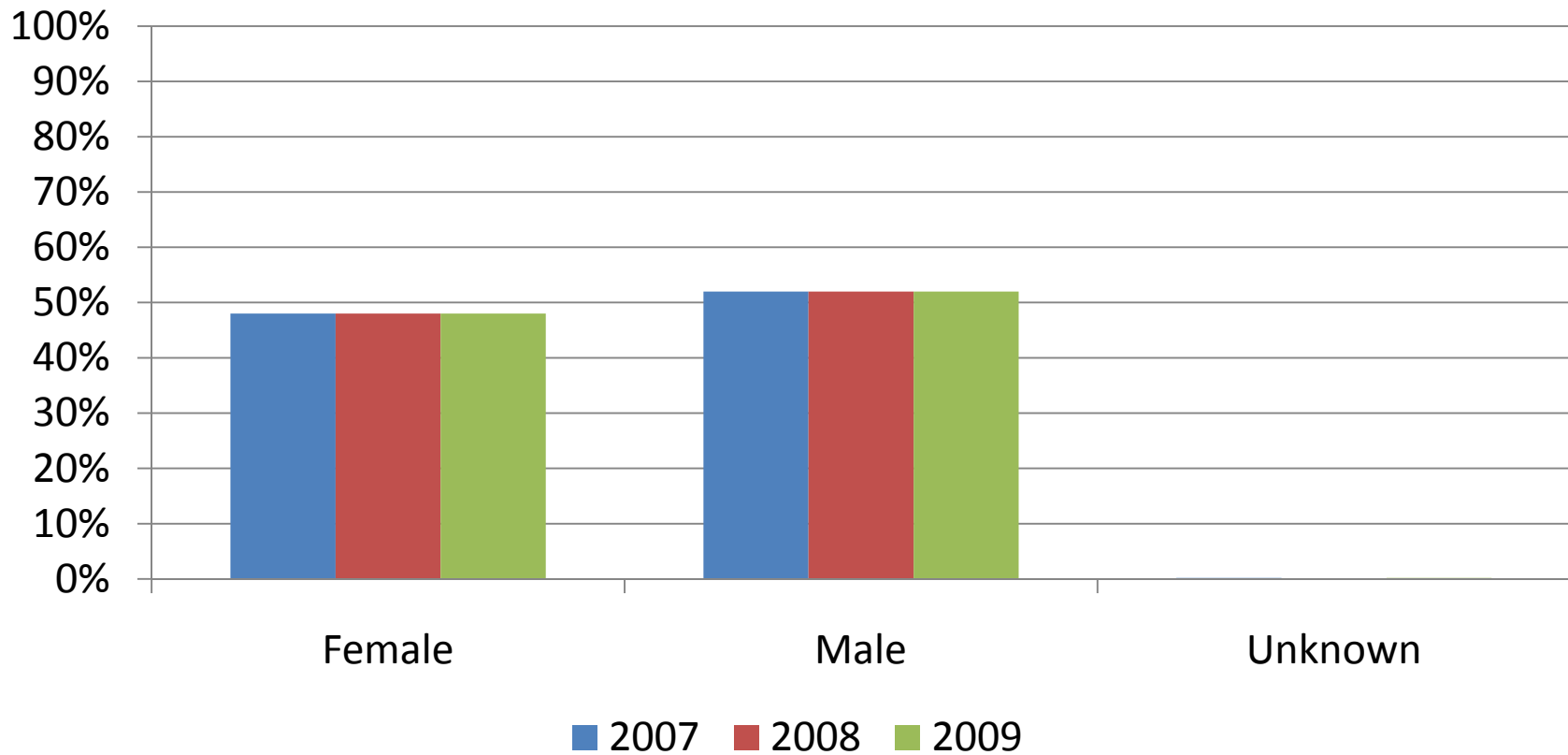
- 39753 births
  - African American- 1534
  - American Indian/Alaskan Native- 239
  - Asian- 518
  - Pacific island- 88
  - White- 24415
  - Hispanic- 3039

## **VR numbers**

- 39640 occurrent births
  - African American- 5% (1988)
  - American Indian/Alaskan Native- 1% (361)
  - Asian/Pacific Islander- 3% (1022)
  - White- 86% (34035)
  - Other- 6% (2234)
  - Hispanic- 9% (3464)

# EHDI Demographics

## Sex



# 2009 Sex demographics comparison

## **EHDI numbers**

- 39753 births
  - Female- 48% (19052)
  - Male- 52% (20604)
  - Not Known- 0.2% (96)

## **VR numbers**

- 39640 occurrent births
  - Female- 49% (19341)
  - Male- 51% (20298)
  - No Response- 0.003% (1)

# How do we compare with the Metabolic Screening Program?

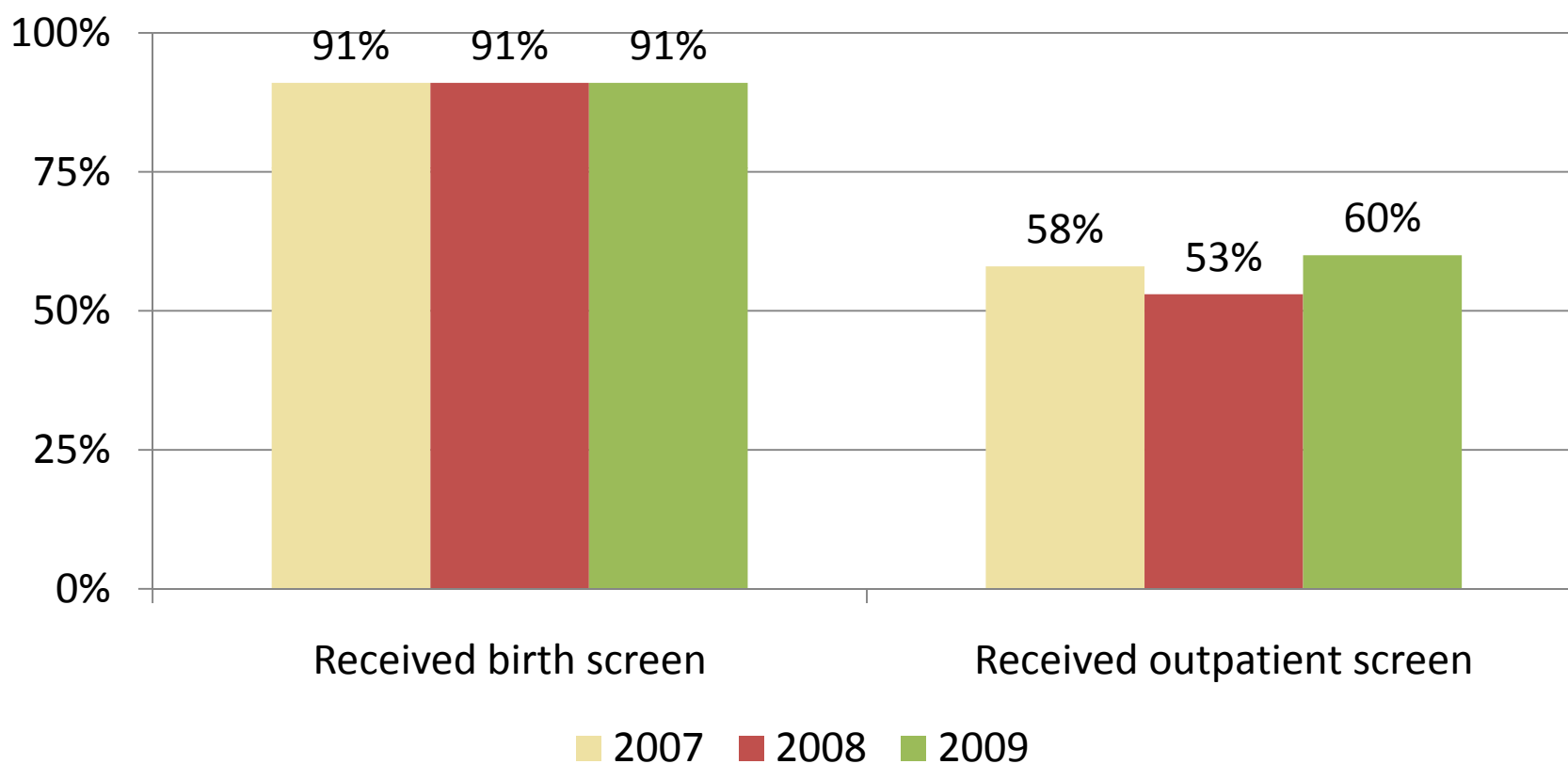
- Of the 54 refusals in the metabolic database in 2009
  - 38 (70%) were marked as refused in eSP
  - 6 (11%) were “lost contact”
  - 10 (19%) were screened and have normal hearing
  
  - 29 (54%) were home births
- Metabolic refusals
  - received by mailed waivers or a phone call from the physician
- EHDI refusals
  - Received by mailed waivers and if refusal indicated on birth certificate

# Amish families

- Grantwood AEA outreach
  - Since April 2009
    - 6 visits
    - 32 families
    - 51 children
- Great Prairie AEA outreach
  - Around 40 families

# Screening rates for children with risk factors

Percent of infants screened by **1 month** of age



# Screening rates by risk factor status

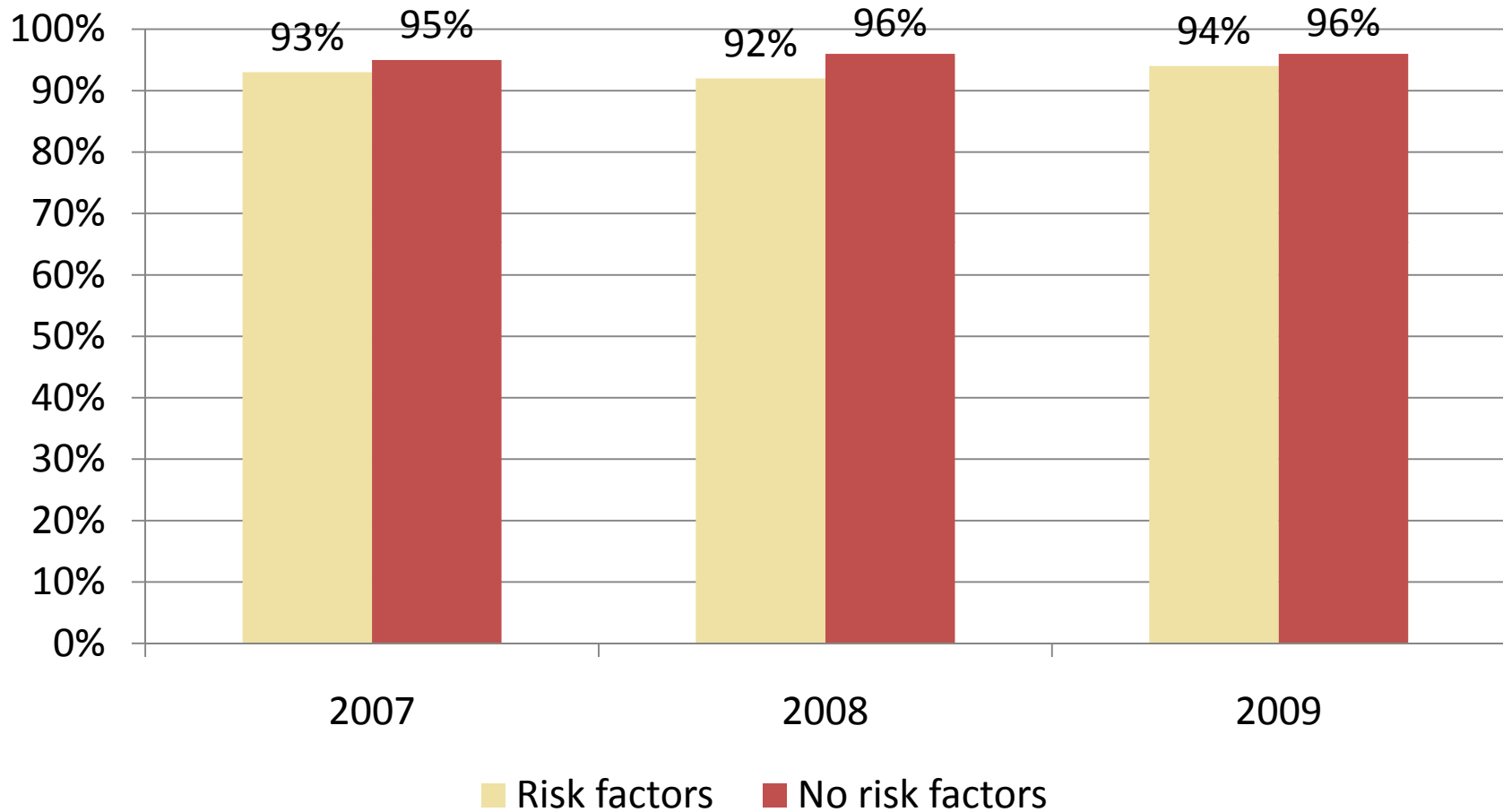
## 2009 with risk factors

- 3869 kiddos
  - 91% (3517) passed their birth screen
  - 8% (320) missed or referred their birth screen
    - 81% (259) received outpatient screen/assessment
      - 73% (188) passed
  - 0.1% (2) refused

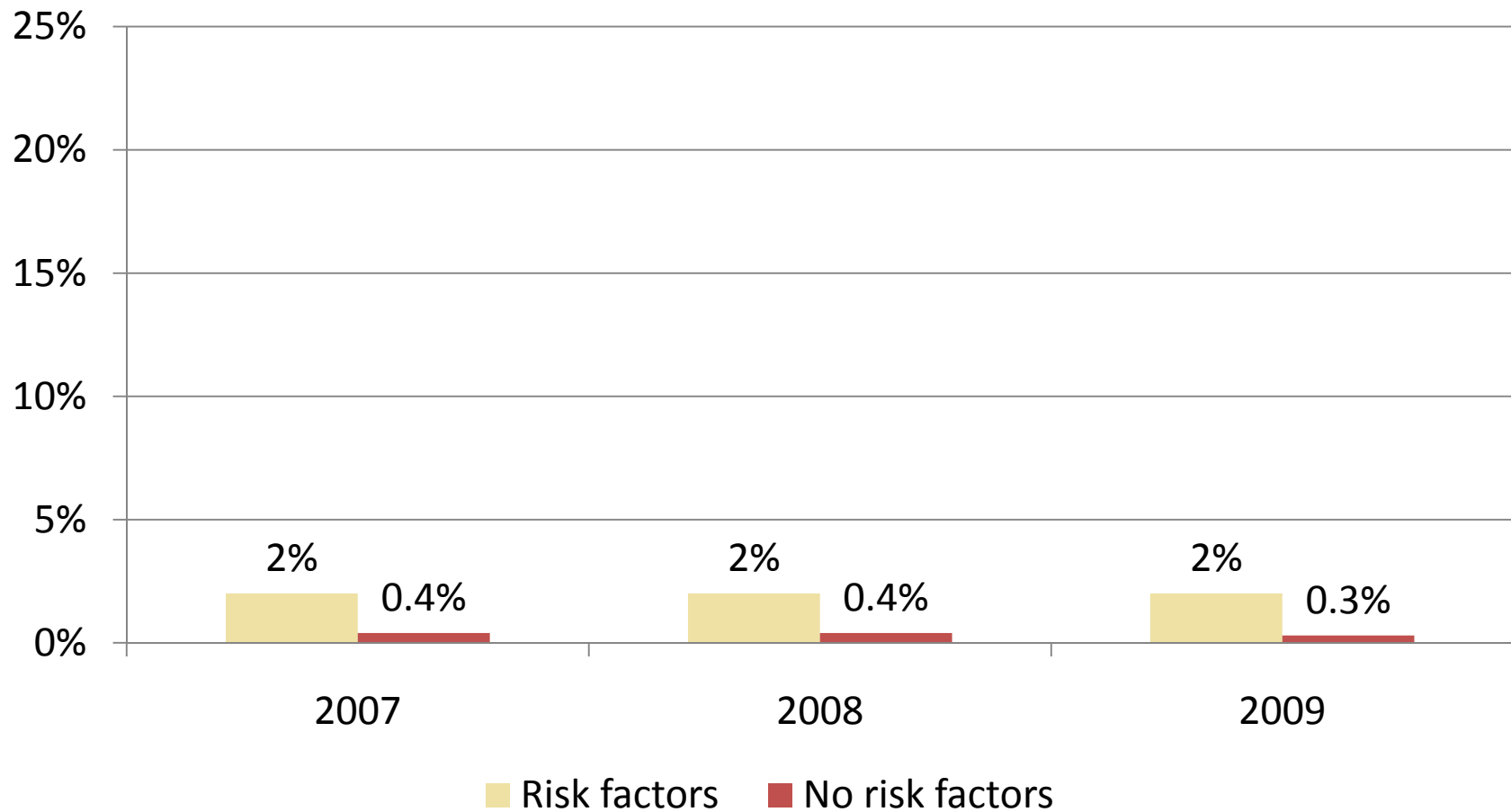
## 2009 without risk factors

- 35882 kiddos
  - 91% (32723) passed their birth screen
  - 8% (2677) missed or referred their birth screen
    - 80% (2140) received outpatient screen/assessment
      - 89% (1907) passed
  - 0.7% (266) refused

# Normal hearing outcome by risk factor status

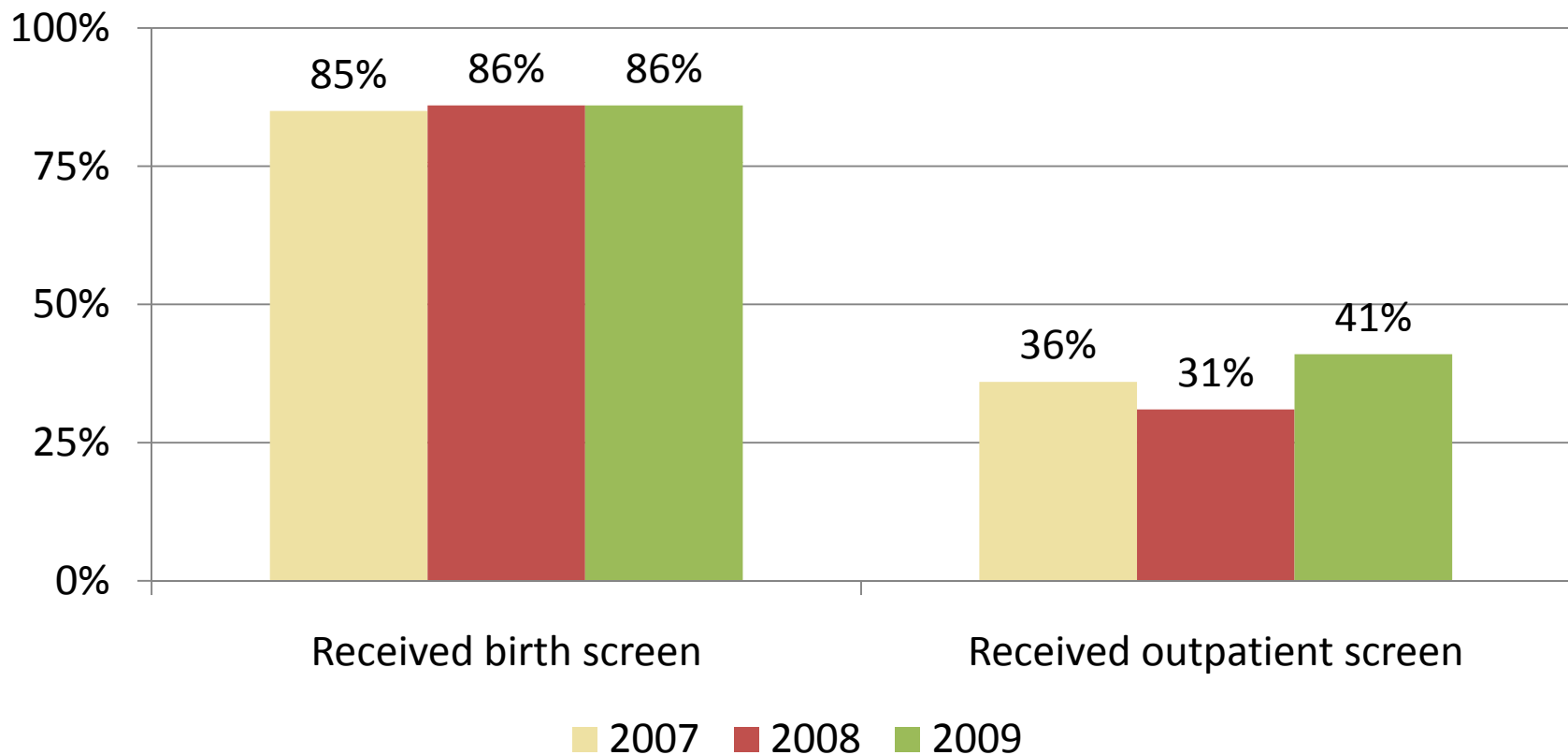


# Hearing loss outcome by risk factor status



# Screening rates for children in the NICU

Percent of infants screened by **1 month** of age



# Screening rates by nursery

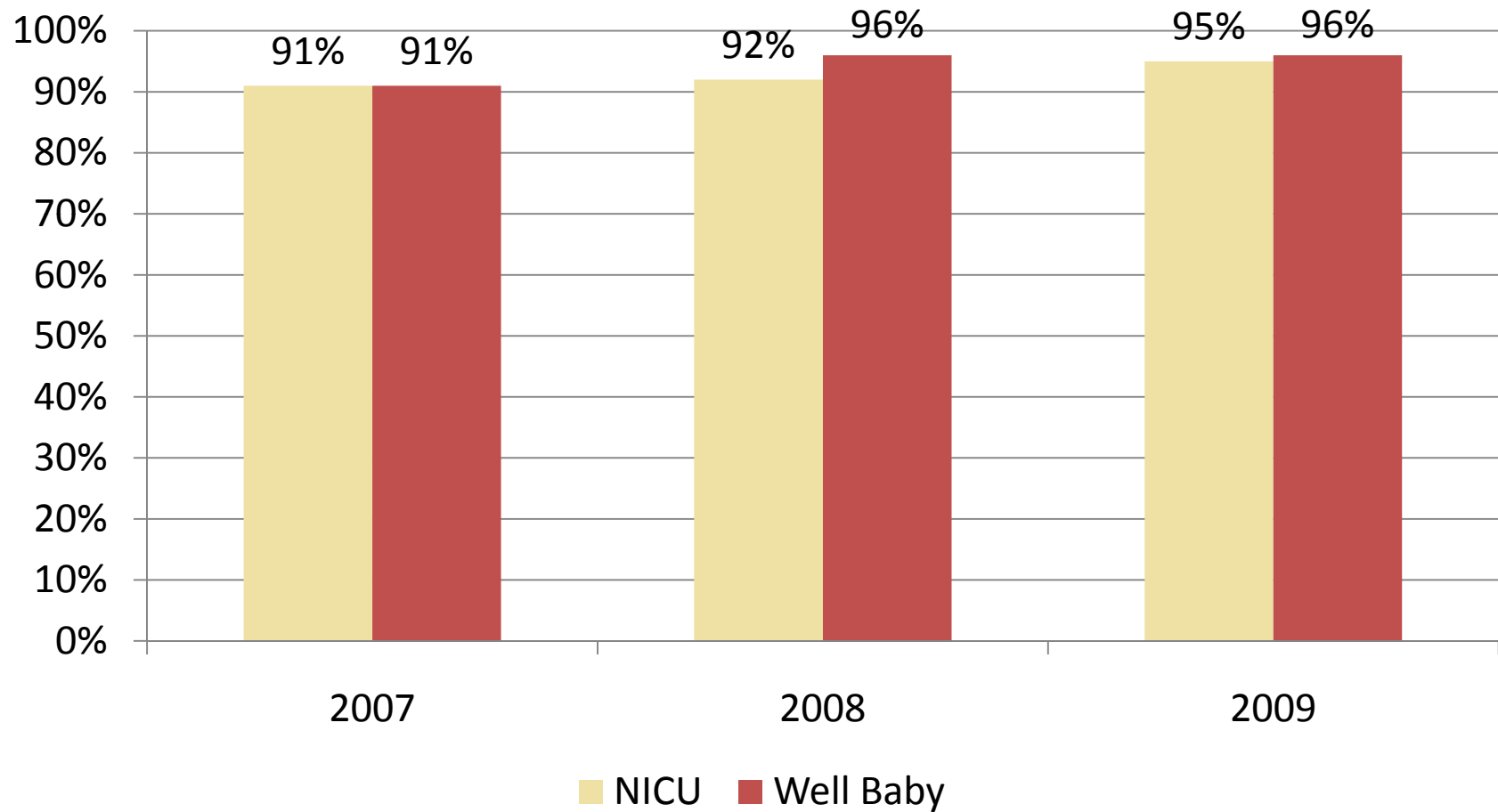
## 2009 NICU

- 93% (2652) passed their birth screen
- 6% (166) missed or referred their birth screen
  - 69% (114) received an outpatient screen/assessment
    - 77% (88) passed

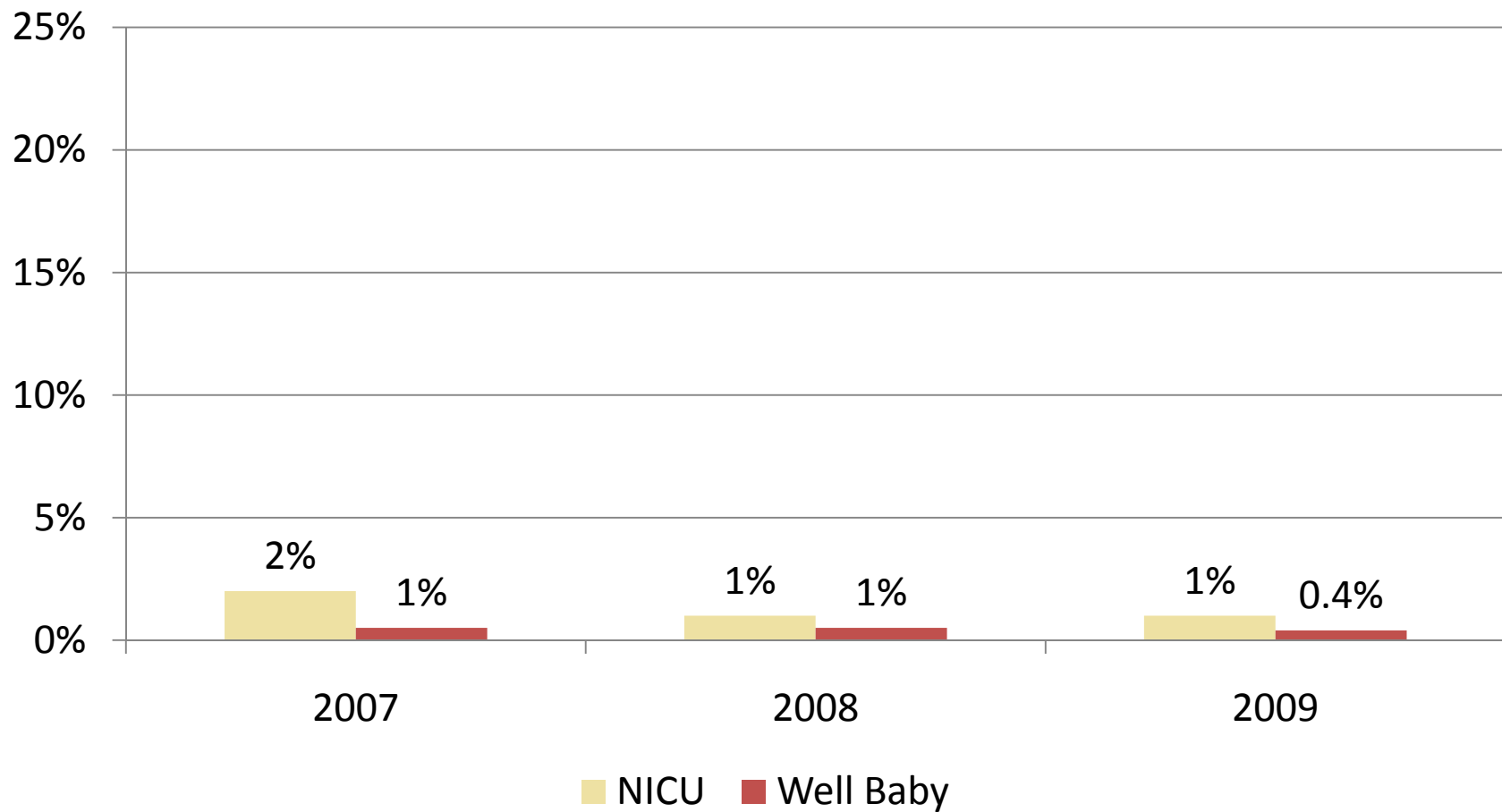
## 2009 Well Baby

- 91% (33364) passed their birth screen
- 8% (2801) missed or referred their birth screen
  - 81% (2263) received an outpatient screen/assessment
    - 88% (1987) passed

# Normal hearing outcome by nursery



# Hearing loss outcome by nursery



# Improvements after site visits

<b>Improvements in refer and miss rates after hospital site visits</b>		
	<b>Refer Rates</b>	<b>Miss Rates</b>
Number improved (decrease in rate)	18 (55%)	7 (21%)
Number stayed the same	5 (15%)	19 (58%)
Number declined (increase in rate)	10 (30%)	7 (21%)
Total number of site visits	33	

# Improvements after site visits

<b>Improvements in refer and miss rates after hospital site visits based on State Refer and Miss Rate Goals</b>		
	Refer Rates	Miss Rates
Number Met State Goal ( $\leq 6\%$ ) in 2009	14 (42%)	27 (82%)
Number Met State Goal ( $\leq 1\%$ ) in 2010	17 (52%)	26 (79%)
Total number of site visits	33	