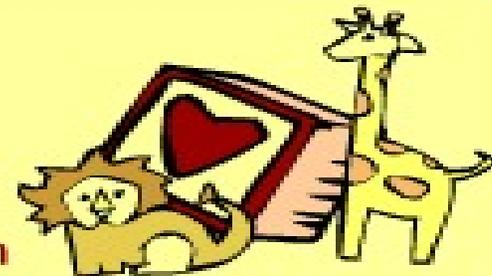


# Iowa EHDI – A Work in Progress

**Coordinating Council for Hearing Services  
November 24, 2008**

***EHDI***

Iowa's Early Hearing  
Detection & Intervention System



# Presenter

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# Background

Prior to legislative mandate January 1, 2004:

- Newborn hearing screening was voluntary
- Inconsistent reporting
- No comprehensive surveillance system
- No way to track individual kids in a central location to ensure follow up

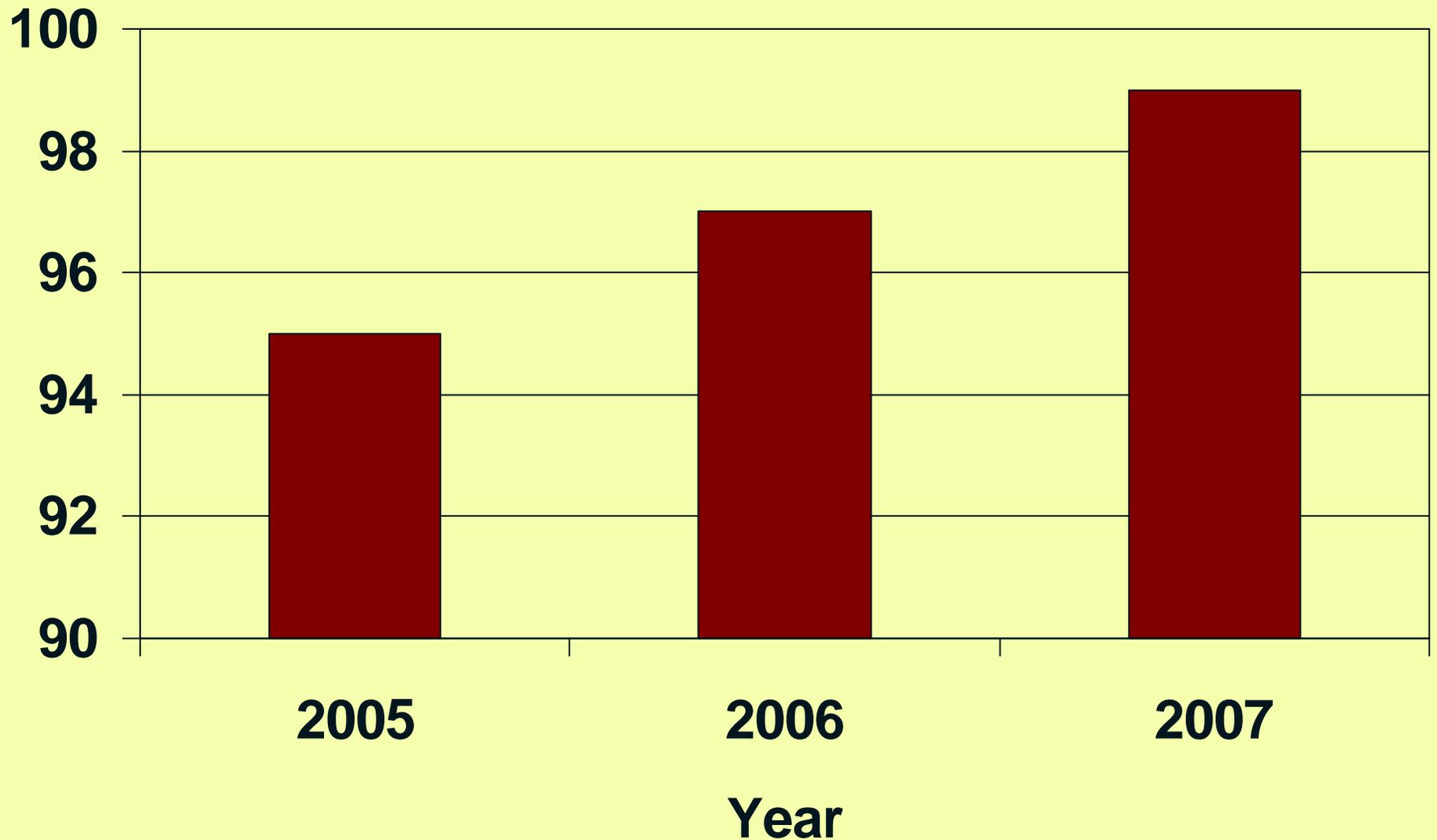
# Screening and Reporting Progress

- Legislative mandate – universal newborn hearing screening & reporting
- Birthing hospitals trained to report hearing screens via eSP
- Area Education Agencies & private audiologists trained to report hearing screens & diagnostic assessments via eSP
- Backlog of hearing screens and diagnostic assessments entered into eSP
- Audiology technical assistance and loaner screening equipment available to decrease refer & miss rates

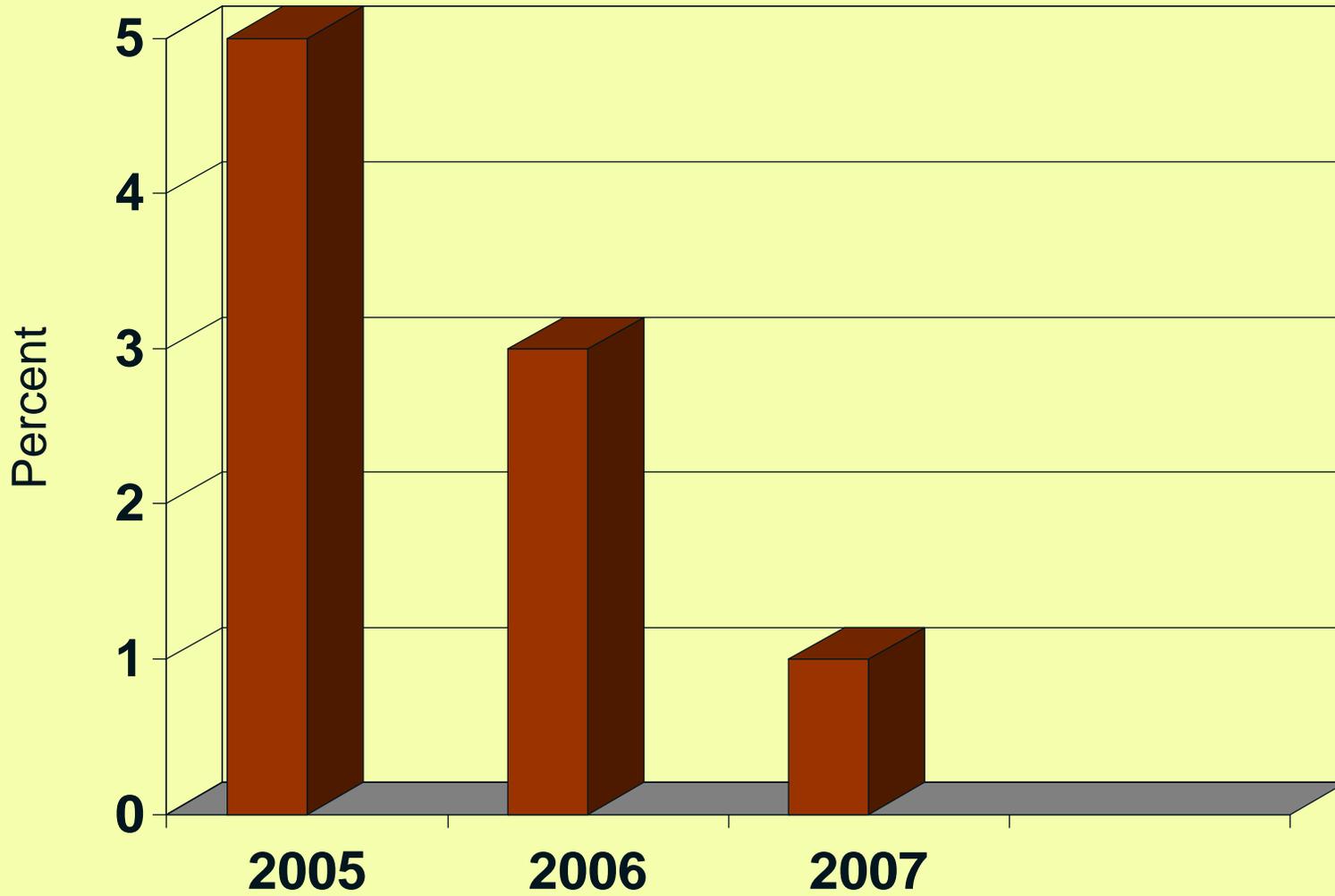
# Referrals

- Where do potential referrals come from?
  - Hospitals
  - Parent
  - PCP/Medical Home
  - EHDI program
  - Provider
- What are the referrals for:
  - Re screens
  - Initial screening, if missed at hospital
  - Risk Factors

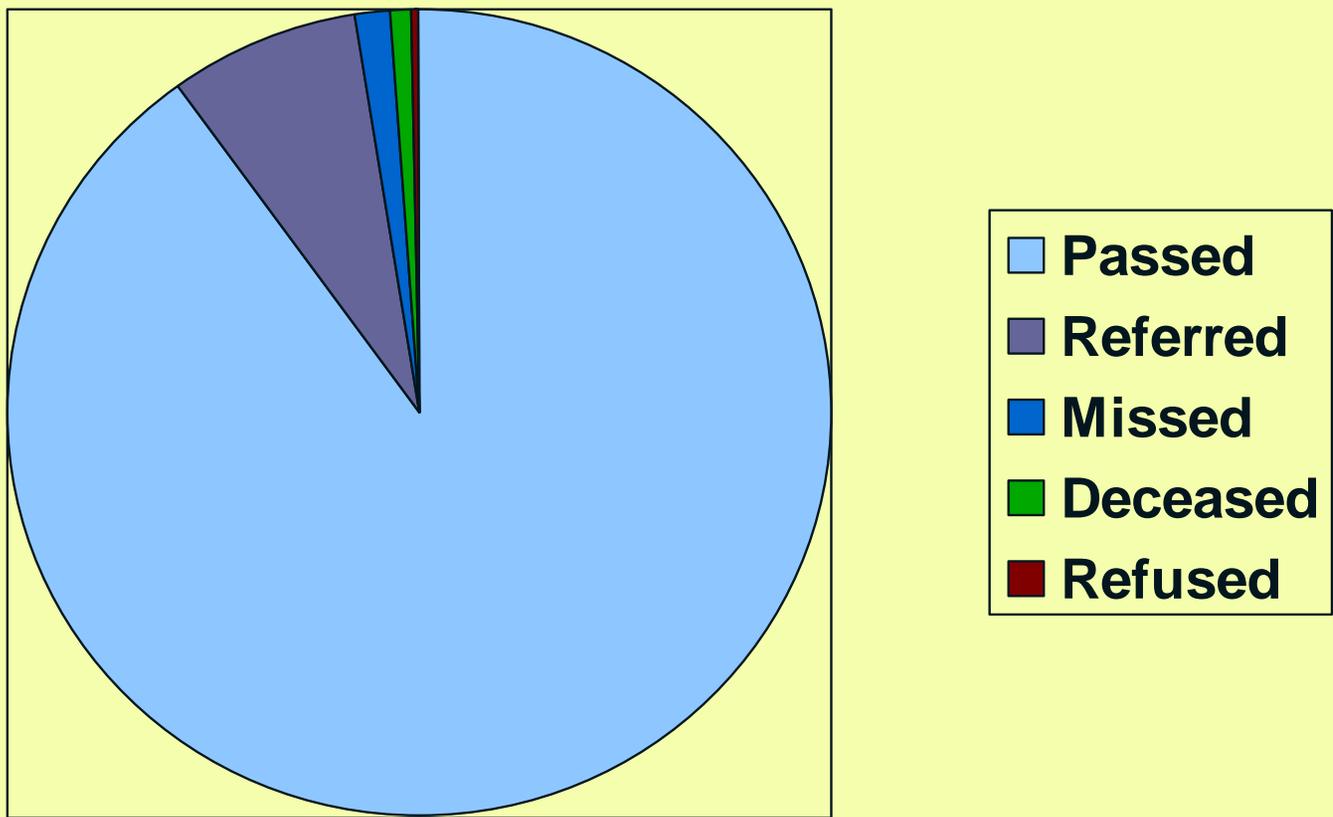
## Percent of Iowa Children Receiving a Newborn Hearing Screen Prior to Discharge



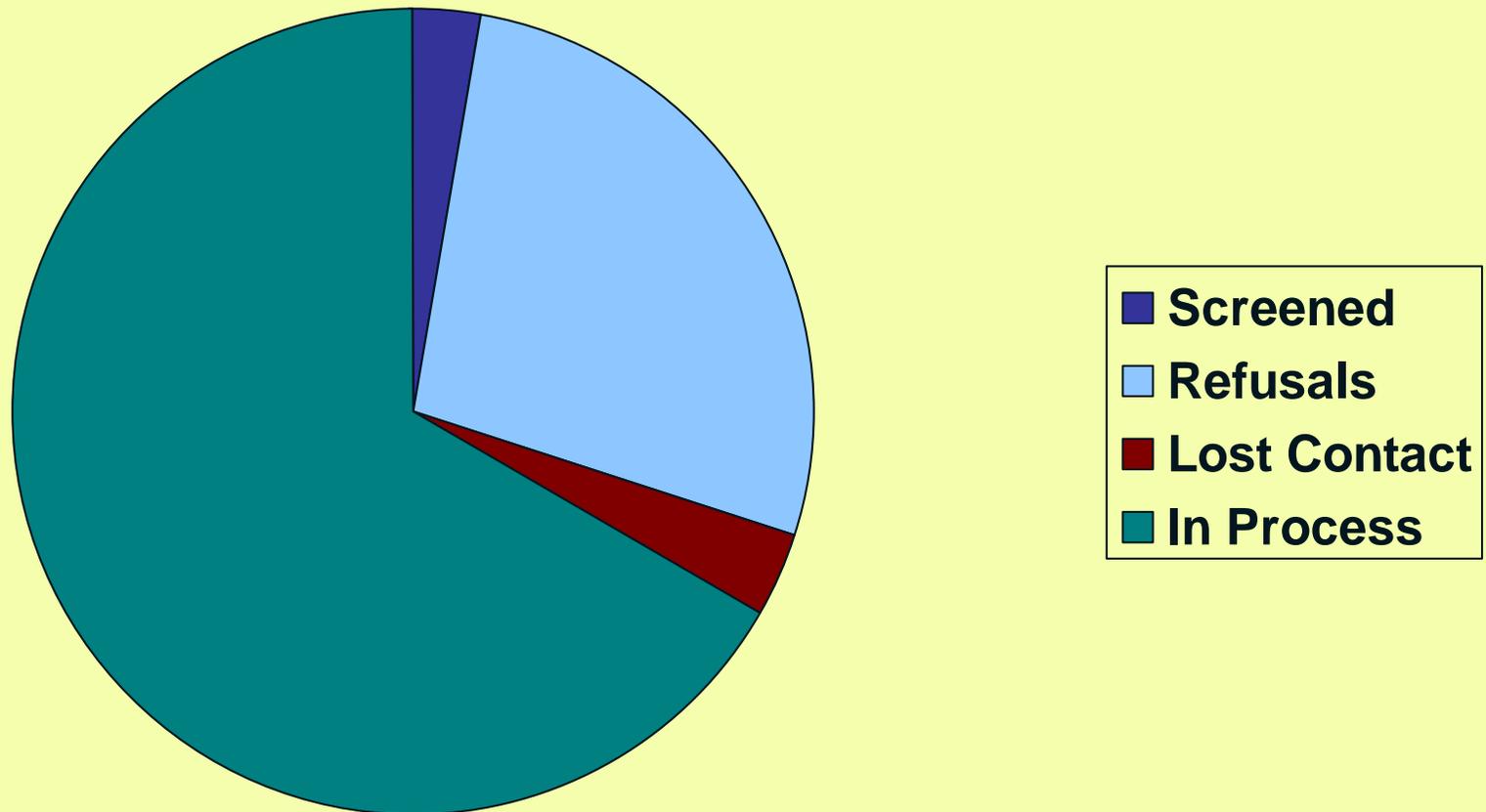
# Children who Missed a Hearing Screen at Birth



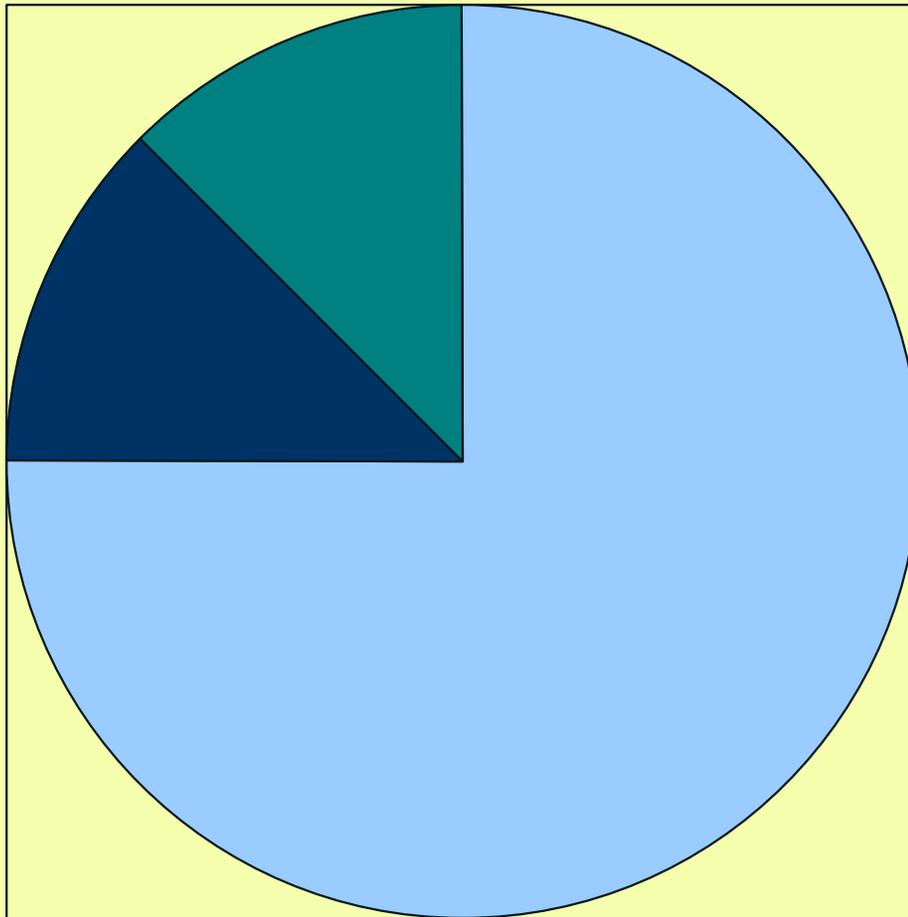
# Initial Newborn Hearing Screening Outcomes ~ 2007



# Iowa Home Births



# Outpatient Screening Outcomes



# Challenge – Children Lost to Follow Up

**3669** Children who **need follow up** following newborn hearing screen (children that have referred, unilaterally or bilaterally on the newborn hearing screen or were missed on the newborn screen).

**2889** Children **available for follow-up**. (excludes patients that have moved out of state, refused any further follow-up, have died, or that have been marked as lost contact)

**2499** Children who **returned for follow up** hearing screen.

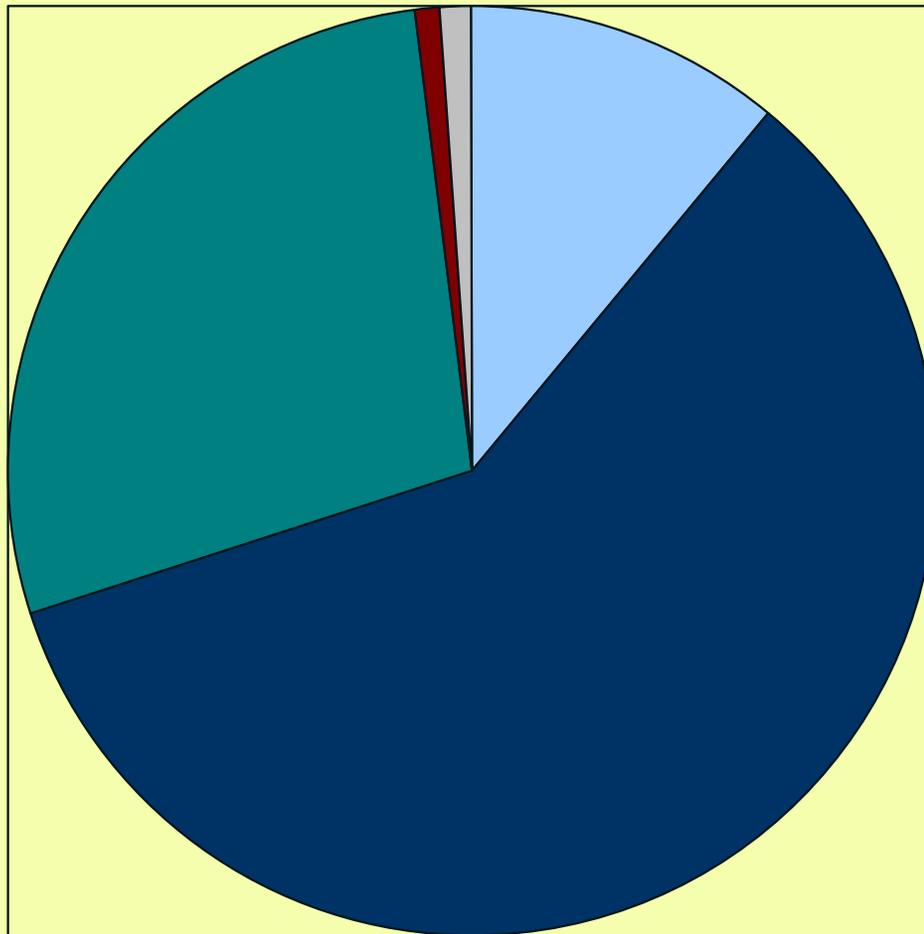
**2275** Children who **passed their follow up** hearing screen in both ears (91%)

**825** Total number of kids **in process or lost contact** (28%).

**430** Children **lost to follow up** (efforts made to reach them individually or through Medical Home to get them back in, but unsuccessful).

**395** **In Process** (follow-up is not yet complete, in need of an appt., kids who were transferred and we are waiting on results from another state, or home births).

# Audiological Assessment Outcomes



■ **Sensorineural**

■ **Not Yet  
Determined**

■ **Conductive**

■ **Auditory  
Neuropathy**

■ **Mixed**

**Celebrate Iowa Success**

# Screening and Reporting

- Birthing hospitals trained to report hearing screens via eSP
- Area Education Agencies & private audiologists trained to report hearing screens & diagnostic assessments via eSP
- Backlog of hearing screens and diagnostic assessments entered into eSP
- Audiology technical assistance and loaner screening equipment

# Referral/Follow-up

- Administrative Rule Change – Border baby
- Began referral/follow up – babies missed or who referred
- Family support program developed (GBYS)
- Border baby referrals – exchange of information
- Dissemination of high risk factor letters

# Quality Assurance

- Surveyed families regarding their knowledge of newborn hearing screening before, during their stay, assistance with follow up
- Quality assurance measures put into place (i.e. data entry, merging duplicates, searching for deceased babies to avoid dup, accounting for all births)
- QA subcommittee formed (Best Practices Manual)
- Protocols revisited, updated, new ones written

# Education

- Development of quarterly newsletter (Iowa *EHDI News*)
- Letter mailed to licensed audiologists reminding them of reporting requirement
- EHDI display created
- Development of new hearing screening brochure (English and Spanish) and communication guide for hospital personnel
- Web site overhaul

# Funding

- Draft sustainability plan
- Developed funding program for children in need of hearing aids & audiological services
- Successful applicants for CDC and HRSA funding ~ 2008-2011

**Where does EHDl go from here?**

# Screening and Reporting

# Changing Law and Rules

- Bring Iowa rules into line with JCIH 2007 recommendations
- Improve our ability to do follow-up
- Standardize practices across state

# Data System

- Improved audiology assessment section is being programmed now
- More systemic data system – better for tracking and follow-up past initial screening into early intervention

# Data Integration

- Will happen over the long term
- We have a commitment from Information Management to look at integration that will avoid duplicate entry into multiple data bases with vital records being a main feed.

# Referral and Follow-up

# Reducing Loss to Follow-up Rate

- EHDI working with other providers to decrease number of kids lost before getting all the services they need
  - Early ACCESS
  - AEAs
  - Private practice providers
  - Hospital screening programs
- Working with other IDPH programs to find families

# More AABR screening

- Joint Committee on Infant Hearing recommends AABR screening only for NICU babies
- Any baby who fails an AABR should be rescreened with AABR
- Identifies auditory neuropathy/dyssynchrony

# Referrals for diagnosis and intervention

- Follow kids through diagnosis, early intervention and family support
  - Working on rescreens and risk factors now
  - New assessment section in eSP should help
  - Will require working closely with audiologists

# Expanding Family Support

- Increase usage of Guide By Your Side
  - What can we do to make it more appealing to families and professionals?
  - Collecting data to support training
- Coordinate other family support groups

# Quality Assurance

# EHDI Best Practice Manual

- Based on JCIH 2007 Statement and Iowa EHDI protocols
- Written by subcommittee of EHDI Advisory representing
  - EHDI staff
  - AEAs
  - Iowa Department of Education
  - Private Practice Audiologists

# Hospital Site Visits

- Will visit each hospital
- Look at strengths and areas for improvement
- Will discuss:
  - Compliance with EHDI law
  - Program quality
  - Best practices that could help other hospitals
  - Follow-up/reducing number of children lost to follow-up
  - Parent perspective

# Program Evaluation

- Comprehensive evaluation of entire EHDI system
- Done by someone outside the system
- Use data to drive program decisions whenever possible

# Education

# AEA Visits

- Discussions with Early ACCESS Regional Liaisons, audiologists, itinerant teachers, anyone else who should be involved
- Discuss:
  - EHDI referrals for EA Pre-service Coordination
  - Follow-up process
  - Guide By Your Side
  - Other family support for families of children with hearing loss

# Update Training

- Updates for:
  - New users
  - Current users
- eSP and EHDI program

# Working with Amish Communities

- In some parts of the state, Amish families often refuse the newborn hearing screening
- Amish parents in focus groups stated that they didn't have an objection to screening
- Will work with community leaders to determine best way to increase screening rates

# Questions

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**Thanks for all you have done and will do  
for Iowa children!**

**E H D I**

Iowa's Early Hearing  
Detection & Intervention System

