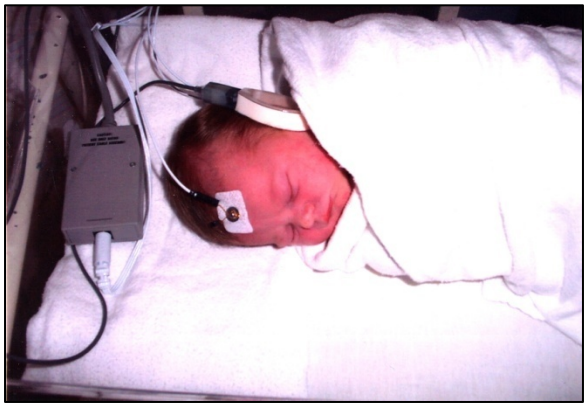
Newborn Hearing Screening
Improving Follow-up by Working Through the Medical Home

Shirley Russ MD, MPH
Cedars-Sinai Medical Center
Associate Clinical Professor of Pediatrics, UCLA

Doris Hanna, RN, CPNP, Sc.D
The National Initiative for Children's Healthcare Quality, NICHQ

Project Description

The Newborn Hearing Screening Collaborative sought to improve the quality of care delivered to newborns with hearing loss through system redesign using proven, evidence-based practices.



NICHQ
National Initiative for Children's Healthcare Quality

Project Description

- >95% US newborns are now screened for hearing loss at birth.
- National data suggest that up to 50% screen “refers” are lost to follow-up.
- Linkage with diagnostic and intervention services must be improved if the screening program is to be successful.

NICHQ
National Initiative for Children's Healthcare Quality

Project Description

- MCHB Funded NICHQ Learning Collaborative
- Multidisciplinary Teams from 8 States-AZ, CA, FL, KS, MI, NE, PA and WI
- Parents, Neonatologists, Primary Care Providers, Audiologists, Interventionists, State EHDI Coordinators.

NICHQ
National Initiative for Children's Healthcare Quality

Project Aim

To achieve, in 15 months, a breakthrough improvement to reduce delays in care and improve follow-up for infants who do not pass their newborn hearing screen

- Reduce by 50% the number of infants who “do not pass” the newborn hearing screening test who are lost to follow up one year from their date of birth
- Increase by 50% the number of infants with hearing loss who achieve normal developmental milestones (babbling, signing) by 12 months of age
- Double the number of infants with hearing loss who are fitted with hearing aids before 3 months of age

NICHQ
National Initiative for Children's Healthcare Quality

Key Process Measures

- Increase by 50% the number of infants with audiologic diagnostic testing by 3 months of age
- Increase by 50% the number of infants enrolled in early intervention by 6 months of age
- Increase by 50 % the number of infants with hearing loss who are linked with a Primary Care Provider (PCP)/Medical Home (MH)

NICHQ
National Initiative for Children's Healthcare Quality

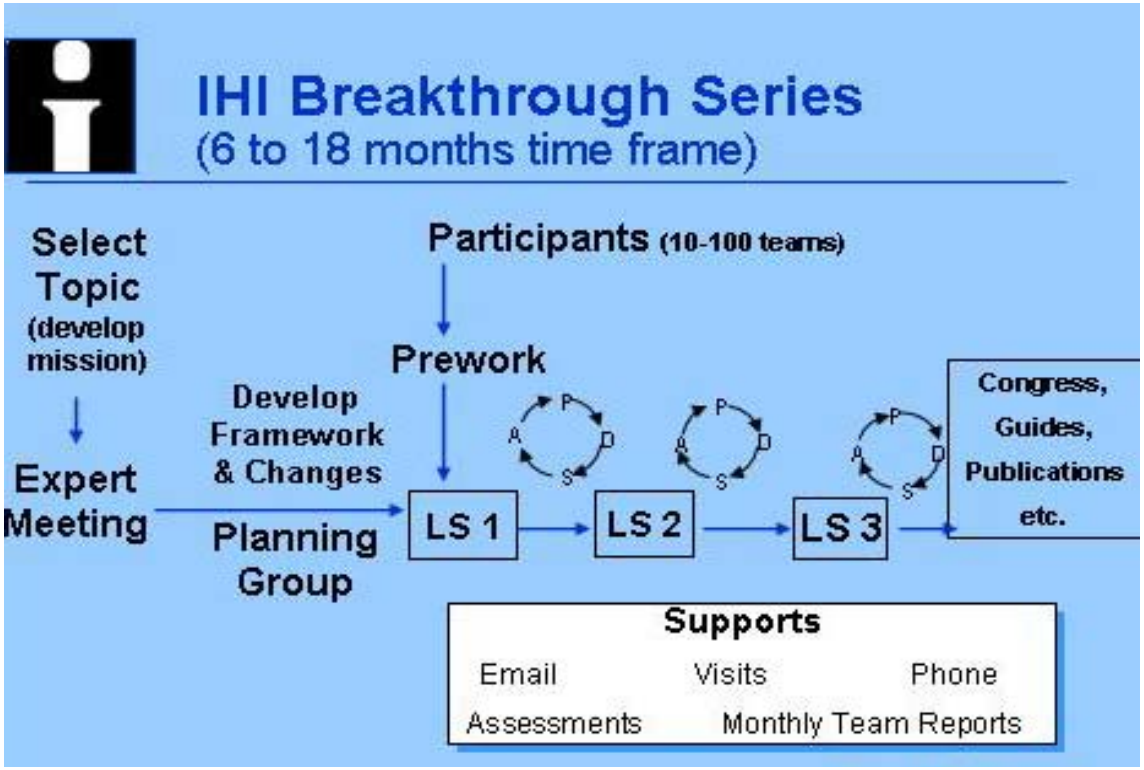
Key Design Elements

- Create a team that includes all stakeholders in care continuum – view as part of same system
- Acknowledge key role of medical home/PCP
- Embed reliability principles in design
  - Every system is perfectly designed to achieve the results it yields; to get different results, the system must be changed. (Plsek); try to take waste (rework) out of system
- Consider as “critical test result” for PCP’s, align with existing notification processes (take advantage of existing habits and patterns)
- Use Learning Collaborative Model
- Parents integral member of improvement team

NICHQ
National Initiative for Children's Healthcare Quality

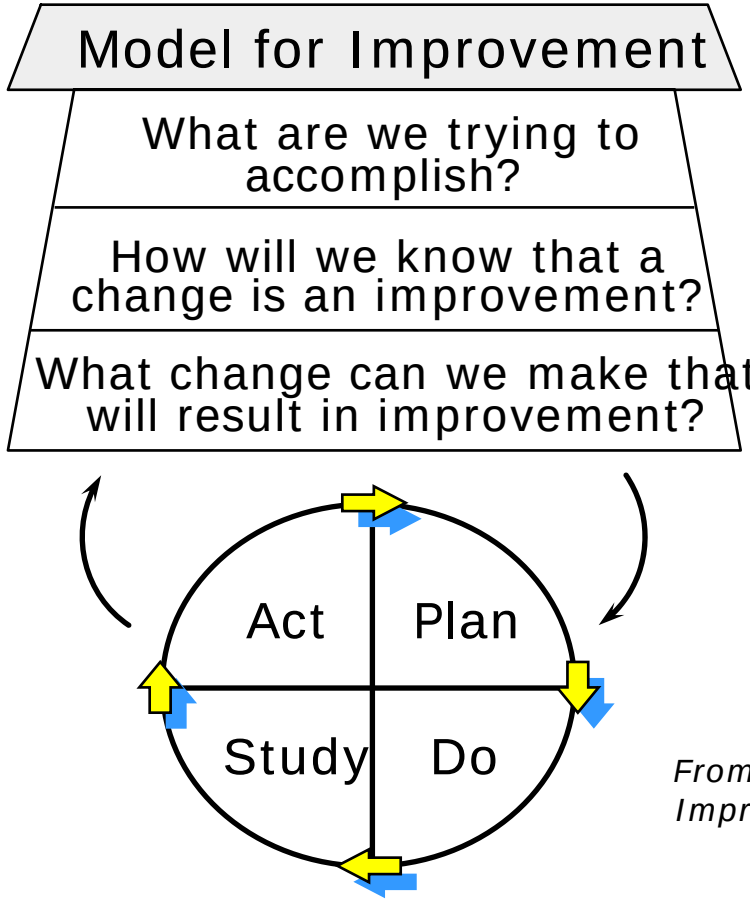
Methods and Strategies

The Breakthrough Series Collaborative Model



NICHQ
National Initiative for Children's Healthcare Quality

Methods & Strategies



Aim

Measures

Ideas

From: Associates in Process Improvement

NICHQ
National Initiative for Children's Healthcare Quality

Methods and Strategies

- Teams suggested and trialed small tests of change.
- All teams met together twice in person (LS1 And LS3) and once by virtual conference (LS2).
- Teams were coached in the Breakthrough Series Learning Collaborative approach and in the Model for Improvement.
- Tests of change were initially on a small scale “What can we do by next Tuesday?” “Try this on 2-3 cases and monitor the results.”
- Teams kept data on all tests of change, and on progress toward project goals.

NICHQ
National Initiative for Children's Healthcare Quality

Methods and Strategies

- Most measurement and improvements occurred in the screening and early diagnostic phases of the care process.
- Less than half of teams reported on effective changes in later intervention phases.

NICHQ
National Initiative for Children's Healthcare Quality

Change Package Analysis

- Identified which changes “had legs”
- Teams were confident in results of PDSAs.
- Data showed consistent trends to improvement.
- Changes were perceived as effective in achieving desired aims by individual teams, and in aggregate by the whole collaborative

NICHQ
National Initiative for Children's Healthcare Quality

Change Package Analysis

- Many change strategies trialed- some worked, some abandoned.
- Promising strategies moved into “implementation”i.e. became part of the new process.
- Plans for spread.

NICHQ
National Initiative for Children's Healthcare Quality

Changes with Leverage

- "The bottom line of systems thinking is leverage- seeing where actions and changes in structures can lead to significant, enduring improvements. Often leverage follows the principle of economy of means: where the best results come not from large-scale efforts but from small well-focused actions." Peter Senge. The Fifth Discipline: The Art and Practice of the Learning Organization

NICHQ
National Initiative for Children's Healthcare Quality

High Leverage Changes

- HLC 1 Changes Implemented and/or Spread by more than 1 team
  - *Verify (with parent and provider) the PCP/Medical Home at the time of the DNP before the family leaves the hospital*
  - *Standardize process for recording results of newborn screening results on the newborn records – improve accuracy of information*
  - *Schedule follow up appointment (rescreen, or diagnostic evaluation appointment) at time of DNP screening – before they leave the hospital and stress its importance*
  - *Confirm audiologist appointment with parents at time of PCP visit*
  - *Use fax-back form at the time of diagnostic evaluation to alert the PCP of the results and the need for prompt follow up*
  - *Organize internal and external resources to facilitate use by family*

High Leverage Changes con't.

- HLC 2 Changes
  - *Standardize process for collecting additional contact information for all DNPs - get a second point of contact for the family, eg., phone number of a relative or friend at time of screen referral*
  - *Create a letter template to fax communication results to PCP/MH*
  - *Educate PCP about medical work-up for infants with hearing loss – link with reporting results and provide "just in time" information*
  - *Use fax-back form between all parts of care continuum - audiology, PCP, specialists, EI*
  - *Create a registry of newborns who did not pass the screening phase*
  - *Provide EI reports with clinically useful and timely information for providers*

NICHQ
National Initiative for Children's Healthcare Quality

Other High Value Changes

- Additional changes with high value
- Standardize “script” the message given the parents when an infant does not pass the initial screening test
- Make reminder calls before diagnostic audiology appointments to verify appointment time and place and reinforce the importance of the visit
- Make two audiology appointments for diagnostic evaluation; if incomplete first test, second is already scheduled within reasonable timeframe; cancel the second if not needed; minimize need for sedated exam
- Obtain a consent for release of information at first contact with Early Intervention so that information can be entered in the State database

Results from Participating Teams

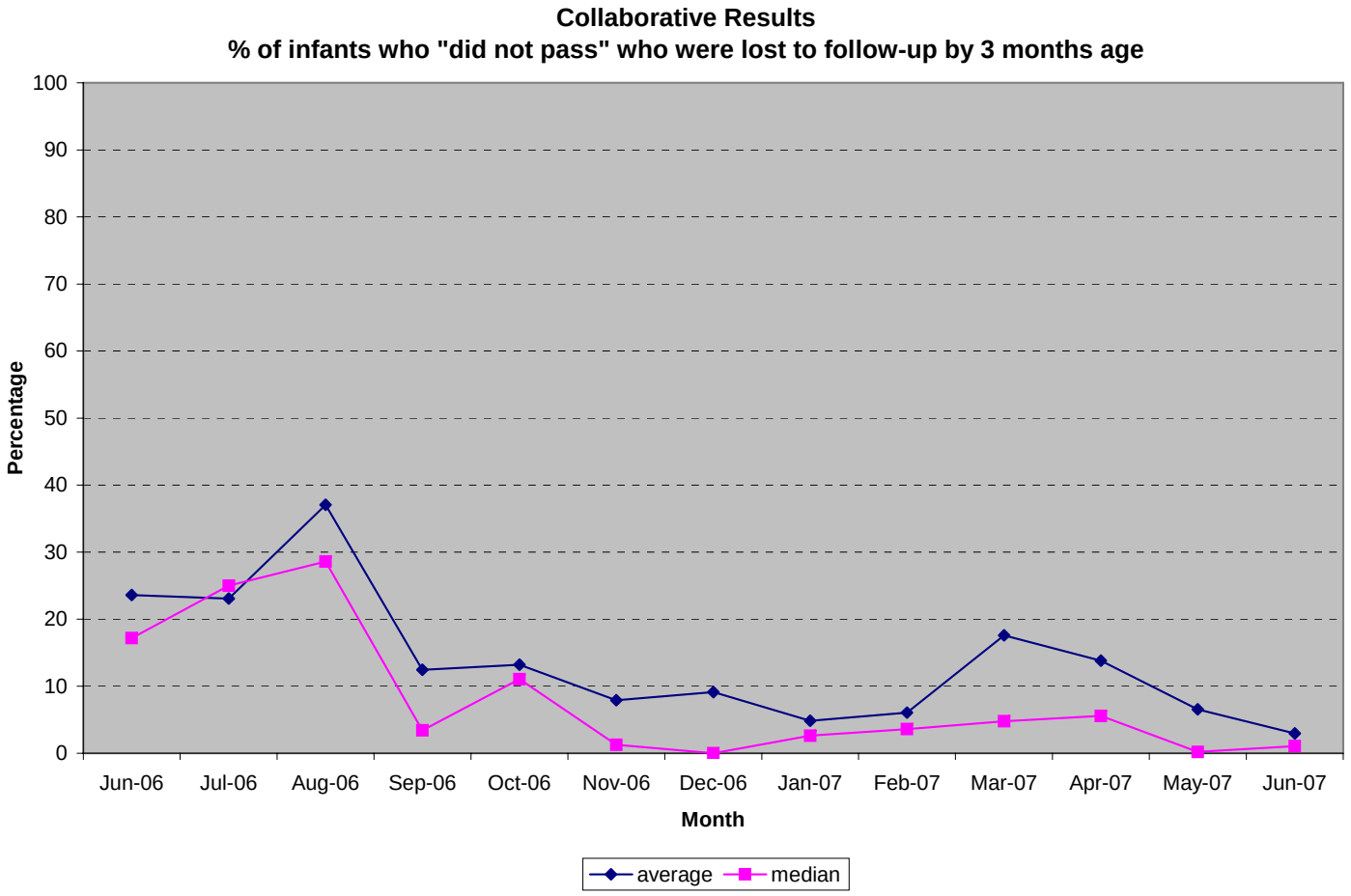
- The proportion of infants who “did not pass” the hearing screening lost to follow-up at 3 months fell from a median of 20% at baseline to a median of 1%.

- The proportion of “did not pass” screen referrals with a documented PCP increased from a median of 70% to 87.5%.

- Delays in ENT appointments were reduced by liaising with provider’s office to prioritize appointments for newborns with confirmed hearing loss.

NICHQ
National Initiative for Children's Healthcare Quality

Results and Impact



NICHQ
National Initiative for Children's Healthcare Quality

Two Key Challenges

- Limited capacity of diagnostic audiology services in some geographic areas
  - Creates barriers for families

- A range of views are held about the “ideal” role of the PCP in the newborn hearing screening follow-up process.

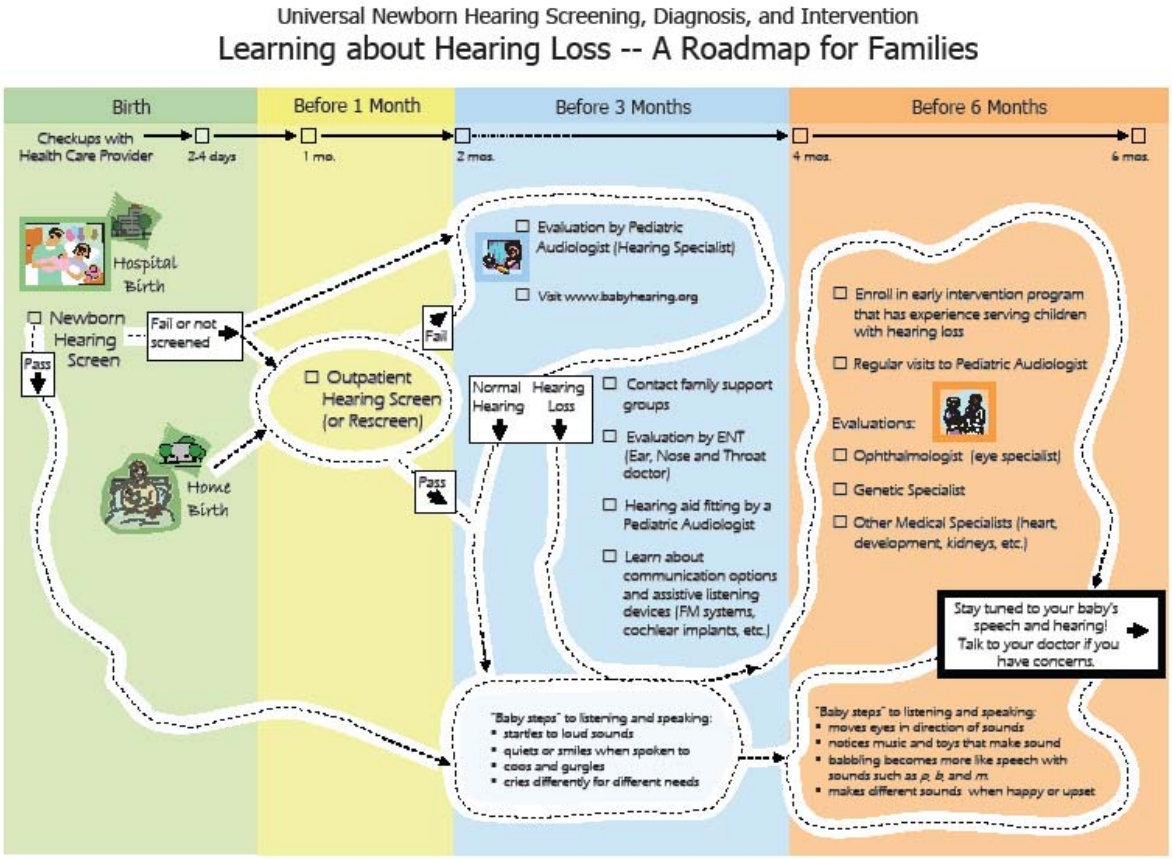
NICHQ
National Initiative for Children's Healthcare Quality

Two Key Opportunities

- HIPAA/FERPA release forms
- Create a Parent Roadmap that aligns to the 1,3,6 guideline recommendations
  - Partner with parent to meet timeline
  - Assure that stakeholders are “all on the same page”

NICHQ
National Initiative for Children's Healthcare Quality

Sample Roadmap



NICHQ
National Initiative for Children's Healthcare Quality

Removing waste from the system

- **California**
- Previous system - state (Hearing Coordination Center) called on outreach workers to assist in finding families
- Change tested:
  - Identifying PCP and having second point of contact on newborn hearing screening referral form (to state office)
- Results: Est. saving 45-75 hours/month for outreach team
  - Pre referral cases/month – 20
  - Post referral cases/month - 5
  - 15 cases saved @ 3-5 hours each
    - (30 minutes per phone call + 2 ½ to 5 hours for 1-2 home visits (2 ½ hours per home visit)

NICHQ
National Initiative for Children's Healthcare Quality

Removing waste from the system

- Pennsylvania
- Existing system – DPH sent certified letter to family from state with no request for parent response
  - approx 25 open cases/month
  - average 2.2 contacts to close a case
  - 55 calls at 15 minutes/contact
  - 13 hours/month
- Change tested:
  - Modified referral letter to include 800 number for families to encourage parent initiated contact
- Results - 65% parent response rate to letters (9 needed call x 2.2)
  - Post: 5 hours/month (20 calls/month @ 15 minutes/call)
  - 8 hours saved/month

Reflections

- Much more “happened” in the collaborative than can be represented by the data or team reports alone.
- The breakthrough series model facilitated teamwork, professional collaboration, and personal relationships necessary for improvement work.
- Team work was “fun.”
- Teams found that the Model for Improvement, and PDSA cycles were an effective way to implement change.
- Data collection was challenging for many teams, especially those with least resources.
- No “single change” stood out as “most important.”

NICHQ
National Initiative for Children's Healthcare Quality

Reflections

- Accomplishments: "Gaining an understanding that each specific change will only reduce a certain number of babies from being lost to follow-up; the lost to follow-up rate improves when multiple changes occur at the local and the state level.

- "As a result of the survey, we received a parent story that described the anguish and uncertainty they experienced even though the "numbers" (age at re-screening, diagnostics, amplification) were very good. Without the survey, this story would not have emerged. This stresses the need for a much improved parent-to-parent support system in our state, which is now unfolding."

NICHQ
National Initiative for Children's Healthcare Quality

Three recommendations for next steps

Parent Experience of Care Survey

- Parents' experiences with systems of care can be used to generate ideas for systems improvement, and guide development of successful change strategies

2. **Results indicate small tests of change generated by local experts can lead to measurable improvements**
   - Further work is needed to determine whether these promising practices can be sustained over time and spread within states

3. **Explore system barriers within diagnostic phase**

NICHQ
National Initiative for Children's Healthcare Quality

NICHQ Collaborative: The California Experience

Hallie Morrow, MD, MPH

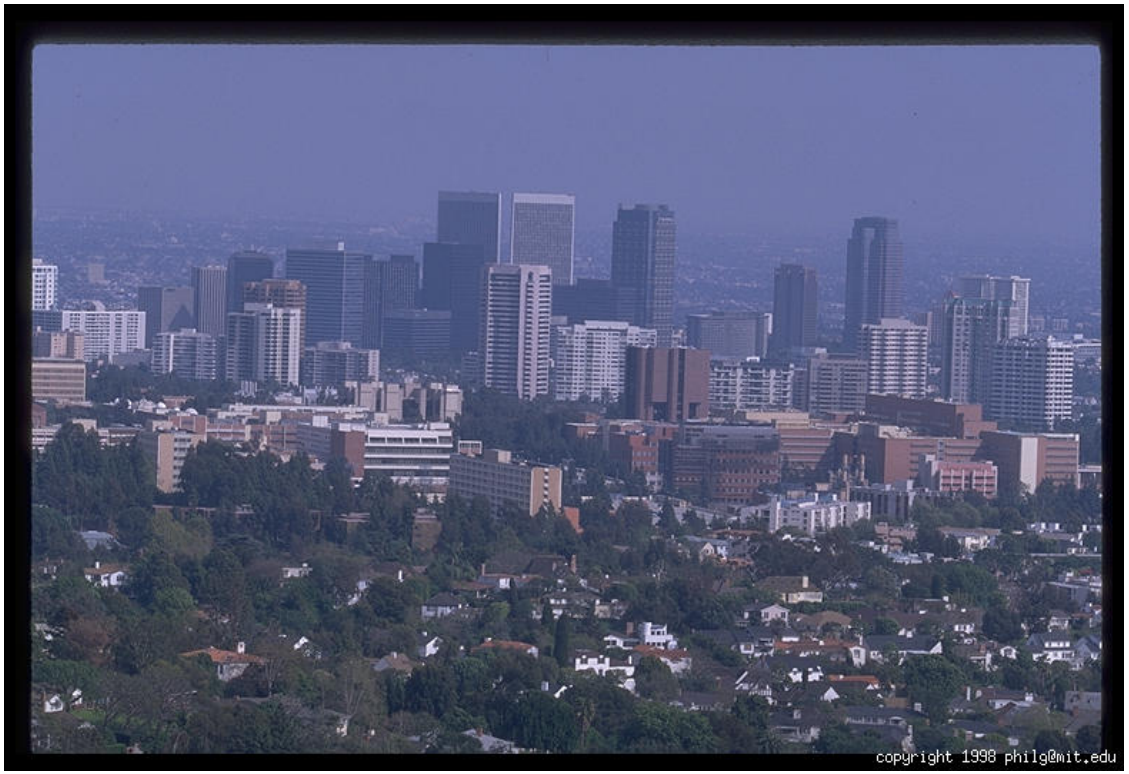
California Department of Health Care Services

NICHQ

National Initiative for Children's Healthcare Quality

NICHQ Collaborative

- Focused on Los Angeles area
  - Population - 10.3 million
  - Total births – 158,600



NICHQ
National Initiative for Children's Healthcare Quality

NICHQ Collaborative

- University affiliated birth facility (2000 births annually), primary care practice, and specialty care practices (Audiology, ENT)
- EI – Local Education Agency
- Parents/deaf adults/advocates
- Hearing Coordination Center
- AAP Chapter Champion
- Health insurance representative

NICHQ
National Initiative for Children's Healthcare Quality

Collaborative Infrastructure

- Every other week conference calls
- Agendas and minutes
- Call facilitator
- Monthly data collection and reporting

Collaborative Infrastructure

- Staff member to manage the data
  - Spreadsheets for reporting
  - Reminders to report
  - Recording data in Excel with graphs

NICHQ
National Initiative for Children's Healthcare Quality

Challenges

- Keeping team members engaged
- Ongoing participation of team members
- Most of interventions and data collection done by HCC
- Small test of change is not a familiar or comfortable concept
- Data collection and reporting was time consuming

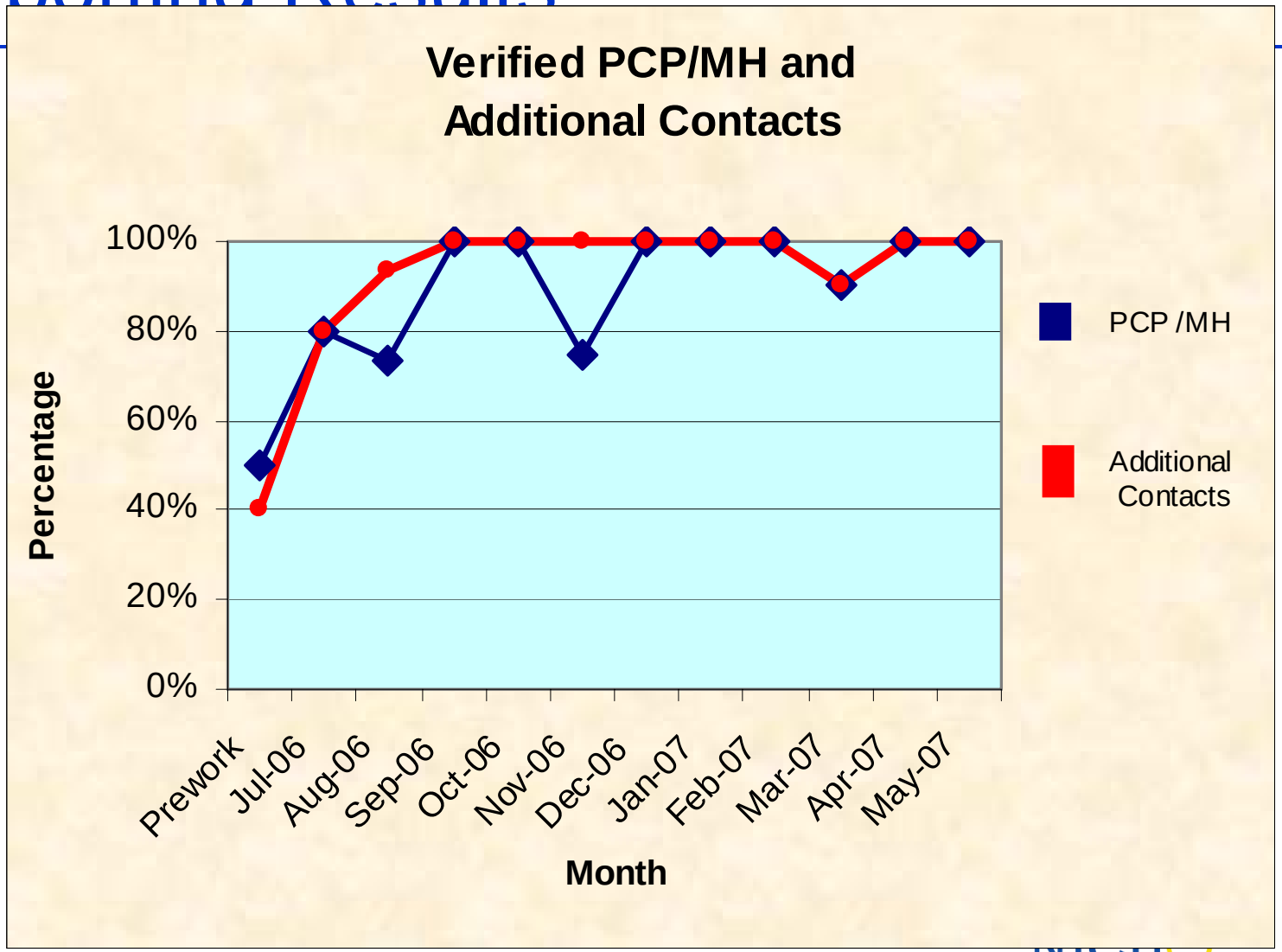
NICHQ
National Initiative for Children's Healthcare Quality

Aim and Progress

- **Birth Hospital**
  - **85%** of infants who do not pass (DNP) have PCP identified on the Infant Reporting Form (IRF) sent to the Hearing Coordination Center (HCC).
    - **Baseline - 50%**
  - **85%** of DNP have at least one contact name and number, in addition to the mother, on the IRF sent to the HCC.
    - **Baseline - 40%**

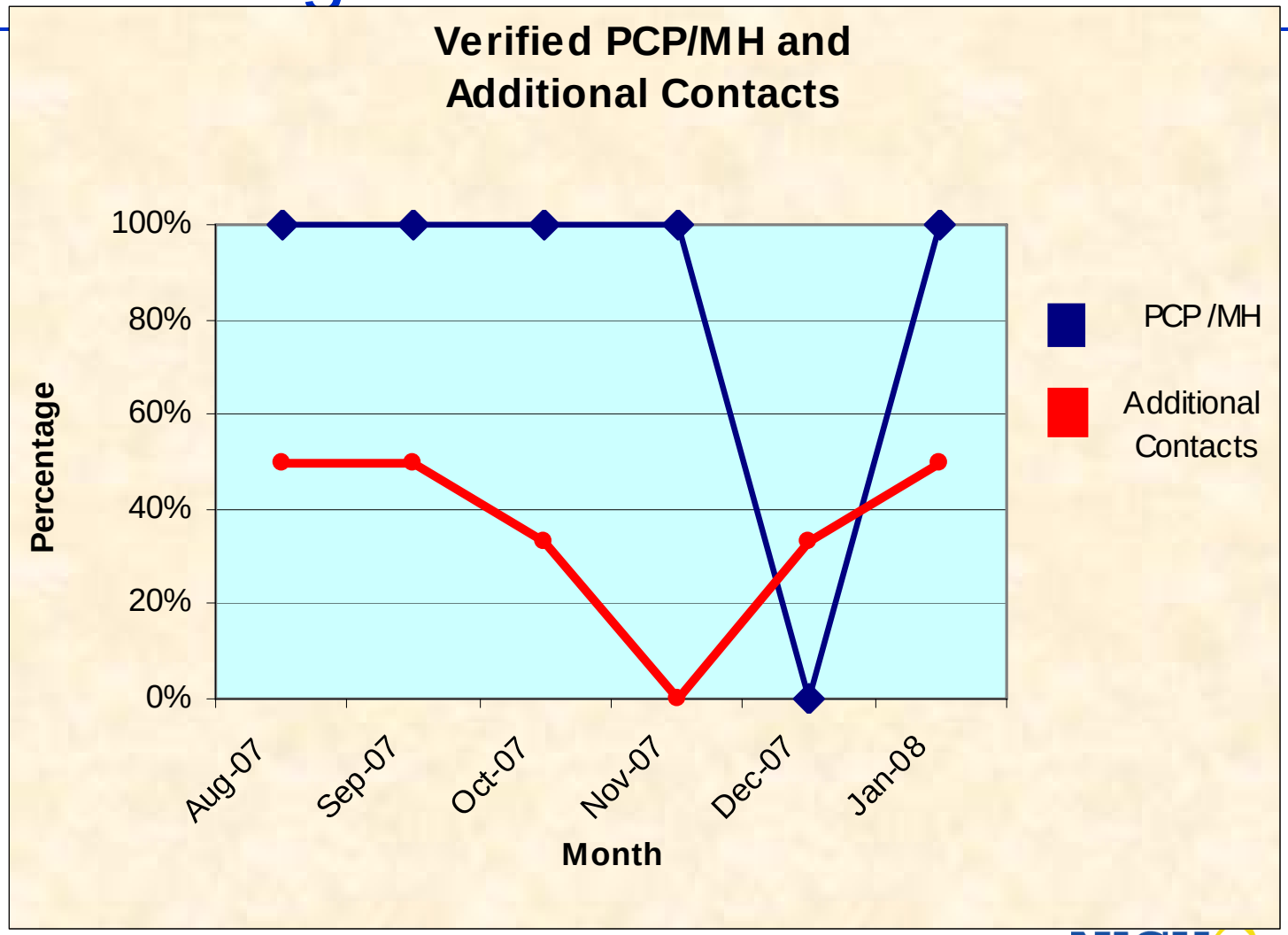
NICHQ
National Initiative for Children's Healthcare Quality

Reporting Results



National Initiative for Children's Healthcare Quality

Maintaining the Gain



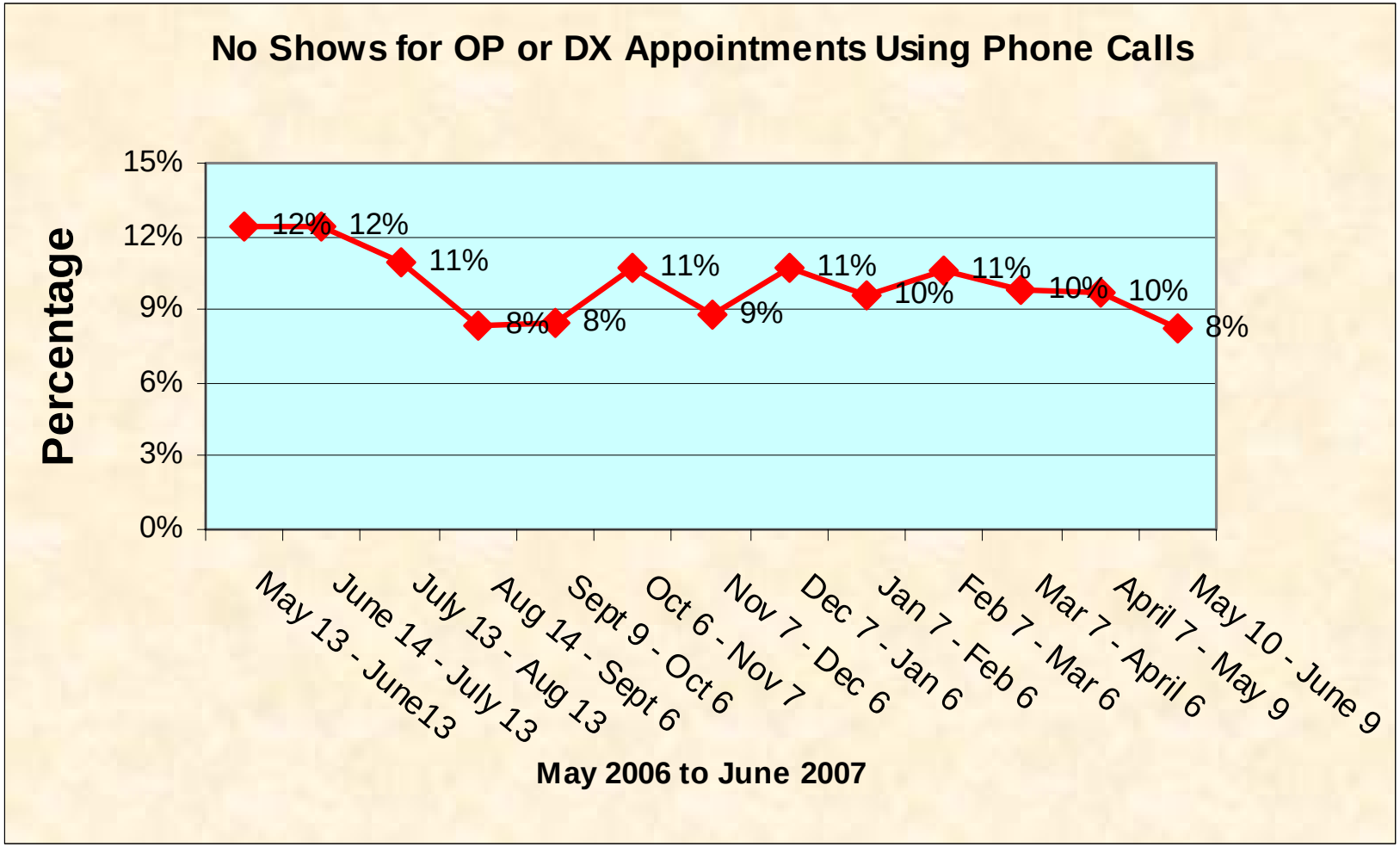
NICHQ
National Initiative for Children's Healthcare Quality

Aim and Progress

- **Hearing Coordination Center**
  - ↓ **by 25%** the number of No Shows for OP screening and DX evaluation appointments.
  - **Baseline - 12.4%**

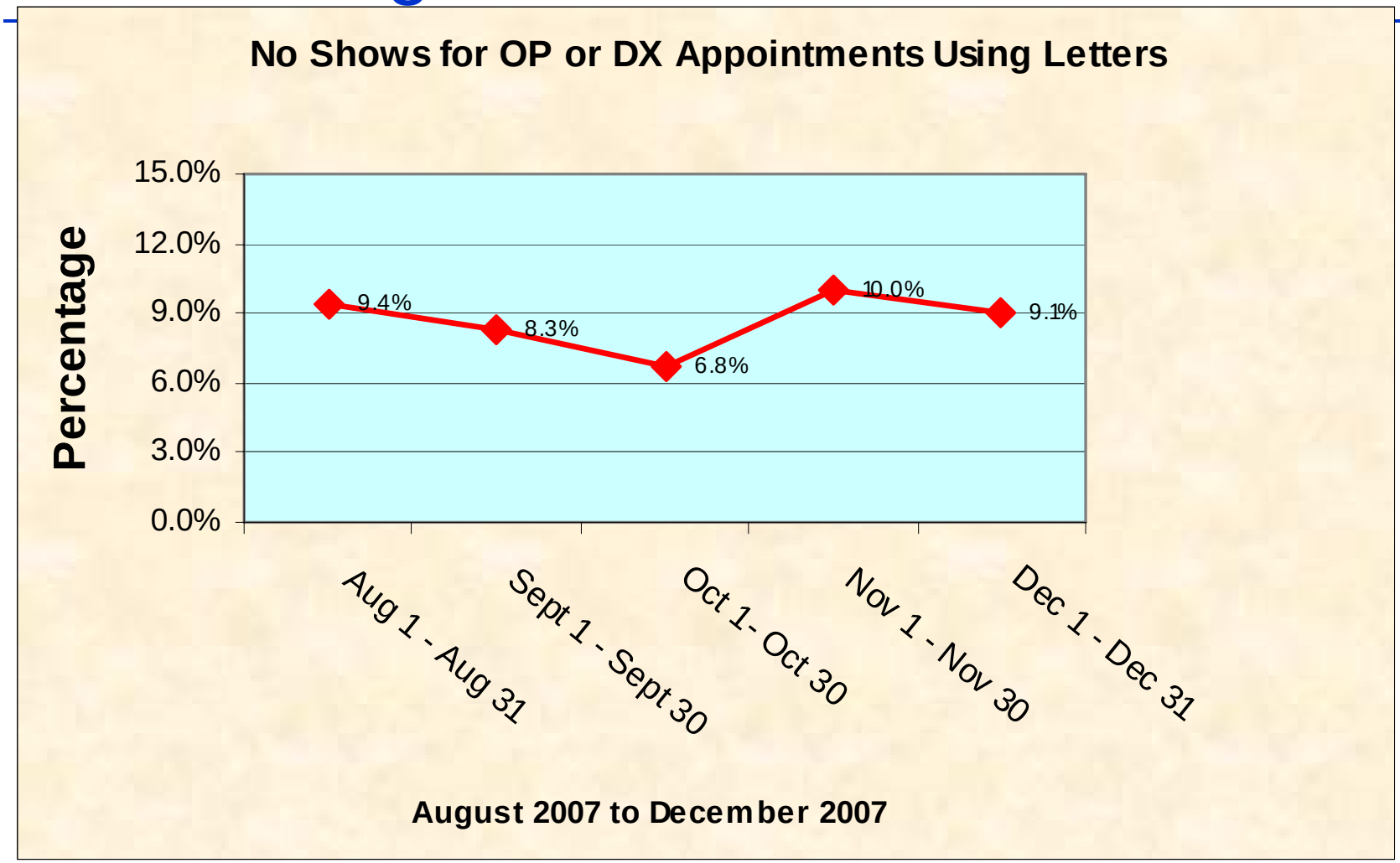
NICHQ
National Initiative for Children's Healthcare Quality

Results



NICHQ
National Initiative for Children's Healthcare Quality

Maintaining the Gain



NICHQ
National Initiative for Children's Healthcare Quality

Lessons Learned

- Partner with parents
- New paradigm
- Education is key – Once is not enough
- Maintaining the gain is hard!!

NICHQ

National Initiative for Children's Healthcare Quality

The NICHQ Collaborative and Parent Involvement

Janet DesGeorges

National Parent Chair

With thanks to all the other parents who served on this Collaborative!! – Molly, Jayne, Erin, Genevieve, Cindy, Sandra…

NICHQ

National Initiative for Children's Healthcare Quality

Parents are an essential element in helping to create a sustainable, quality EHDI system that meets the needs of the children and families we serve!

NICHQ
National Initiative for Children's Healthcare Quality

Factors Leading to Successful Collaboration

- Identifying at the outset family leaders who had some prerequisite level of a ‘skill set’ to participate. This skill set could include:
  - -Ability to share insights and information about their experiences in ways that others can learn from.
  - -See beyond their own personal experiences and represent the needs of other families.
  - -Respect the perspectives of others.
  - -Speak comfortably in a group with candor.
  - -Work in partnership with others.

NICHQ
National Initiative for Children's Healthcare Quality

Support from one another…

- *"What I found very helpful, and exciting, is when we actually had the face to face learning sessions, like learning session one in Boston and then the one we had just right before the EHDI conference. I really enjoyed the parent meeting. You know, I felt* really connected to the other parents from the other states."

NICHQ
National Initiative for Children's Healthcare Quality

- *"The face to face meetings were probably the most beneficial part of the whole NICHQ. When we all got together, we could talk about our personal experiences. I think like we all said, unless it happens to you, or it's in your own home, nobody really truly understands, you know, and all of us as parents understand what -- well, as for myself, to be deaf and also to be raising a deaf child."*

NICHQ
National Initiative for Children's Healthcare Quality

Things that worked or were recommended

- Establishing recommended scope of involvement for family leaders so that they understood what would be expected of them, and so that teams would understand how to utilize family leaders.
- Opportunities for family leaders to convene with one another at the face-to-face meetings and through phone meetings periodically throughout the collaborative to collaborate with the other family leaders on other teams.
- Ensuring good communication from the team kept the parent plugged in…

NICHQ
National Initiative for Children's Healthcare Quality

- *"I think what really helped me was how our state team leader e-mailed weekly and the day before to remind us of the team calls that we would have, and also would remind us of the NICHQ update calls. That was very helpful."*

NICHQ
National Initiative for Children's Healthcare Quality

The Learning Curve

- *"I found it interesting that NICHQ tends to have some terminology that is kind of acculturated in their organization that I had to learn and stumble through over time, and I think maybe some of it had to do with the 'models of change' and things like that. It would have helped to have a primer prior to the collaborative on terms I might need to know."* On the same topic, **another parent said:** "I have to agree that I wish I had more of the list of terminology, to better understand some things that they were using, some very big words, I have to say. That would have been more helpful."

NICHQ
National Initiative for Children's Healthcare Quality

- *"For a lot of doctors and staff that I worked with on my team, this was the first time they ever had a parent involved, and it was a really new dynamic and it took a while to kind of figure out how that was all going to work together."*

NICHQ
National Initiative for Children's Healthcare Quality

- *“When we started the collaborative, I didn't really know exactly how I was going to be involved. I think that feeling also came from the team, as they weren't quite sure what direction they were going to take in this project, so there wasn’t a strong expectation of what the parent might do in this role.”*

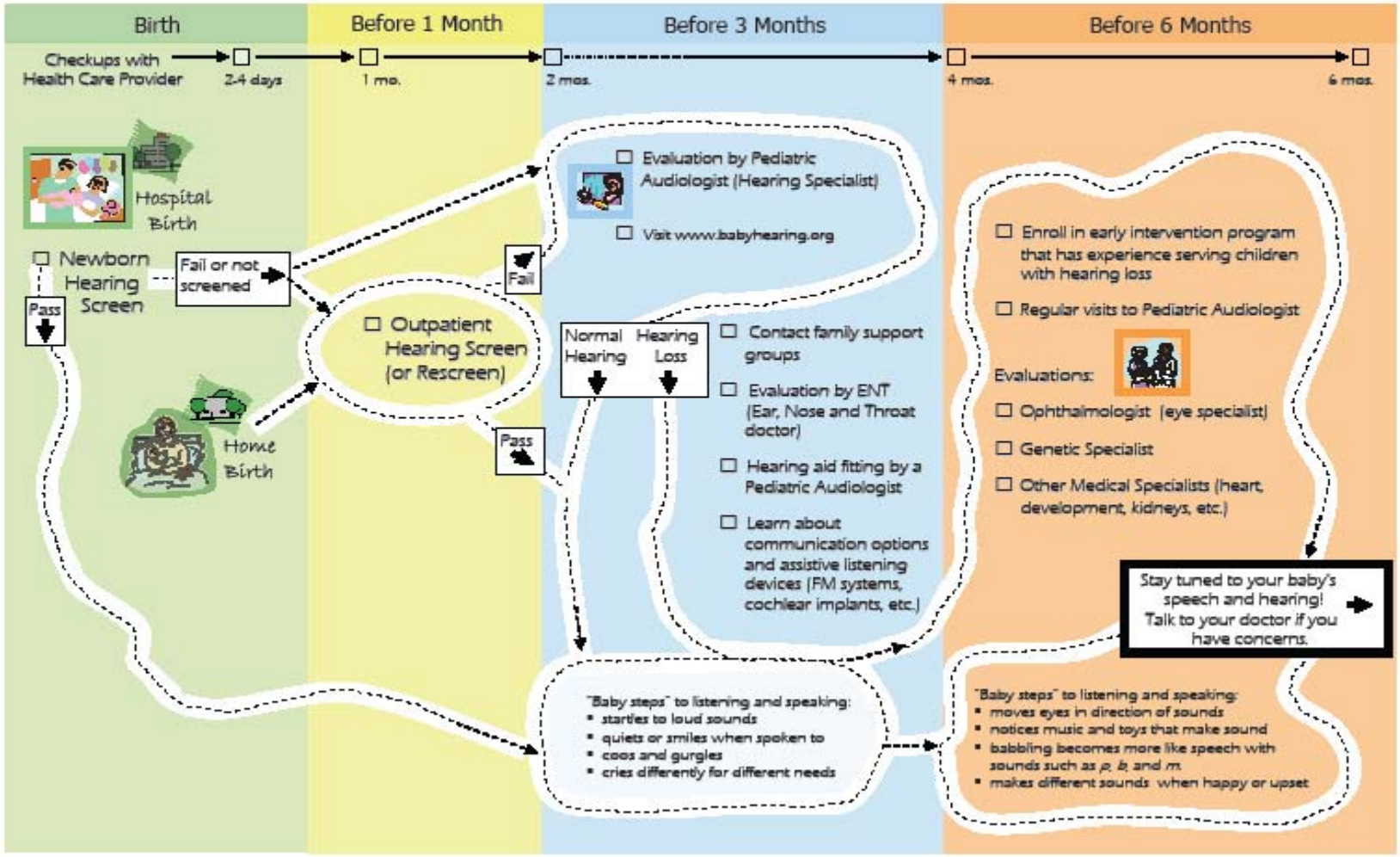
NICHQ
National Initiative for Children's Healthcare Quality

- Several projects emerged throughout the collaborative that family leaders were particularly qualified to represent their expertise on. These included:
- The Parent Roadmap
  - in individual states, parents often took the lead to make the 'template' more family-friendly; parents in states utilized their parent-to-parent connections to get input about the tool.
- The Ottowa Decision Guide

NICHQ
National Initiative for Children's Healthcare Quality

Universal Newborn Hearing Screening, Diagnosis, and Intervention

Learning about Hearing Loss -- A Roadmap for Families



NICHQ

National Initiative for Children's Healthcare Quality

The Parent Survey on Experiences of Care

- The national parent chair developed this survey with support from the NICHQ and national staff.
- This tool could be used to measure 'from the parent's point of view' whether measures were being completed by state teams (i.e. state measure: faxback form to PCP about screening results could be used to compare parent report that screening results were shared with them by the PCP at time of well-baby visit).

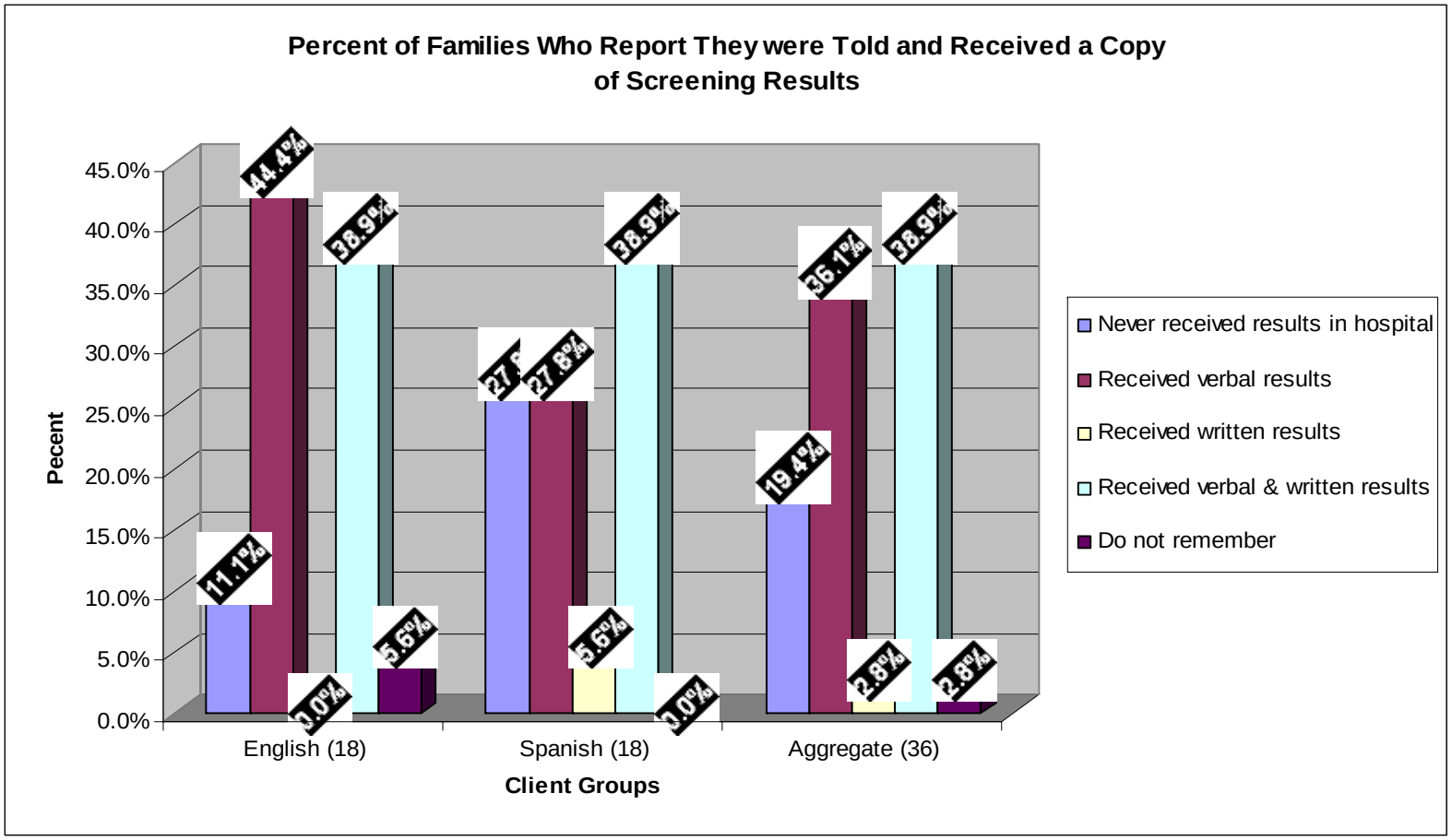
NICHQ
National Initiative for Children's Healthcare Quality

The Four Required Measures

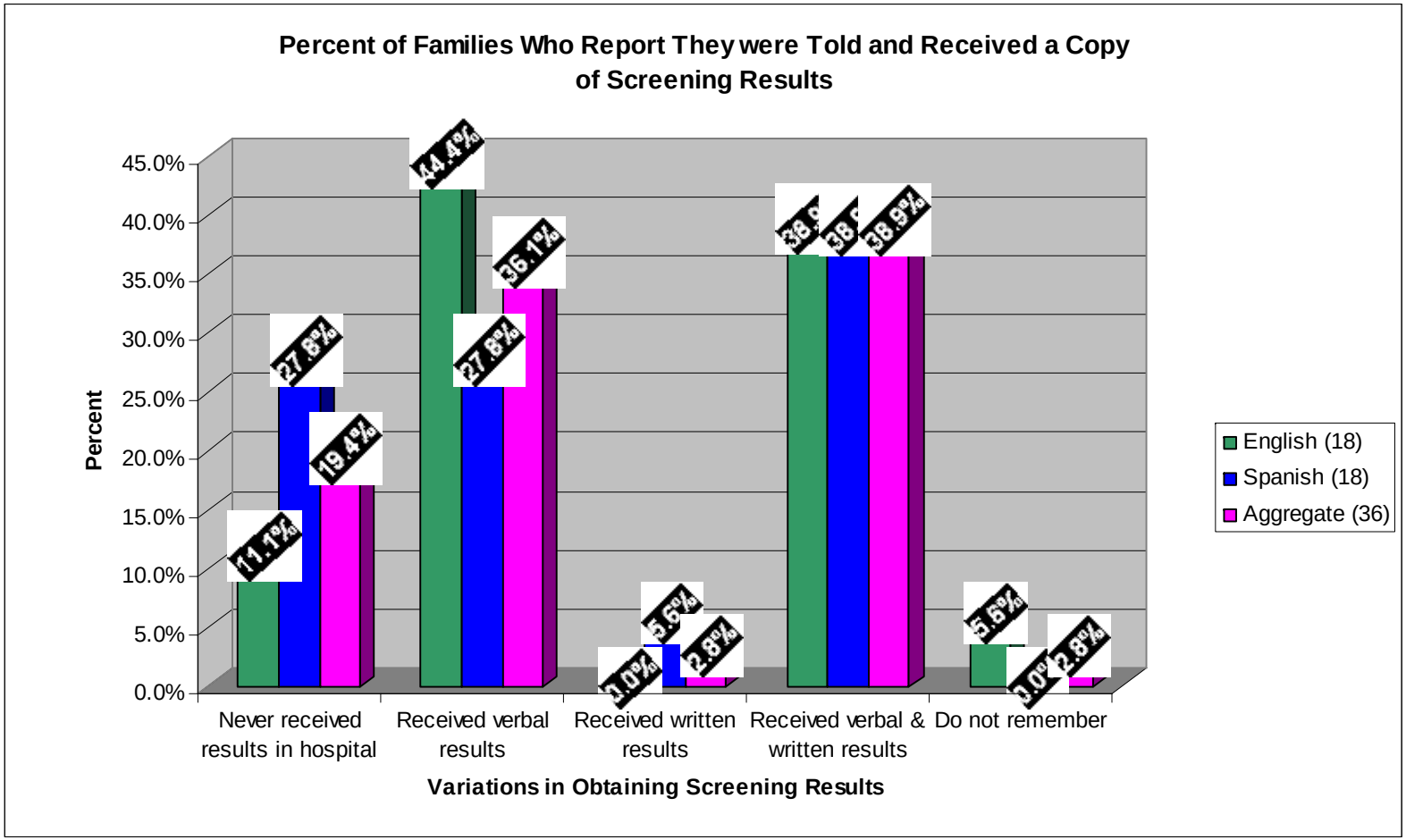
- % of families who report they received the hearing screening results in the hospital verbally and in writing.
- % of families whose medical home/PCP had the results of the newborn hearing screening on hand at their first well baby visit.
- % of families who report they *always* received the help they needed from their providers between screening and diagnosis.
- % of families who report they *always* received specific information they needed about diagnosis, treatment and service options for hearing loss.

NICHQ
National Initiative for Children's Healthcare Quality

California Parent Survey



NICHQ
National Initiative for Children's Healthcare Quality



NICHQ
National Initiative for Children's Healthcare Quality

Who we do this for….

- *"Our family will be forever grateful for the Newborn Hearing Screening offered at our local hospital Through the efforts of the EHDI program, we were able to find out about our son's hearing loss at birth, which is a great advantage for him."* **–**
  A Parent whose child was identified through EHDI

NICHQ
National Initiative for Children's Healthcare Quality

Acknowledgements

This project would not have been possible without the support of the National Center for Hearing Assessment and Management (NCHAM)

This collaborative was made possible by funding from HRSA contract number HHSH240200535016C.

This collaborative would not have been possible without the generous participation of teams from AZ, CA, FL, KS, MI, NE, PA, and WI

NICHQ
National Initiative for Children's Healthcare Quality