

Developing Community Partnerships for Cultural Diversity Training

*Jill Ellis, M.Ed., Executive Director
Helisa Katz, MA, Medical Trainer*



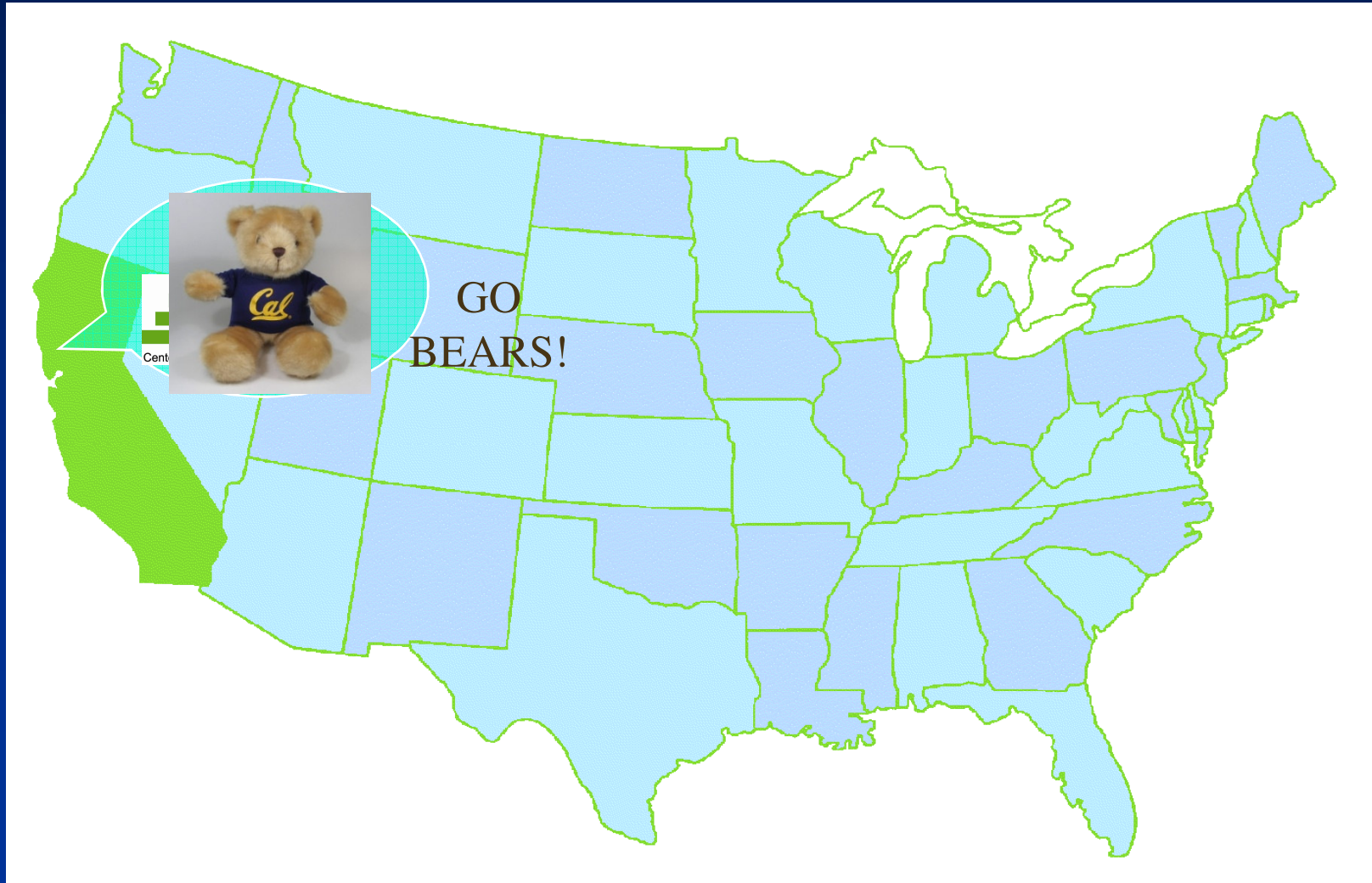
EHDI -March 10, 2009
Funded by The California Endowment

What is CEID ?...

29 year-old, non-profit organization
Started in 1980; US Federal HCEEP grant
Family Focused EI + Audiology + Inclusive
Childcare



Where are we located ?



Comprehensive Service Delivery

1. Early Intervention: Intensive & Family Focused

- ✓ Home visits
- ✓ Individual speech and auditory training
- ✓ Weekly parent education/sign classes
- ✓ Monthly Saturday Family School & Play Groups
- ✓ Sensory integration and occupational therapy services
- ✓ Morning Nursery School Classes for:
 - Preschool: children 3 -5 years of age
 - Toddlers: children 18 months-3 years of age
 - Friday Family Transition: 12-18 months & caregivers

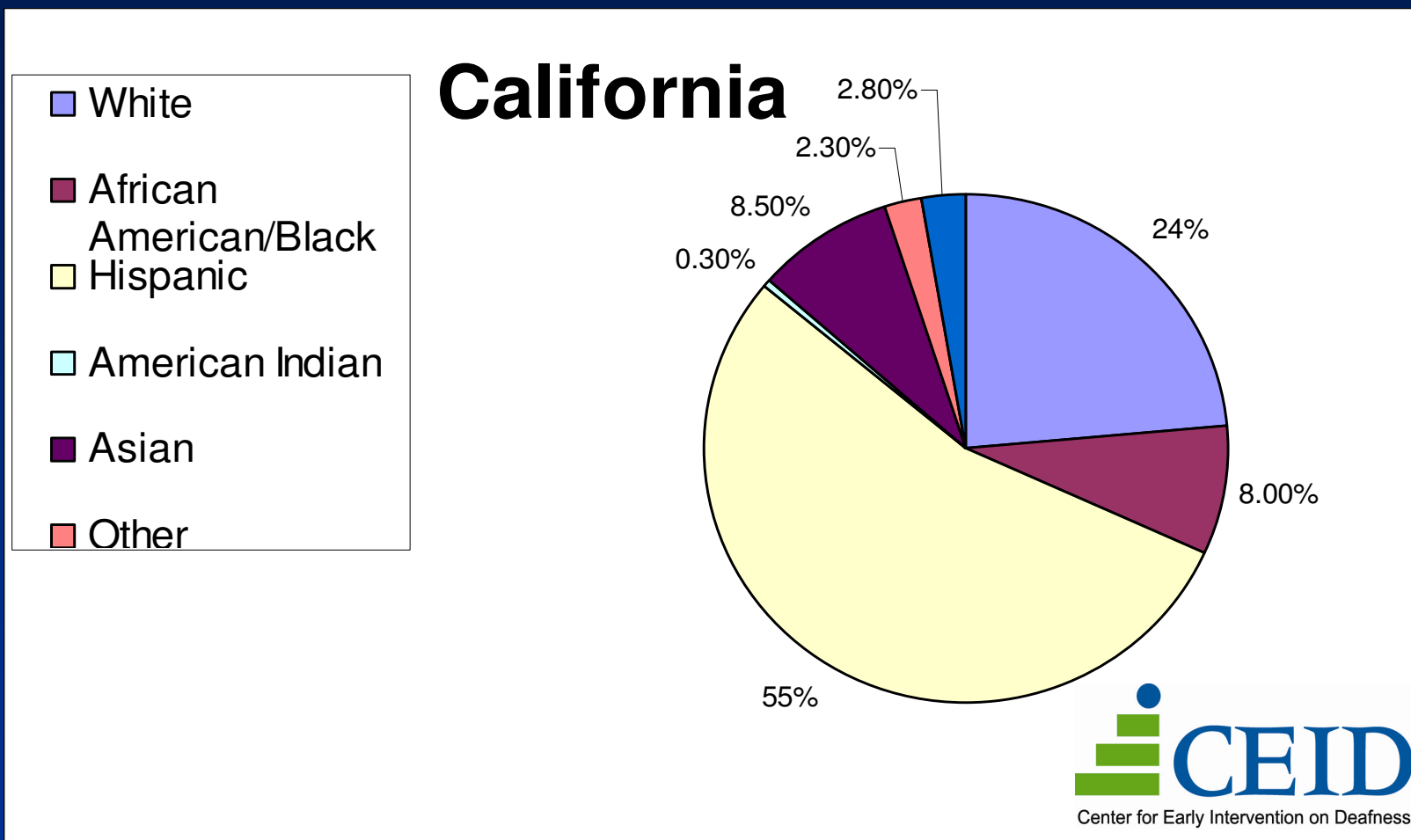
2. Community Outreach and Training

3. Pediatric Audiology & Dispensing

4. Inclusive Childcare - Sunshine Preschool

California Demographics

based on 5,091 total students reported for educational (K-12) services



Gallaudet Research Institute (December 2005).
Regional and National Summary Report of Data from the 2004-2005 Annual Survey of Deaf and Hard of Hearing Children and Youth.
Washington, DC: GRI, Gallaudet University.

Children in our community who are identified through NHS particularly those who do not have full access, **are not consistently referred to** and enrolled in quality early intervention programs within the first 6 months of life.

Nationally, approximately 66% of those referred for follow up through Newborn Hearing Screening come back for their follow up appointments.

*97% receive screening at birth

*77% enrollment in Early Intervention by 6 months

*30% of children with hearing loss are identified after they have passed newborn hearing screening

Alexander Graham Bell Association

http://agbell.org/DesktopDefault.aspx?p=2007_National_EHDI_Panel

State Update: Findings

- Difficulty collecting data from all agencies (Dept. of Health and Dept. of Education)
- Follows approximately 550,000 babies per year
- California's original program served about 70% of all births;
- 2008 legislation - "universal" program targets approximately 120,000+ more babies

Why is CEID increasing efforts to expand community partnerships?



Because ..Developing successful community partnerships . .

- Parallels our own strategic plan
- Endorses successful EI outcomes: 1,3,6
- Position in Community: Only non-profit organization in San Francisco Bay Area that provides early intervention, inclusive childcare, audiology, parent education and medial outreach and training
- History of annual community meetings and seminars with inter-agency representation



Collaboration between systems helps us to **identify barriers to access** and reverse continued late identification and early intervention

We are in This Together

- **Collaboration**- Building Healthy Communities requires a number of diverse tactics from multiple stakeholders
- Recognizing, Supporting, and **Strengthening** the framework that provides the **relationship** between communities, cultures, and systems, environmental factors, commitments, priorities, and goals.

Findings to date . . .

Collaboration = a huge investment!

- Building healthy communities requires a number of diverse tactics from multiple stakeholders.
- Recognizing the framework that provides the relationship between communities, cultures, systems, and commitments supports and strengthens our goals.

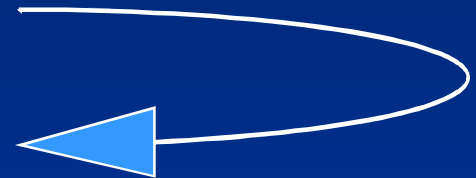
Our Most Important Team Members

- Newborn Hearing Screening

- Hearing Center & Medical

- Early Intervention

PARENTS



A Parent's Perspective on Doctors



Project Cross Talks

Objectives

- * To promote improved access to diagnosis and early intervention for underserved children who have hearing loss by building partnerships with pediatric providers in Alameda County
- * To build leadership within the community; innovate partnerships and new alliances for systemic change through knowledge, skills and connections

funded by: *The California Endowment*

Project Cross Talks: Goals

- #1 - Increase data availability that documents key barriers to early detection and intervention from the perspective of the local providers
- Create Survey (include questions that identify cultural and linguistic barriers & provider skill level)
- Make site visits to each clinic - meet staff and observe their system in action

Project Cross Talks: Goals

- # 2 - Strengthen physician and clinic staff awareness & skills regarding the importance of early detection and intervention
 - 1 hour trainings on site
 - 2 ½ day seminars for stakeholders
 - Dissemination of CEID GUIDE
 - Translated handouts
 - Community “drop off” points
 - Case study specific to culture

Project Cross Talks

- # 3 - Increase information sharing and collaboration among key stakeholders charged with detection and intervention for underserved communities

Discussion comparing use of:

- Cultural Identity
- Cultural Sensitivity
- Cultural Competency
- Cultural Humility

Alameda Health Consortium

association of community health centers
serving nearly:

112,000 patients per year

461,000 visits per year

33,400 prenatal care visits

50% patients are uninsured

52% are not primary English language users

10 languages

Asian
Health
Services

Lifelong
Medical
Care

Native
American
Health
Ctr.

Tri-City
Health
Ctr.

**ALAMEDA
HEALTH
CONSORTIUM**

W.
Oakland
Health
Council

Tiburcio
Vasquez
Health
Ctr.

La Clinica
de la
Raza

Valley
Community
Health
Ctr.

Our goals for increasing provider skills



To Learn:

- Why it is important that children are identified **EARLY**?
- The referral process and links to community resources
- Specialized vocabulary and how to explain testing processes and results
- Sources of family support
- Sources of information for ourselves and for families

Through Training . .

Service providers learn to offer a balanced approach to services, by providing adequate information and resources about choices making sure they are empowering families through culturally sensitive practices to make decisions.

Survey

Questions included:

- Do you think families under your care have the same opportunities for access to timely services as other families?
- How confident are you in explaining the newborn hearing screening process to parents who have questions about their infant's results?
- Do you believe that your clinic/agency addresses the cultural and linguistic differences of the families you serve in its missions, goals, and values?

Surprising Result

Question:

Think about the physicians with whom you work and know; how informed do you think most of them are about issues related to permanent hearing loss ?

Most providers answered:



Very informed compared to themselves

Responding to Training Feedback

Surveys of medical and early childhood professionals reveal, most people want to know more about:

- The referral process
- Intervention programs
- Early interventions
- How to read, understand, and explain an audiogram

Two Half Day Conferences

Participants Included: Health care providers, Regional Center case managers, teachers, state policy makers, early interventionists, audiologists, speech therapists, nurses, midwives, doulas, and parents

Key note speakers focused on experiential activities and discussions about cultural experiences and uncovering our own biases.

Focus on equity & eliminate health disparities

- Capture the Broader sense of urgency and concern and use it to **strengthen a focus** on the needs
- Willingness to engage in debates about the specific challenges confronting the communities and partnering to create approaches to address them ***
- Willingness to look at system's history and take responsibility for changing

Barriers Parents Face

- Health Insurance
- Legal status
- Religious views may be positive towards accepting deafness and not viewing it as pathological (to be fixed).
- Family (extended) as decision makers in determining outcomes
- Separation from family members due to migration
- Lack of accessible resources (language, technology, literacy)

survey data from providers and parents

- Cultural views towards normalcy
- No permanent address
- No phone
- Lack of transportation
- More flexible view of time
- Silence viewed as politeness rather than resistance
- Parents might nod as if they understand according to cultural rules of politeness, when they really do not
- Parents do not fully understand the results or implications of them
- Use of alternative medicine and folk remedies







Multicultural Premise

- We believe that we are all CULTURAL BEINGS
- We believe our cultural identities are *multidimensional, multifaceted, and include characteristics on the individual/group/universal levels.*
- We bring the fullness of our identities into any human interactions we engage in and so all of our relationships are "*cross-cultural*" in nature.

Cultural Competency

- Comprises behaviors, attitudes, and policies that can come together on a continuum that will ensure that a system, agency, program or individual can function effectively and appropriately in diverse cultural interactions and settings;
- Assures understanding, appreciation, and respect of cultural differences and similarities within and among and between groups.
- A goal that a system, agency, program or individual continually aspires to achieve

Cultural Humility

- a process that dovetails with cultural competency yet it requires humility in **how** physicians bring into check the power imbalances that exist in the dynamics of physician-patient communication by using **patient-focused interviewing and care**; a process that requires humility to develop and maintain mutually respectful and dynamic partnerships

Melanie Tervalon, MD, MPH
Children's Hospital - Oakland

Reaching Out to Communities

- English and translated materials were distributed and posted at clinics, libraries, community centers, laundromats, and parks.
- Contacts made to Spanish radio stations and Spanish websites; agreements made to broadcast or post the CDC's public service announcements about infant hearing screening.
- Article was published in *The Globe*, a predominately African American community newspaper, directed at raising parents' awareness about newborn and infant hearing.

Materials Created for Providers

Pediatric Resource Guide to Infant and Childhood Hearing Loss training guidebooks are distributed to all residents and all clinic providers and staff to review:

- *Incidence and facts about hearing loss*
- *Syndromes associated with hearing loss*
- *Pre/post natal Risk factors*
- *Professional to contact who are part of the TEAM*
- *Legislation and the IFSP*
- *The Intervention Process*

Providers are given a list of questions to ask professionals (ENT, the Speech Language Pathologist, and the Audiologist) to share with parents

More Materials



- Posters and Bookmarks for waiting rooms emphasizing the time lines for follow up.
- Local, State, and National resource lists in English and Spanish
- Forms for each clinic to create their own internal **Appropriate Referrals** sheet to ensure consistency between providers

Materials Created for Diverse Communities

- Professional translations of *The Guide's* stages of language and auditory development into Spanish, Chinese, and Japanese.
- Reprinting of handouts translated into 10 different languages to be given to parents before the baby is born explaining the reason for hearing testing, the test itself, and how to follow up with the doctor if there are concerns.*

*Available at www.healthinfotranslations.org

Pediatric Guide to Hearing Loss

Acknowledgements

1 Introduction and Background

- 1.1 Introductory letters
 - Forward: Ann Parker, M.D., Neurodevelopmental Pediatrics
 - Preface: Parent's Perspective, Tammy and Mike Taylor
 - Purpose: Jill Ellis, M.Ed., Executive Director, Center for the Education of the Infant Deaf
- 1.6 Fact sheet
- 1.8 State and national findings regarding Newborn Hearing Screening

2 Role of the Healthcare Providers

- 2.1 How the Healthcare Provider, Pediatrician, and Medical Home can help support Newborn Hearing Screening and Early Intervention
- 2.3 Responses to questions frequently asked by the pediatrician

3 Clinical Aspects in Identifying Hearing Loss

- 3.1 Defining the "At Risk" population
- 3.2 Identifying children not in the "At Risk" population
- 3.3 Stages of auditory development
- 3.4 Anatomy and physiology of the Auditory System
- 3.6 Medical conditions, disorders, and syndromes related to childhood hearing loss
- 3.7 Causes of childhood hearing loss in infants and children: medical conditions, disorders, syndromes, genetic and environmental causes
- 3.10 Physical markers related to hearing loss—examining a child from head to toe



4 Components of the Diagnostic and Intervention Process

- 4.1 Comparing screening measures used to identify Newborn Hearing Loss
- 4.5 Interpreting results of the screening: a guideline for the Medical Practitioner
- 4.8 The Medical Home: professionals involved in the team process
- 4.9 Professionals involved in the diagnosis and therapeutic process
- 4.11 Pediatric Audiologist: role and diagnostic measurements
- 4.16 Review of the Audiogram
- 4.20 Overview of hearing aids and other amplification devices
- 4.24 Classification of conventional amplification

5 Legislation, Early Intervention, and the IFSP Process

6 Website Resource List

7 Glossary of Terms

8 References

1. Audiologist knowledgeable in pediatric screening and amplification

Name:
Telephone number:
Fax:
Date of referral:

5. Speech/language therapy and/or aural rehabilitation therapy

Name:
Telephone number:
Fax:
Date of referral:

9. Equipment vendor(s)

Name:
Telephone number:
Fax:
Date of referral:

2. Otolaryngologist knowledgeable in pediatric hearing loss

Name:
Telephone number:
Fax:
Date of referral:

6. Sign language classes if parents choose manual approach

Name:
Telephone number:
Fax:
Date of referral:

10. State EHDI coordinator

<http://www.infanthearing.org/status/cnhs.html>

Name:
Telephone number:
Fax:
Date of referral:

3. Local early intervention system

Name:
Telephone number:
Fax:
Date of referral:

7. Ophthalmologist knowledgeable in co-morbid conditions in children with hearing loss

Name:
Telephone number:
Fax:
Date of referral:

11. AAP Chapter champion

<http://www.medicalhomeinfo.org/screening/Champions%20Roster.pdf>

Name:
Telephone number:
Fax:
Date of referral:

4. Family support resources, financial resources

Name:
Telephone number:
Fax:
Date of referral:

8. Clinical geneticist knowledgeable in hearing impairment

Name:
Telephone number:
Fax:
Date of referral:

12. Family physician(s)

Name:
Telephone number:
Fax:
Date of referral:

National Resources

Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell)
202/337-5220
www.agbell.org

American Academy of Audiology (AAA)
800/AAA-2336
www.audiology.org

American Academy of Pediatrics
www.aap.org

American Society for Deaf Children
717/334-7922
www.deafchildren.org

American Speech-Language-Hearing Association (ASHA)
800/498-2071
www.asha.org

Boys Town Center for Childhood Deafness
www.babyhearing.org

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/ehdi

Cochlear Implant Association, Inc.
202/895-2781
www.cici.org

Families for Hands and Voices
303/300-9763
www.handsandvoices.org

Laurent Clerc National Deaf Education Center and Clearinghouse at Gallaudet University
www.clerccenter.gallaudet.edu/InfoToGo

National Association of the Deaf (NAD)
301/587-1788
www.nad.org

National Center on Hearing Assessment and Management (NCHAM)
www.infanthearing.org

National Institute on Deafness and Other Communication Disorders
www.nidcd.nih.gov

Oberkottter Foundation
www.oraldeafed.org

The recommendations in this document do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Copyright © 2002 American Academy of Pediatrics. No part of this document may be reproduced in any form or by any means without prior written permission from the American Academy of Pediatrics except for 1 copy for personal use.

This project is funded by an educational grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services.



Waiting Room Bookmark

My Baby's Hearing

Birth to 3 Months

- ◆ Startles to loud sounds
 - ◆ Quiets to familiar soft voices
 - ◆ Eyes widen or blink to new sounds

3 to 6 Months

- ◆ Turns head toward source of sound
 - ◆ Responds to changes in tone of voice
 - ◆ Turns head when name is called

6 to 9 Months

- ◆ Understands a few commonly used words
 - ◆ Enjoys vocal play with others
 - ◆ Makes a variety of many different sounds

9 to 12 Months

- ◆ Repeats single words and sounds
 - ◆ Points to a favorite toy when asked
 - ◆ Responds when told "no"

If you think your baby is having trouble hearing sounds, it is important you get his or her hearing checked as soon as possible.

In order for your baby to learn, he or she needs to be able to understand language.

Your baby's pediatrician can help you schedule an appointment for a hearing test.

What Can I Do To Know If My Baby Is Hearing?

At birth: make sure your baby's hearing was checked before leaving the hospital. If your baby was not checked at the hospital, ask your doctor to schedule an appointment at an outpatient clinic.

By 1 month: If your baby did not pass in both ears the first time, bring him or her to a second appointment to be rescreened.

If your baby was referred after the second screening, make an appointment with both an audiologist and an ENT.

By 3 months: your baby should have completed all hearing screening and testing.

By 6 months: If your baby has a hearing loss, by 6 months, he or she should be fitted with hearing aids by the audiologist and enrolled in early intervention. Ask your doctor for information on communication options and early intervention programs in your area.



1035 Grayson Street
Berkeley, CA 94710

Voice 510.848.4800
Fax 510.848.4801
TTY 510.848.5658
www.ceid.org
ceid@ceid.org

Stages of Auditory Development

Birth to 3 months

- ◆ Recognizes and quiets to familiar voices.
- ◆ Startles or jumps in response to sudden loud sounds such as a pot falling, telephone ringer, or dog barking.
- ◆ Awakens to loud sounds (door knock, horn, lawn mower).
- ◆ Makes cooing sounds; vowel sounds such as “ooh” and “aah”.

3 to 6 months

- ◆ Awakens to sounds or speech
- ◆ Turns head toward noise toys and interesting sounds (singing, bell, finger snap, and music).
- ◆ Makes a variety of sounds. “baba” and “gaga”.
- ◆ Babbles frequently and for pleasure; takes turns making sounds with an adult.

6 to 12 months

- ◆ Understands first words such as “bye-bye”, “shoe”, “eat”, “no”, and “up”.
- ◆ Responds to his or her name from across the room.
- ◆ Enjoys making and hearing sounds produced from rattles and similar toys.
- ◆ Coos and moves to music.
- ◆ Imitates speech with non-speech sounds “la, la, la, la”, “ga, ba, boo, ba”.



12 to 18 months

- ◆ Says 6-10 first words such as: “more”, “milk”, “kitty” and “cracker”.
- ◆ Responds to names of favorite toys by pointing to them when asked.
- ◆ Responds to sounds coming from across the room.
- ◆ Points to Mommy/Daddy/sibling when named.
- ◆ Turns head quickly toward loud or soft sounds presented on both sides.
- ◆ Understands routine expressions such as: “where is your bottle?” or “let’s change your diaper”.

18 to 24 months

- ◆ Uses a spoken vocabulary of approximately 20 words by 18 months.
- ◆ Speaks using two word phrases, “more cracker”, or “Daddy working.”
- ◆ Understands simple “yes” and “no” questions.
- ◆ Recognizes and names environmental sounds (doorbell, microwave, telephone).
- ◆ Refers to self by name.
- ◆ Follows simple directions such as: “Get your shoe,” or “Bring me your socks.”



1035 Grayson Street
Berkeley, CA 94710

Voice 510.848.4800
Fax 510.848.4801
TTY 510.848.5658
www.ceid.org
ceid@ceid.org

听觉发展的阶段



- 出生后到**3个月**
- 识别出熟悉的声音，并在其中安静下来。
- 被突如其来的吵杂声音吓到或跳起来，例如：水壶掉到地上的声音、电话铃响或是犬吠的声音。
- 被吵杂的声音吵醒（敲门声、喇叭声、割草机发出的声音）。
- 发出像“哦”和“啊”元音声的喔啊声。
- **3到6个月**
- 被声音或说话声吵醒
- 会把头转向有声响的玩具和有趣的声音（唱歌、门铃、打响指和音乐）。
- 发出各种声音，“爸爸”和“呶呶”。
- 经常牙牙学语并为了好玩；和大人轮流发出声音。

Etapas del desarrollo auditivo

De 0 a 3 meses

- ◆ Reconoce voces familiares y se tranquiliza al oírlas.
- ◆ Reacciona sobresaltado o asustado ante fuertes sonidos repentinos, tales como la caída de una cacerola, la campanilla del teléfono o los ladridos de perros.
- ◆ Se despierta al ruido de sonidos fuertes (toquidos en la puerta, pitido de claxon, ruido del cortacésped de motor).
- ◆ Hace sonidos como gorjeos; sonidos vocálicos, tales como “ooh” y “aah”.

De 3 a 6 meses

- ◆ Se despierta a los sonidos o voces.
- ◆ Gira la cabeza hacia los juguetes que producen ruidos y sonidos interesantes (cantos, campanas, chasquido de los dedos y música).
- ◆ Produce una variedad de sonidos: “baba” y “gaga”.
- ◆ Balbucea con frecuencia y por placer; repite alternadamente con un adulto la reproducción de algunos sonidos.

De 6 a 12 meses

- ◆ Comprende las primeras palabras, tales como “adiós”, “zapato”, “comer”, “no”, y “upa”.
- ◆ Responde a su nombre desde el otro lado de la habitación en que se encuentre.
- ◆ Le encanta hacer y escuchar sonidos provenientes de sonajeros y juguetes por el estilo.
- ◆ Se arrulla y se mueve con la música.
- ◆ Imita el habla con sonidos que no son palabras, tales como “la, la, la, la”, “ga, ba, buu, ba”.



De 12 a 18 meses

- ◆ Dice las primeras 6 a 10 palabras, tales como: “más”, “leche”, “gatito” y “galletita”.
- ◆ Responde a los nombres de los juguetes favoritos señalándolos con el dedo cuando se le preguntan.
- ◆ Responde a los sonidos que provienen del otro lado de la habitación.
- ◆ Señala con el dedo a la mamá, al papá y a los hermanos cuando se los nombran.
- ◆ Voltea la cabeza rápidamente hacia los sonidos suaves o fuertes que escuche en ambos lados.
- ◆ Comprende las expresiones habituales, tales como: “¿dónde está tu biberón?” o “vamos a cambiarte tu pañal”.



1035 Grayson Street
Berkeley, CA 94710

Voice 510.848.4800
Fax 510.848.4801
TTY 510.848.5658
www.ceid.org
ceid@ceid.org

Hearing Test for Your Baby

Babies learn to understand and speak words through hearing. If your baby has a hearing problem and it is not found, your baby will have a hard time learning words and how to talk. When a hearing loss is found early, treatment can begin right away to prevent long-term problems.

Hearing Test

As a part of your baby's care, a hearing test will be done. The test measures how your baby responds to sound. It takes about 10 minutes and can be done while he or she is sleeping.

- A small microphone is placed near the baby's ear that sends soft clicking sounds into the ear.
- Small pads are put on your baby's head. These measure how the baby's brain responds to the sounds.

The Results

The results of the hearing test will be given to you and to your baby's doctor. If your baby does have a hearing loss, you will get more information about treatment and resources and more tests will be done.

If you have any questions about having your baby's hearing tested, talk to your baby's doctor or nurse.

Changes made by CEID

- Identified public transportation support
- Identified Incentives for families
- Hired interpreters (Spanish)
- Gained appreciation for "all day clinic" experience
- Revised our patient interactions; increased time to explain "personal" appointment
- Implemented system for 2-3 reminder calls
- Created schedule for flexible appointments (evenings and weekends)

Challenges and Lessons Learned

- Release time for providers – free CEUs
- Maintaining supportive and close communication with partners
- Changing staff and point of contact within community clinics- prepare for at least 10 calls
- Support Overworked professionals- bring food, on- site, breakfast/lunch time
- 2-3 months lead time for seminars

Successes

- Developed and provided a referral form that includes point of contact , available pediatric audiological facilities, and community resources offering full accessibility
- Reviewed confirmed course of action for scheduling, follow up appointments, and service delivery
- Witnessed positive outcomes of our disseminated handouts and guidebook

Continued Commitment

- Commit to creating and supporting new policies and practices that are equitable and help overcome previous barriers to full inclusion and participation
- Commit to “cultural humility” practices that recognize need of providers
- Commit to including families in seminars and presentations

REFERENCES

Alexander Graham Bell Association

http://agbell.org/DesktopDefault.aspx?p=2007_National_EHDI_Panel

Best Practices for Early Start For Infants and Toddlers Who are Deaf or Hard of Hearing, California Department of Education 2005

<http://www.deafkids.org/Legislation/BEST%20PRACTICES%20FOR%20EARLY%20START%20NH%20no%20letter.pdf>

California Newborn Hearing Screening Flow Chart

<http://www.dhs.ca.gov/pcfh/cms/nhsp/pdf/flowchart.pdf>

Cultural tunnel syndrome: a disabling condition - culture and disability

PARKS & RECREATION, May, 1997 by Valerius, Hodges, Perez

Deaf Counseling, Advocacy, and Referral Agency

www.dcara.org

EHDI Educational & Training Videos

<http://www.infanthearing.org/videos/index.html>

Florida Resource Guide May 2005: Questions Parents Can Ask

<http://www.cms-kids.com/InfantHearing/13Resources.pdf>

Latino access to rehabilitation services: evidence from Michigan

AMERICAN REHABILITATION, Spring, 1996 by Anna M. Santiago, Anna M. Villarruel, Francisco A. Villarruel, Michael J. Leahy

Providing links to services, programs, information and parent-to-parent support

<http://www.parentlinks.org/>

When a Newborn Doesn't Pass the Hearing Screening: How Health Professionals Can Encourage Follow-up Hearing Evaluations for Newborns

<http://www.nidcd.nih.gov/health/hearing/professionals.asp>



Thank You!
CEID

510-848-4800

www.ceid.org

The Center for Early
Intervention on Deafness

For more information and training contact:



The Center for Early
Intervention on Deafness

510-848-4800

www.ceid.org