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‘The Building Blocks of a Medical Home for Children with Hearing Loss’


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Vicki Hunting, Parent

February 22, 2010

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Today's Discussion:

- 1. Clinical Perspective:**
MH/EHDI in today's clinical practice – Dr. Grimes
- 2. Title V Perspective:**
MH in State Systems – Dr. Waldron
- 3. Parent Perspective:**
What do parents want/need? – Vicki Hunting, Parent





Evidence²

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Clinical Perspective: *Medical Home/EHDI in today's clinical practice*

Alan Grimes, MD, FAAP

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What is a Medical Home?



Medical Home?



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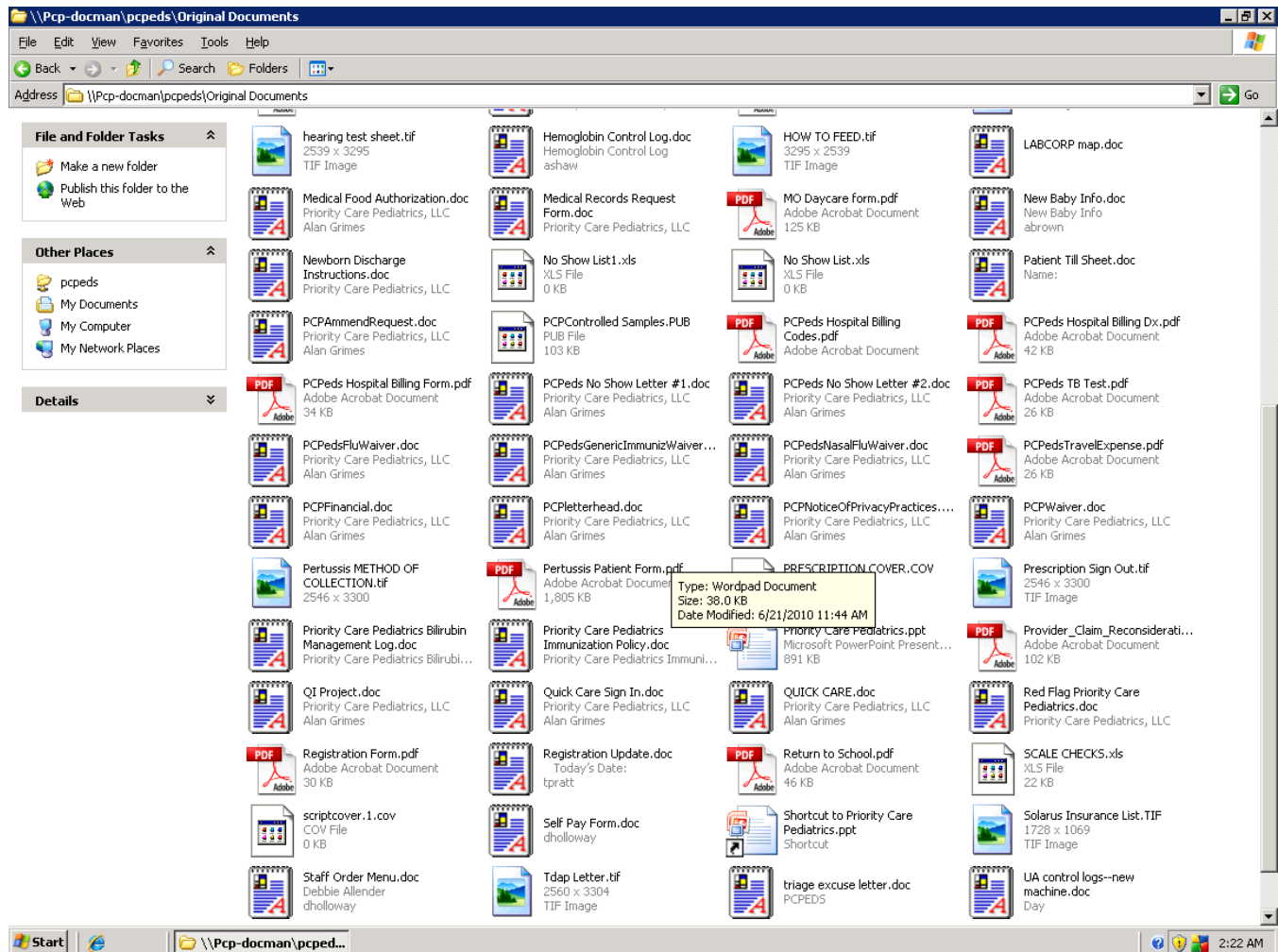
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Medical Home?



Medical Home?



Medical Home.



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AAP Medical Home Definition

A Medical Home is not a building,
a house, or a hospital...

...it is an approach to health care
that emphasizes the partnership between
pediatric clinicians and families,
providing care for children and
youth with special health care needs

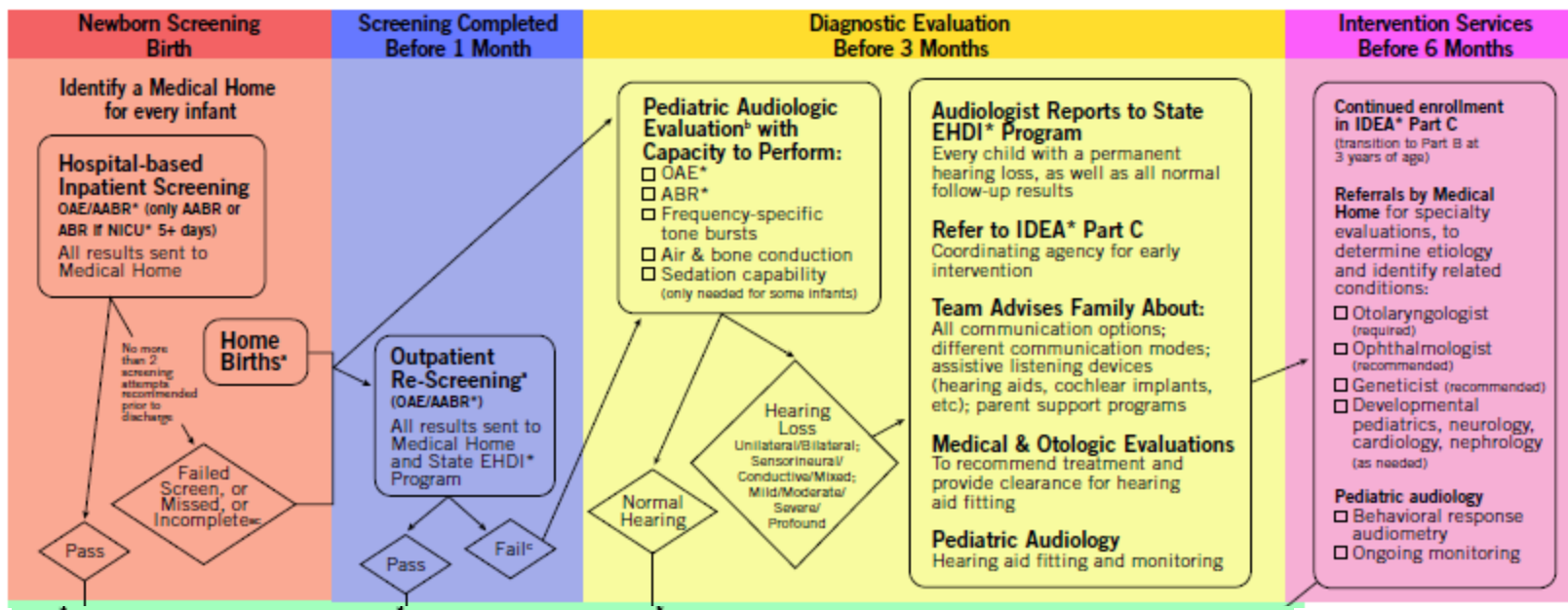
(CYSHCN) that is:

- accessible
- continuous
- comprehensive
- family-centered
- coordinated
- compassionate, and
- culturally-effective



Patient centered goals are formed in partnership with a care provider to enhance **care co-ordination** of services and health outcomes that are **safe, equitable, effective, and culturally sensitive.**

Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers



Ongoing Care of All Infants^d; Coordinated by the Medical Home Provider

- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Provide vision screening (and referral when indicated) as recommended in the AAP "Bright Futures Guidelines, 3rd Ed."
- Provide ongoing developmental screening (and referral when indicated) per the AAP "Bright Futures Guidelines, 3rd Ed."
- Refer promptly for audiology evaluation when there is any parental concern[‡] regarding hearing, speech, or language development
- Refer for audiology evaluation (at least once before age 30 months) infants who have any risk indicators for later-onset hearing loss:
 - Family history of permanent childhood hearing loss[‡]
 - Neonatal intensive care unit stay of more than 5 days duration, or any of the following (regardless of length of stay):
 - ECMO[‡], mechanically-assisted ventilation, ototoxic medications or loop diuretics, exchange transfusion for hyperbilirubinemia
 - In utero infections such as cytomegalovirus[‡], herpes, rubella, syphilis, and toxoplasmosis
 - Postnatal infections associated with hearing loss[‡], including bacterial and viral meningitis
 - Craniofacial anomalies, particularly those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies
 - Findings suggestive of a syndrome associated with hearing loss (Waardenburg, Alport, Jervell and Lange-Nielsen, Pendred)
 - Syndromes associated with progressive or delayed-onset hearing loss[‡] (neurofibromatosis, osteopetrosis, Usher Syndrome)
 - Neurodegenerative disorders[‡] (such as Hunter Syndrome) or sensory motor neuropathies (such as Friedreich's ataxia and Charcot Marie Tooth disease)
 - Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
 - Chemotherapy[‡]

February 2010 - American Academy of Pediatrics Task Force for Improving Newborn Hearing Screening, Diagnosis and Intervention (www.medicalhomeinfo.org)

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Early Hearing Detection and Intervention (EHDI)

Patient Checklist for Pediatric Medical Home Providers

Patient Name: _____

Date of Birth: ____/____/____

| | | |
|------------------------|--|--|
| Birth | Hospital-based Inpatient Screening Results (OAE/AABR) <small>(also Home Births)</small> | DATE: ____/____/____ |
| | Left ear: <input type="checkbox"/> Missed <input type="checkbox"/> Incomplete <input type="checkbox"/> Failed Screen ^{a, c} <input type="checkbox"/> Pass Right ear: <input type="checkbox"/> Missed <input type="checkbox"/> Incomplete <input type="checkbox"/> Failed Screen ^{a, c} <input type="checkbox"/> Pass | |
| Before 1 month | Outpatient Screening Results (OAE/AABR) | ____/____/____ |
| | Left ear: <input type="checkbox"/> Incomplete <input type="checkbox"/> Failed Re-Screen ^{a, c} <input type="checkbox"/> Pass Right ear: <input type="checkbox"/> Incomplete <input type="checkbox"/> Failed Re-Screen ^{a, c} <input type="checkbox"/> Pass | |
| Before 3 months | <input type="checkbox"/> Pediatric Audiology Evaluation^b | ____/____/____ |
| | <input type="checkbox"/> Hearing Loss <input type="checkbox"/> Normal Hearing <input type="checkbox"/> Document child and family auditory history <input type="checkbox"/> Report to State EHDI Program results of diagnostic evaluation <input type="checkbox"/> Refer to Early Intervention (IDEA, Part C) <input type="checkbox"/> Advise family about communication options and assistive listening devices (hearing aids, cochlear implants, etc.) <input type="checkbox"/> Medical & Otologic Evaluations to recommend treatment and provide clearance for hearing aid fitting <input type="checkbox"/> Pediatric Audiology for hearing aid fitting and monitoring | ____/____/____ ____/____/____ ____/____/____ ____/____/____ ____/____/____ |
| Before 6 months | <input type="checkbox"/> Enrollment in Early Intervention (IDEA, Part C) <small>(transition to Part B at 3 years of age)</small> | ____/____/____ |
| | <input type="checkbox"/> Medical Evaluations to determine etiology and identify related conditions <input type="checkbox"/> Otolaryngology (required) <input type="checkbox"/> Ophthalmologist (recommended) <input type="checkbox"/> Geneticist (recommended) <input type="checkbox"/> Developmental pediatrics, neurology, cardiology, and nephrology (as needed) | ____/____/____ ____/____/____ ____/____/____ ____/____/____ |
| | <input type="checkbox"/> Ongoing Pediatric Audiology Services | ____/____/____ |

Ongoing Care of All Infants^d

Provide parents with information about hearing, speech, and language milestones

Identify and aggressively treat middle ear disease

Vision screening and referral as needed

Ongoing developmental surveillance/referral

Risk Indicators for delayed-onset hearing loss:

(If risk factors are present, refer for audiology evaluation at least once prior to age 30 months)

Service Provider Contact Information

Pediatric Audiologist:

Early Intervention Service Coordinator:

Other:

Other:

Other:

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss (or loss to follow-up) also may be referred directly to Pediatric Audiology.

(b) Part C of IDEA* may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Even infants who fail screening in only one ear should be referred for further testing of both ears

(d) Includes infants whose parents refused initial or follow-up hearing screening.

OAE = Otoacoustic Emissions
 AABR = Automated Auditory Brainstem Response
 ABR = Auditory Brainstem Response
 IDEA = Individuals with Disabilities Education Act
 EHDI = Early Hearing Detection & Intervention

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.



Medical Homes

The screenshot displays the e-MDs Chart - agrimes software interface. The top navigation bar includes icons for Run, Tracking Board, Chart, TaskMan, Schedule, Order Tracking, Bill, Template Editor, and Code Linker. The main window title is "e-MDs Chart - agrimes". Below the title bar, there are menu options: File, Demographics, Reference, Tools, Reports, and Help. The "Current Chart" dropdown shows "ZzzLightyear, Buzz". The patient information bar displays "ZzzNewbaby, Ima DOB: 02/02/2011 12 day female \$ %". A toolbar contains various icons for Reminders, Visit / HS, Chart View, FlowSheets, and other functions. The interface is divided into several panels:

- Health Summary:** Includes expand/collapse options and font settings. It features a "Current Problems" section with a "Detail View" tab and a "Current" radio button selected. Below this is a large empty box for notes or images.
- Allergies - NKDA Reviewed 2/14/2011 2:29:11 AM:** Shows a "NKDA" status with "Current" and "Past" radio buttons. A text box indicates "Last Reviewed on 02/14/2011 02:29:11 AM by Grimm".
- Medications:** Shows "NKM" with "Current" and "Past" radio buttons.
- Doctor's Note [Contains shortcut]:** Contains a detailed note with sections for "Procedures", "ASSESSMENT", and "PLAN".

Procedures:

- Well child exam
- Newborn Metabolic Screening: Results from the screening are not yet available.
- Newborn Hearing Screening: Results from the screening are not yet available.
- Screening for depression

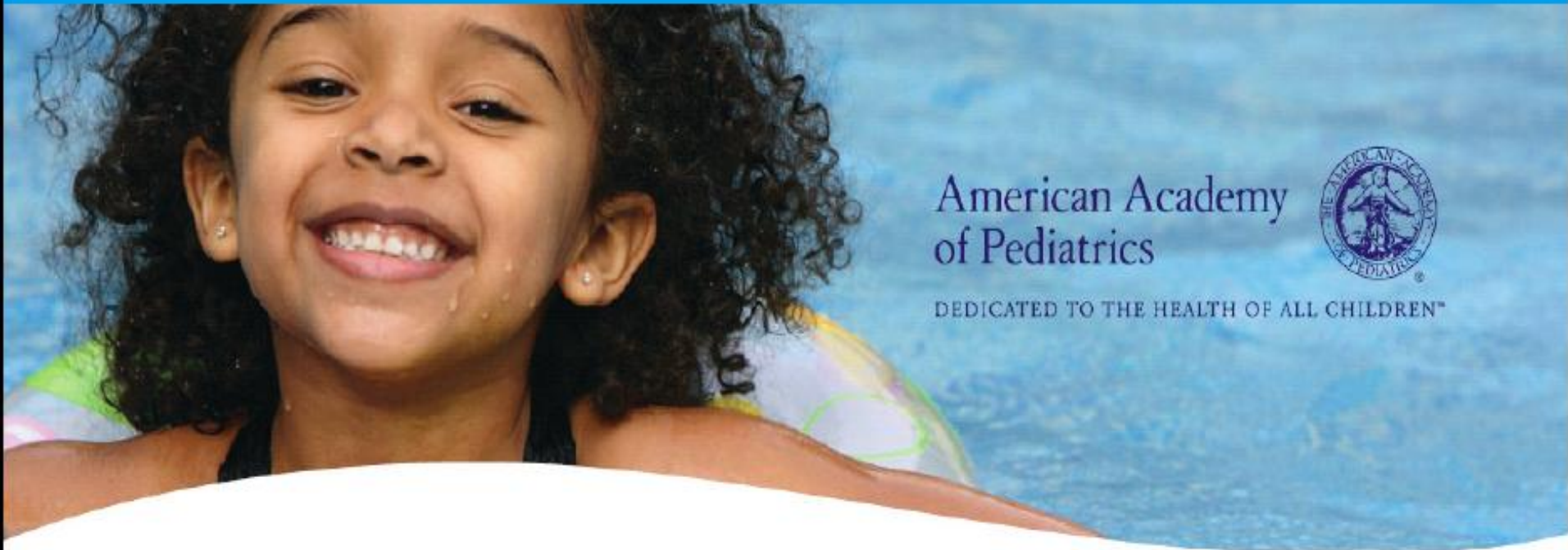
ASSESSMENT:

- v20.2 Well child exam
DDx:
- v79.0 Screening for depression
DDx:

PLAN:

- Well child exam
- RECOMMENDATIONS: Vitamin D supplementation (for BF infants).
- ANTICIPATORY GUIDANCE: was given on the following topics: safety (i.e. signs of illness to watch for; car seats; supine sleeping position; appropriate toy selection; water thermostat setting; avoidance of shaking the baby; effects of passive tobacco smoke; recommended immunizations for parents), nutrition (i.e. proper amount of feeds; avoid addition of solid foods until 4 months of age), and development (i.e. upcoming developmental advances, such as sleeping a bit less, becoming more alert, increased vocalization, and increasing head control; importance of talking to baby).
- FOLLOW-UP: Schedule a follow-up visit in 2 months.
- Immunizations typically due for the next visit were listed for the family's review and are DTaP-Hib-IPV, Hepatitis B, Pneumococcal, and Rotavirus. The parents/guardians were advised to check on insurance benefits prior to the next well child exam.
- Prescriptions:
- Orders:
99391 Periodic comprehensive preventive medicine E&M, established patient, age <1 year (In-House)
NBSNED Newborn Metabolic Screen results are needed. (Send-Out)
NHSNED Newborn Hearing Screen results are needed
- Patient Education Handouts:
Well Child Exam, 2 weeks, Breast Fed
- Screening for depression
Edinburgh Postnatal Depression Scale scoring: 0-9: Screening is normal; continue routine care.
- Prescriptions:





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Title V Perspective: *the Medical Home in state systems*

Debra Waldron, MD, MPH, FAAP



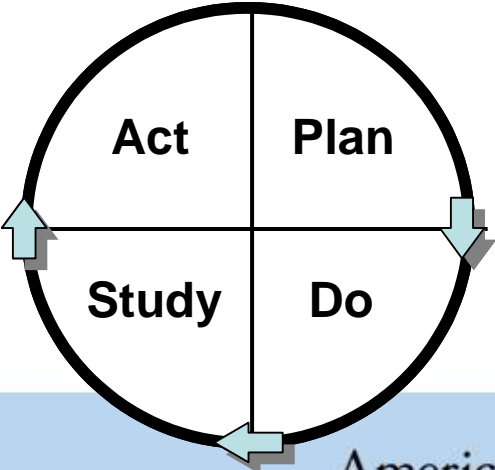
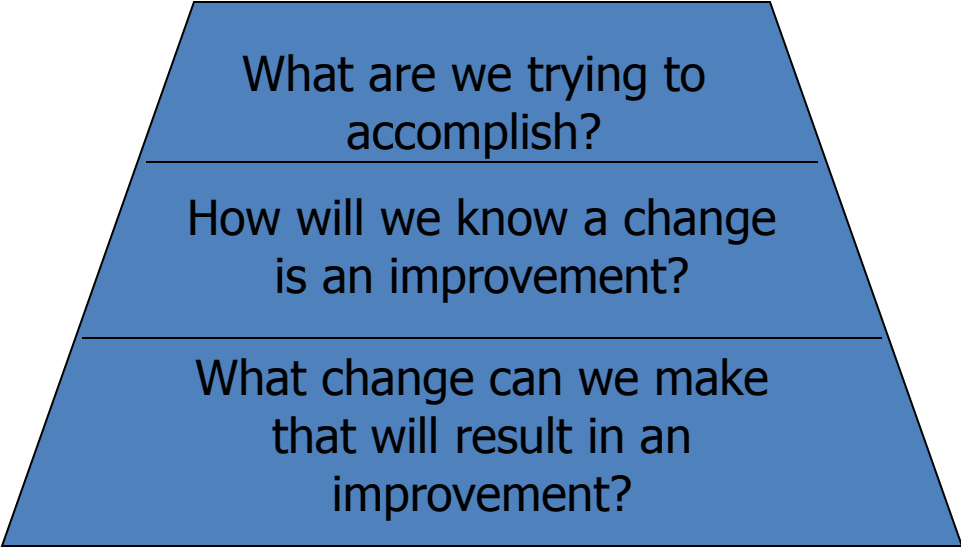
NICHQ – NBHS, LC B

- National Initiative for Children's Healthcare Quality (NICHQ)
- Newborn Hearing Screening (NBHS)
- Learning Collaborative B

NICHQ Overview

- Improve the **health and well being** of Children and Youth with Special Health Care Needs (CYSHCN) and their families through building the capacity of state Title V programs—in concert with other state based partners—to **create and sustain effective community based systems of care**
- Use **real world case studies** to identify opportunities for improvement in their system of care
- Use **state level resources** to facilitate improvement in these areas
- Use the **Model for Improvement**
- Engage **parents** in this work and embed strategies to **measure and address** disparities in care and outcomes throughout the process.

Model for Improvement



Role of Clinical Teams

- Meeting Facilitation
- Day to day Project Management
- AIM statement development
- Included:
 - Parents
 - Audiologists
 - State EHDI Coordinators
 - PCPs
 - Nurses
 - Other specialties
 - AAP EHDI Chapter Champion



Role of Title V

- Provide Technical Support and resources to facilitate improvements at the clinical level
- Work with state teams to develop approaches (policy) to facilitate state level system change
- Be informed by clinical teams of statewide issues
- Identify resources; MH providers
- Remove barriers
- Spread system change state-wide

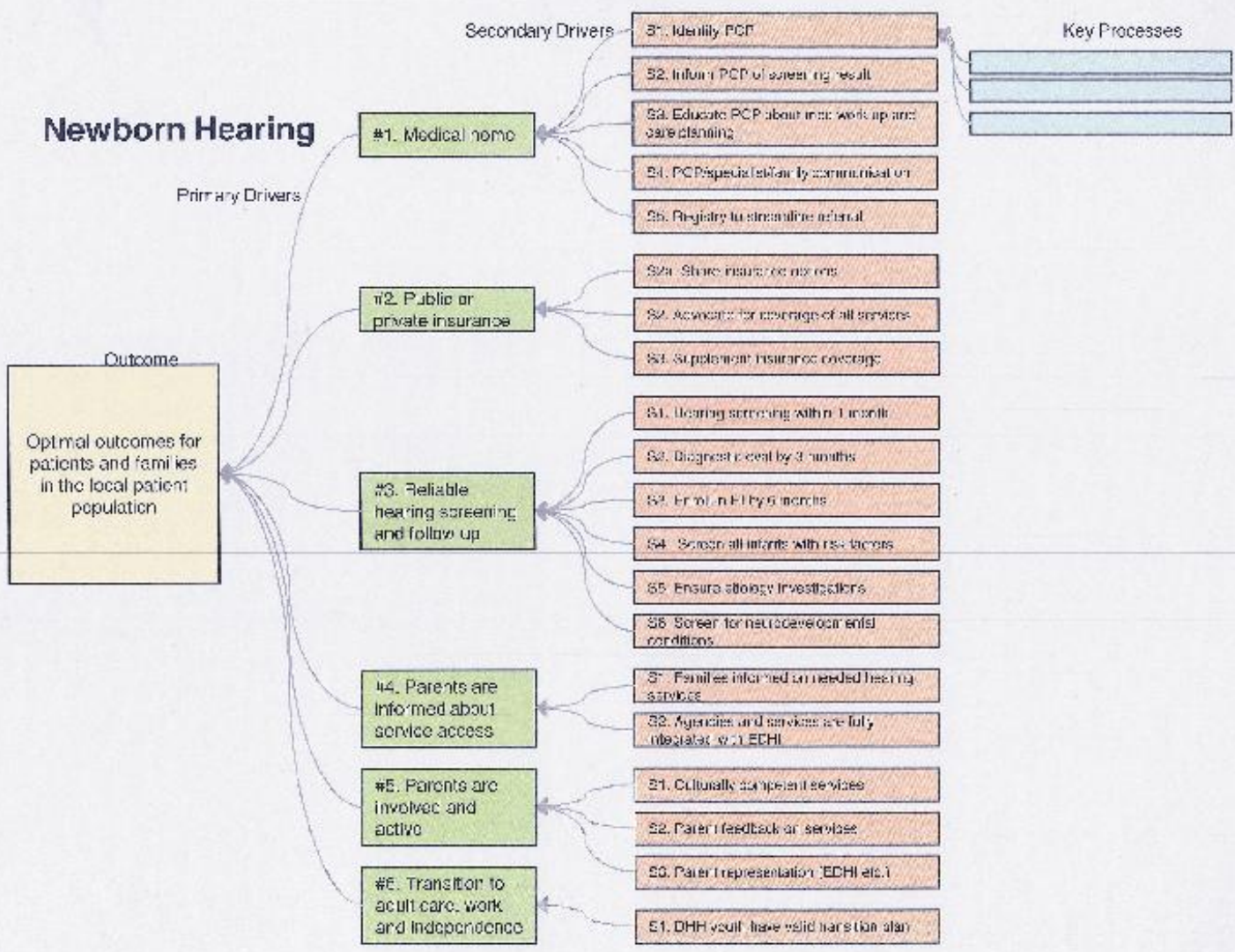
Aim Statement: To have state systems that are capable of creating and sustaining integrated systems of care for children with special health care needs as indicated by the 6 core MCHB outcomes.

| Preparation | Preliminary action steps | Implementation | Mastery | Sustainability |
|--|---|---|---|--|
| <p>1. Strategic leadership: A strategic plan for the Title V program has been established.</p> | The strategic plan has been shared and communicated across the Title V program. | The will and trust for realizing the strategic plan has been established within the Title V program and key stakeholders and partners. | The strategic plan is embedded within the Title V program. A number of goals associated with the strategic plan have been achieved and long term plans for sustaining these achievements are being developed. | Goals associated with the strategic plan are met consistently. Lessons learned are shared and acted on across the Title V program in an environment of mutual trust. Plans for the long term sustainability of the goals are being executed. |
| <p>2. Partnerships across public and private sectors: The Title V program strategic plan includes areas that are specific to partnerships across public and private sectors/constituency.</p> | Key public and private sector constituencies have been identified and initial relationships have been established. | A number of programs have begun to partner effectively with key public and private sector constituencies. | A number of targets in the Title V strategic plan have been met in partnership with key public and private sector constituencies. | Partnerships with key public and private sector constituencies have been sustained and have led to the realization of relevant targets in the Title V program strategic plan. |
| <p>3. Quality Improvement: The Title V program strategic plan includes areas that are specific to quality improvement.</p> | The quality improvement strategic plan has been shared and communicated across key stakeholders and partners | A number of quality improvement projects, in partnership with key stakeholders, partners and families are underway. | A number of quality improvement projects, in partnership with key stakeholders, partners and families have achieved positive results. | Quality improvement is embedded in all programs and process. Sustained results have been achieved. Lessons learned are consistently shared across key stakeholders, partners and families. |
| <p>4. Use of available resources: The Title V program understands the need to maximize the use of available resources.</p> | The Title V program is cognizant of available resources, including financial, personnel skill sets and knowledge systems. | Are actively engaged in maximizing productivity in some system of care areas by directly or indirectly influencing available resources. | Has achieved some success in achieving targets by directly or indirectly influencing available resources effectively. | Available resources are consistently levered so as to maximize the likelihood that the targets associated with the overall strategic plan are achieved. |
| <p>5. Coordination of service delivery: The Title V program strategic plan includes areas that are specific to service coordination.</p> | Have identified where there are gaps in the provision and coordination of services. | Plans are in place to reduce gaps in the provision and coordination of services. | Some success has been achieved in reducing gaps in the provision and coordination of services. | Rapid improvements in service and coordination are consistently realized in partnership with key stakeholders and families to remove these. |
| <p>6. Data Infrastructure: The Title V program strategic plan includes areas that are specific to data infrastructure.</p> | The need to establish effective data systems has been communicated across key stakeholders and partners. | A number of data systems have been established. | A number of data systems exist and are routinely used to share system of care performance information across key partners and stakeholders. | Information of the whole system of care is shared routinely across key partners and stakeholders in a manner that informs the knowledge and actions required to meet the targets of the overall strategic plan of the Title V program. |

This Index was developed by NICHQ as part of the Learning Collaborative "Improving the System of Care for Children and Youth with Special Healthcare Needs"

Process Phases & Change Strategies

1. Screening
2. Refer to audiology and notify Medical Home
3. Confirmation of hearing loss
4. Identify etiology
5. Treatment/amplification
6. Enroll in EI/EA



6 Primary Drivers



1. All CSHCN receive coordinated on going, comprehensive care in a medical home
2. All families of CSHCN have adequate private and insurance to pay for the services they need
3. All children are screened early and continuously for special needs
4. Services for CSHCN are organized in ways families can easily use
5. Families of CSHCN partner in decision-making at all levels and are satisfied with services they receive, resulting in active, well-informed patients and families
6. All youth with special healthcare needs receive the services necessary for transition to adult health care, work and independence



Primary Driver #1: All CSHCN receive coordinated on going, comprehensive care in a **medical home**

Secondary Drivers

- S1. Identify PCP
- S2. Ensure PCP has results of hearing screen and diagnostic tests
- S3. Educate PCP about medical work-up and care planning for infants with hearing loss *
- S4. Streamline communication between PCP-specialists and family *
- **S5. Registry of DHH children is used to streamline referral processes and ensure families receive all needed services ***



S3. Educate PCP about medical work-up and care planning for infants with hearing loss

- **PC3a.** provide “just in time” information to PCP/MH about follow up for infants who “did not pass” the newborn screen; use standardized evidence-based materials; provide outreach with phone call to practice offering guidance and support
 - **T3a(i).** Assure “just in time” information to PCP/MH about follow up for infants who “did not pass” the newborn screen
 - **T3a(iv).** Integrate MH EHDI work with other CYSHCN/MCH MH related activities – create interface with MCH to impact other MH initiatives occurring in state (NCHAM Goal Bank).



S4. Streamline communication between PCP-specialists and family.

- **C4a.** PCP office confirms follow-up appointment for diagnostic audiology with parents at time of first newborn PCP/MH visit; stress it's importance.
 - **T4a(i).** Assure appointment follow-up e.g. to audiologist, ENT as part of EHDI tracking system.
- **C4b.** Agree on minimum content of referral and response letters e.g between audiologist and PCP and use templates
 - **T4b(i).** Convene consortium of stakeholders including families and professional organizations to create and distribute best practice guidelines; template agreements, office-based practice improvements, standardized tools (care map/ care summary etc.)



S4. Streamline communication between PCP-specialists and family. - Continued

- **C4c.** Build service agreements, co-management plans, between primary and specialty care (ENT/ORL, audiology, genetics, ophthalmology, EI); include core competencies, referral guidelines, communication and expectations for access to one another.
 - **T4c(i).** Develop and make available to practices service agreements, co-management and practice management tools.
 - **T4c(ii).** Work with Medicaid and private payers to establish mechanism for coverage of collaborative visits.
 - **T4c(iii).** Provide or support care coordination to facilitate shared visits as needed.
 - **T4c(iv).** Work with Hands and Voices, Family to Family Health Information Centers to get buy-in of family leaders and familiarize families with co-management concept.
- **C4d.** Families of DHH children sign universal consent form allowing sharing of information (HIPAA-FERPA) between PCP, audiology, family, EI and state EHDI program at time of referral to EI.
 - **T4d(i).** Develop shared consent form /MoU/ /Interagency agreements to streamline data sharing between EHDI, PCP and EI.



S4. Streamline communication between PCP-specialists and family. - Continued

- **C4e.** Use standardized process, fax-back, phone call, etc. to communicate EI enrollment information and care plan to the PCP/MH within 2 days of IFSP.
 - **T4e(i).** Convene consortium of stakeholders including families and professional organizations to create and distribute best practice guidelines; template agreements, office-based practice improvements, standardized tools (care map/ care summary etc.)
- **C4f.** Parents have copies of case summary, care plans, medication lists in care notebook.
 - **T4f(i).** Develop in collaboration with families and providers standardized tools/templates like care maps/ care plans and care summary and make available to providers and parent organizations.



S5. Registry of DHH children is used to streamline referral processes and ensure families receive all needed services.

- **C5a.** Create and use a registry for infants with hearing loss; create a “worry list” monthly of those infants with no screening results, and all “did not pass” with no diagnostic results or not enrollment in EI
 - **T5a(i).** Establishes and maintains statewide EHDI data collection and tracking system. Data system supports referrals to follow up services. Assures monitoring of follow up and referral to other services.
- **C5b.** Eliminate ambiguity; establish accountability for who is responsible for following infant; may vary by state.
 - **T5b(i).** Eliminate ambiguity; establish accountability for who is responsible for following infant; may vary by state. Roles and responsibilities delineated in best practice guidelines, administrative rules.
- **C5c.** Provide active “outreach” at first system failure e.g. non-attendance at audiology appointment.
 - **T5c(i).** Outreach to families and providers of infants on “worry list” as determined by statewide data collection and tracking system





Screen
no later
than **1**
month

Diagnose
no later
than **3**
months

Intervene
no later
than **6**
months

EHDI "1-3-6" National Strategy



The CDC EHDI program is the identified source to report on progress towards the

Healthy People 2020

EHDI "1-3-6" Objectives



EHDI – National “1-3-6” Goals

1. All newborns will be screened for hearing loss no later than **1** month of age, preferably before hospital discharge.

Target: 90.2%: *Healthy People 2020*

2007 Baseline Measure: 82% (Topic 20-ENT-VSL-1.1)

2. All infants who screen positive will have a diagnostic audiologic evaluation no later than **3** months of age.

Target: 72.6%: *Healthy People 2020*

2007 Baseline Measure: 66% (ENT-VSL-1.2)

3. All infants identified with hearing loss will receive appropriate early intervention services no later than **6** months of age (medical, audiologic, and early intervention).

Target >55.0%: *Healthy People 2020*

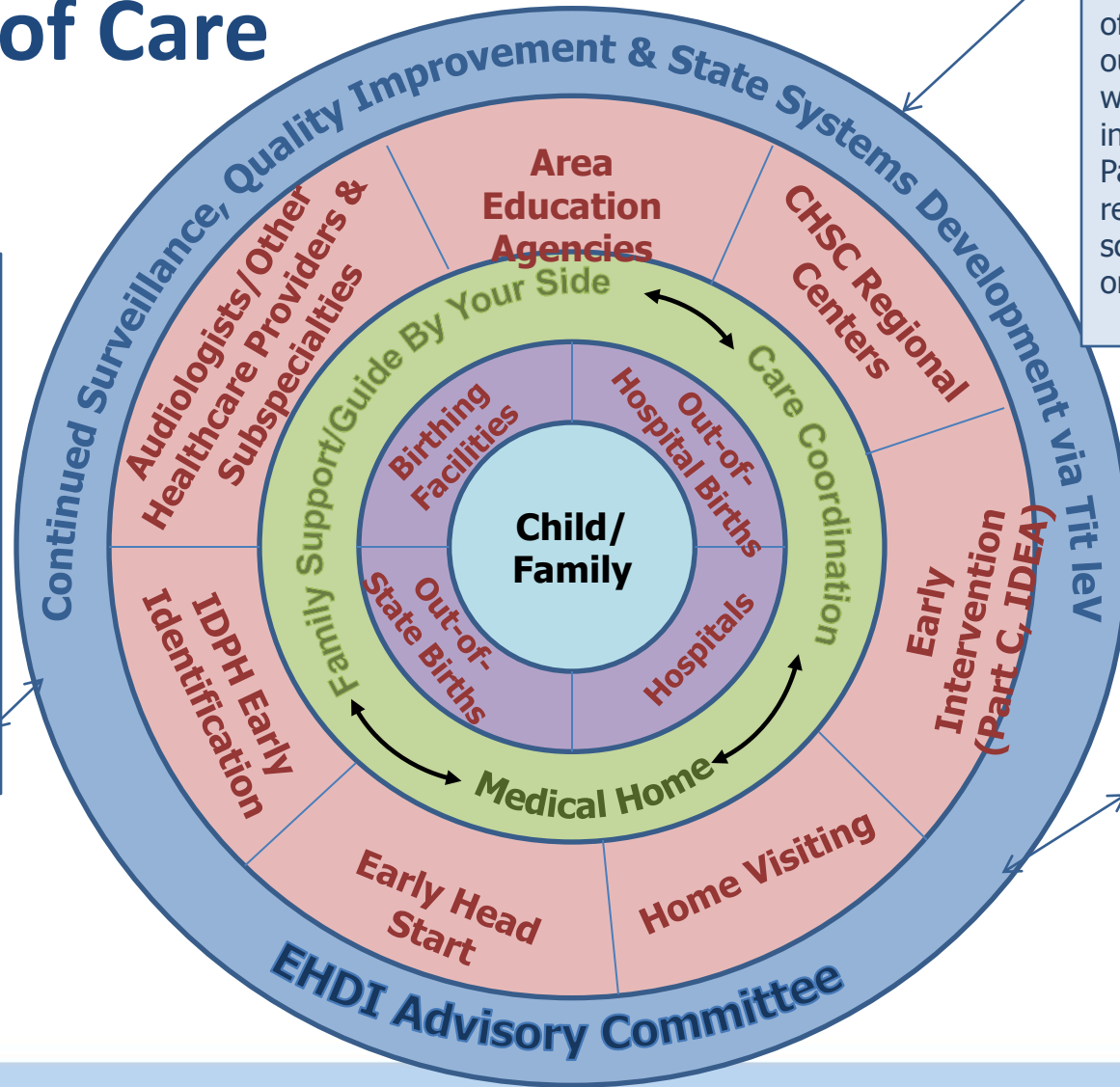
2007 Baseline Measure: 50% (ENT-VSL-1.3)



Iowa EHDI System of Care

GOAL 3:

By March 31, 2014, 95% of children 0-3 years of age with documented hearing loss will have access to the community-based services they need and their families choose, in a timely, efficient, effective, and family centered manner.



GOAL 1:

By March 31, 2014, 95% of Iowa infants (including out of hospital births) who miss, had incomplete, or Did Not Pass the birth screen, will receive screen and re-screen (if necessary) by one month of age.

GOAL 2:

By March 31, 2014, 95% of children 0-3 years of age who Did Not Pass two screens and/or have any risk indicators for late onset hearing loss (as defined by JCIH) receive the follow-up care they need, including care coordination and family support, within a medical home.

Iowa Medical Home Implementation Team (MHIT)



- **Goal 1:** Iowa infants (*including out of hospital births*) who miss, had incomplete, or did not pass the birth screen, will receive screen and re-screen (*if necessary*) by **1** month of age.

– Objectives:

- early screening standards met
- protocols for timely reporting
- promote importance
- provider education.



Iowa Medical Home Implementation Team



- **Goal 2:** Children 0-3 years of age who did not pass 2 screens
 - and/or have any risk indicators for late onset hearing loss (as defined by JCIH)
 - receive the follow-up care they need, including care coordination and family support,
 - within a medical home
- **Objectives:** PCP knowledge; referral guidelines and communication; care coordination; family support.



Iowa Medical Home Implementation Team



- **Goal 3:** Children 0-3 years of age with documented hearing loss will have access to the community-based services they need and choose, in a timely, efficient, effective, and family centered manner.
 - **Objectives:** enhanced collaboration; audiologic followup diagnostics and amplification (if parent choice); enrolled in early intervention; family support services.



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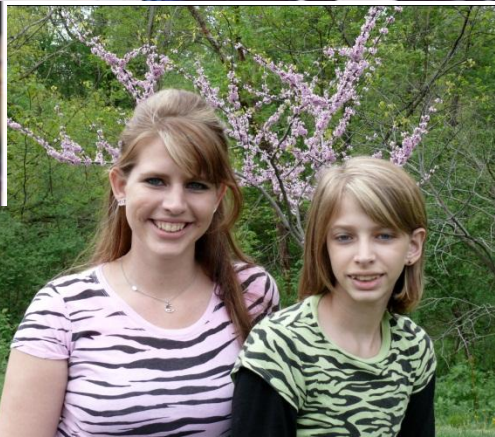
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Parent Perspective: *What do parents want/need?*

Vicki Hunting, Parent
Co-President Iowa Hands & Voices

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Stephanie's Journey

Screen by 1
Month

- Born May 2, 1991; 6 lbs., GBS at birth, oxygen, gentamycin, blood transfusion
- Hospital discharge at 2 weeks old; 5 days NICU, 5 days regular nursery
- No newborn hearing screening, even with risk factors

Diagnosis by
3 months

- 4 months addressed concerns with Pediatrician
- Many attempts to get appointments with ENT, and audiologists

EI by 6
months

- 5-6 months; unsuccessful ENT appointments
- 7 months; initial ABR, indicated loss, fluid,
- 8 months 1st hearing aid
- 8 months; enrolled in Early Intervention, itinerant Teacher of the Deaf home visits began

6 months &
beyond

- 8 months to 2 years; auditory verbal communication, weekly TOD visits
- 2 years; added sign language Signed Exact English (SEE)
- 2 years; began all day in regional day school for the deaf in Total Communication
- 4 years CI, continued sign language, added back auditory verbal
- 2-10 years; school used sign language interpreter
- 10 years old dropped sign language interpreter



What to consider...

- Professionals come and go
- Grief
- Time to digest the information
- Avoid telling us what to do
- Encourage us to take ownership in the decision

A Survey

- ◎ **80%** identified before 3 years old, kids now 5 years old
- ◎ **90%** had bi-lateral loss
- ◎ Majority had significant loss in at least 1 ear, mild to profound
- ◎ Connected to resources and other parents
- ◎ No socio-economic status gathered
- ◎ Professional; Audiologists, Pediatricians, TOD, Gen Ed teachers, EA/EI, SLP, etc.

Crawford, L. *What Do Parents Have To Say About Professional Bias*, Texas Hands & Voices
http://www.handsandvoices.org/articles/parent_pro_collab/V12-4_parprobias.htm

Survey Results

- ◎ **50%** felt they received complete/balanced info about all *communication* options and *educational* programs?
- ◎ **63%** said that professionals did not suggest parents *talk with other* kinds of professionals to learn more
- ◎ **55%** not easy to learn about different communication options
- ◎ **62%** not easy to learn about educational choices

Results continued...

- ◎ **78%** felt they had flexibility to try multiple options and could change their minds
- ◎ Learned on their own or from other parents about controversies in **education** & **communication** options
 - > 10% not aware
 - > 37% learned from professionals
- ◎ **91%** parents **felt in control** of making decision
 - > 92% were happy with their decision
- ◎ **9%** felt professionals in control
 - > 31% not happy with decisions
 - > 62% did not know!

Summary of Challenges

- ◎ Over 50% of children still not being identified before 6 months
- ◎ Only 50% of parents feel they are receiving complete and balanced information
- ◎ Professionals refer parents to other professionals/programs for information only 37% of the time.
- ◎ 55-61% of parents did **not** think it was easy to learn about options. * *This does not mean they were not told - but it implies the information was not understandable. (This relates to challenges identified in the Joint Committee on Infant Hearing 2007 Position Statement)*

The GOOD NEWS

- ◎ **78%** of parents feel like they have/had flexibility to explore options
- ◎ **91%** feel like they are in control of the decisions being made for their child
- ◎ **Parent to parent support is working!**
 - > **80.8 %** of parents list this as the *most helpful way* in which to receive information.

Survey Conclusions

- ◎ Challenges remain - (JCIH 2007) - "*There is a failure to communicate information to families in a culturally sensitive and understandable format*"
- ◎ *Don't limit the information* given to parents, but make sure it is understandable.
- ◎ What contributes to parents not understanding information?
 - Conflicting biased information from professionals, deaf and hard of hearing community members and other parents.

Getting to Success Through Parent Involvement

Parent involvement provides:

- Unique perspective of a vested stakeholder
- Motivated and personal commitment to improvement of the system
- Systems that are appropriate for and acceptable to families
- Better outcomes for kids
- Parent tested

Hands & Voices Style of Parent-to-Parent Support

- Emotional support & mentoring “*We’ve been there*”
- A way to share information, experiences
- A safe place to brainstorm and express feelings
- A sounding board for the choices you are making
- Feedback, Input, Validation, & Non-judgmental support
- Exposure to diverse models
- Support for diverse communication choices
- Accessibility to a strong network
- A network that includes professionals as partners
- Uniting in Strength...Creating the Power to Change

What Parents Want...

- Freedom from misinformation

"There is no test that confirms hearing loss until 6-8 months of age"

"Don't worry, kids grow at different levels/rates"

"You don't have to do anything about this for 6 months or a year"

"It's probably just a little fluid, let's wait and see there's no hurry."

"A cochlear implant will cure this."

"I can tell you right now there is nothing wrong with her hearing, she's babbling."

"If you sign to a child with a CI they won't learn to listen."



What Parents Want...

- **A partnership**
 - Trust must be established
 - Dismantling the barriers of past experiences
 - Physicians and parents understand one another's role
- **Basic Information**

Parent Quote: *"We have learned to be more assertive and insist upon being part of our son's medical team. Any physician or health professional who does not see us as such gets removed from the team."*



What Parents Want...

- Medical information/implications regarding hearing loss
- A Sensitivity to the complexity of the decisions parents make regarding communication choices & education.
 - deafness is different (consider their experience outside the “medical” domain)



Parent's Wish List

We wish for:

1. ...Partnership
2. ...Honesty
3. ...Information
4. ...Amplification Choices
5. ...Communication Options

DesGeorges, J. *A Parent's Wish List for Audiologists: The Parent Perspective*, Hands & Voices (2009)
http://www.handsandvoices.org/articles/parent_pro_collab/wish_list.html

Parent Quotes

I wish that...

- *"...my health professional would read prior information on my child's hearing before we sat down with them"*
- *"...as part of every audiologists training and in every appropriate situation, they have an opportunity to learn from parents of deaf/hh kids. Parent/family perspective"*
- *"...my Audiologist would realize that what my son can hear in a sound proof booth is not what they hear in their classroom or the outside world"*
- *"...my Audiologist would not pretend everything was o.k. or sugar coat the results. Give me the reality and let me figure out how to handle the information"*
- *"...Audiologists would be informative and unbiased."*
- *"...healthcare professionals would listen to us parents - be open to accept the experience of a 'non-professional'"*

Conclusions

- There is still work to be done
- Continue work on defining what a MH is for children with a hearing loss
- Realistic and flexible models
- Ensuring MH model works from family point of view



Be a Champion

*“Act as if what you do
makes a difference. It
does.”*

– William Jones



*In the end, it's not just about
the choices
we made for our children,
but how we
fostered their ability
to make the
right choices for themselves,
and then honored their
choices...*

*Leanne Seaver, Parent
Executive Director,
Hands & Voices*

Resources



- AAP - National Center for Medical Home – EHDI
http://www.medicalhomeinfo.org/how/clinical_care/hearing_screening/
- AAP-EHDI-Medical Home Checklist (The Road Map)
http://www.medicalhomeinfo.org/downloads/pdfs/Checklist_2010.pdf
- AAP-EHDI-Medical Home Guidelines (The Road Map)
http://www.medicalhomeinfo.org/downloads/pdfs/Algorithm1_2010.pdf
- Hands & Voices
http://www.handsandvoices.org/articles/articles_index.html#parents



Pediatrics Supplement August 2010

- Shirley A. Russ, Denise Dougherty, & Padmini Jagadish **Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss** Pediatrics 126: S7-S18.
- Shanna Shulman, Melanie Besculides, Anna Saltzman, Henry Ireys, Karl R. White, and Irene Forsman **Evaluation of the Universal Newborn Hearing Screening and Intervention Program** Pediatrics 126: S19-S27.
- K. Todd Houston, Diane D. Behl, Karl R. White, and Irene Forsman **Federal Privacy Regulations and the Provision of Early Hearing Detection and Intervention Programs** Pediatrics 126: S28-S33.
- Margaret A. McManus, Ruti Levtoy, Karl R. White, Irene Forsman, Terry Foust, and Maureen Thompson **Medicaid Reimbursement of Hearing Services for Infants and Young Children** Pediatrics 126: S34-S42.
- Stephanie J. Limb, Margaret A. McManus, Harriette B. Fox, Karl R. White, and Irene Forsman **Ensuring Financial Access to Hearing Aids for Infants and Young Children** Pediatrics 126: S43-S51.
- Melissa McCarthy, Karen Muñoz, and Karl R. White **Teleintervention for Infants & Young Children Who Are Deaf or Hard-of-Hearing** Pediatrics 126:S52-S58.
- Shirley A. Russ, Doris Hanna, Janet DesGeorges, and Irene Forsman **Improving Follow-up to Newborn Hearing Screening: A Learning-Collaborative Experience** Pediatrics 126: S59-S69.

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