

Accelerating Evidence-Based Recommendations into Practice for the Benefit of Children with Early Hearing Loss

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- No conflicts of interest.
- The findings and conclusions in this presentation have not been formally disseminated by any Federal Agency and should not be construed to represent any agency determination or policy.

USPSTF Position Statement



- USPSTF now Recommends Hearing Screening for all newborns.
- Improved outcomes depend on effective follow-up, diagnosis, and management as well as screening.

Evidence-Based Recommendations

- Many groups have issued recommendations concerning newborn screening and follow-up.
- Substantial gaps in recommendations vs. practice e.g.
 - loss to follow up after screening.
 - delayed diagnostic evaluations.
 - geographic variation in family access to intervention services.
 - lack of outcomes data



How can we accelerate the movement of recommendations into practice in order to close these gaps?

AHRQ Workshop

- January 2008, US Dept HHS held an invitational workshop.
- AHRQ, HRSA (MCHB), NIDCD, NICHD, CDC with HHS OD and Dept Education all represented.
- Representation from DHH communities and from parents of children with hearing loss across a range of communication modalities.
- >50 attendees.-audiologists, interventionists, pediatricians, educators.

Areas of Expertise



- Researchers.
- Clinicians.
- Public Health.
- Evidence Evaluation.
- Information Technology.
- Knowledge Transfer.
- Quality Improvement.
- Family Advocacy
- Cultural Competence

Goals

- Set priorities among existing recommendations.
- Identify areas with most potential for immediate improvement.
- To create an actionable national blueprint for roles and responsibilities in systems improvement for children identified with early hearing loss.

Getting to “How?”

The Right Care for the Right Children at
the Right Time.

Pre-Work

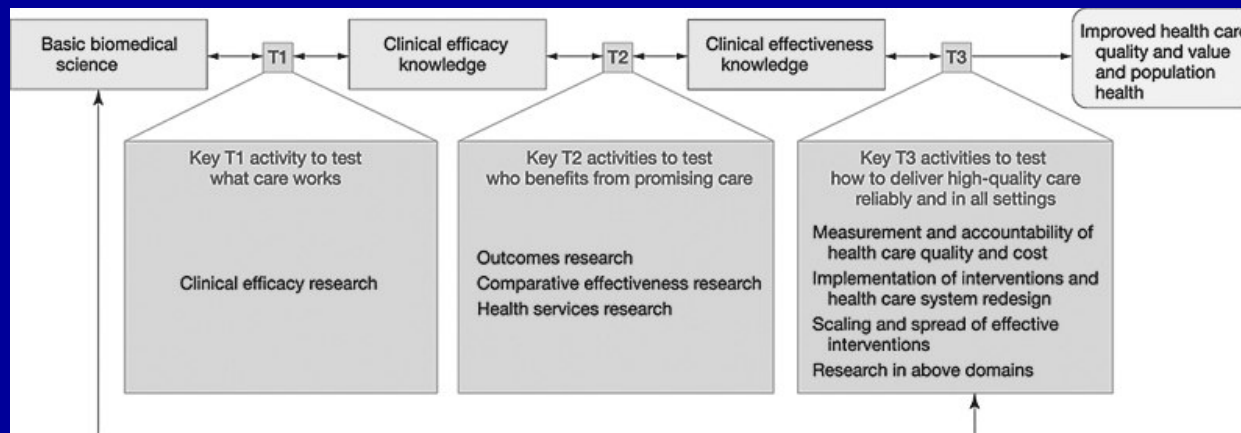
- Reviewed existing literature, reports e.g. JCIH, Mathematica, NIDCD Workshops etc.
- Identified 160 recommendations in 4 domains
 - Diagnosis and evaluation
 - Treatment and intervention
 - Parent resources and public awareness
 - Program evaluation and continuous quality improvement.

Pre-Work

- Modified Delphi process.
- Participants asked to prioritize their “top 5” recommendations in each of the 4 domains.
- Top 2-3 in each domain discussed in detail at workshop.

3Ts Roadmap to Transform US Health Care

Dougherty & Conway JAMA 2008; 299: 2319-2321



3Ts Roadmap to Transform US Healthcare

- T1-Translation of basic science to clinical research e.g. development of the prototype cochlear implant.(Volta 1800-Clark 1974)
- T2- Clinical Outcomes Research e.g. language outcomes after implantation.
- T3- Quality Improvement Strategies e.g. ensuring high quality implant programs are available for and offered to all children that might benefit.

T3- The “How” of Healthcare Delivery

- Translational research
- Health Services research
- Quality improvement
- Policy development

Effective T3 -System Transformation

Existing Services	Vision for System
Paths to diagnosis and intervention variable, often delayed.	Paths direct, rapid, family-centered, transparent to parents and professionals.
Professionals work largely within own discipline, agency. Limited parent involvement.	Cross-agency, discipline communication, collaboration. Parents contribute to system design.
Limited data, of variable quality to guide system development.	High quality data to guide system development.
Limited research. Recommendations based on expert opinion. Process for moving research into practice not defined.	Solid Evidence Base. Defined process for how to move research into practice.
Variable quality of life for deaf and hard of hearing children	Excellent quality of life for deaf or hard of hearing children.

Diagnosis and Evaluation (Gravel)

- Targeted outreach to at-risk families to prevent loss to follow-up.
- Comprehensive assessment of both ears by 3 months of age by an audiologist well-trained in infant assessment.
- Comprehensive coordinated work-up by Core Team: PCP, ENT, EI, and SLP.
- EI assesses language, cognitive skills, social-emotional, auditory.
- Innovative models for rural and under-served populations.

Matrix of Responsibility

Modified Recommendation	Action Step	Professional Organization	Advocacy Groups	State/Local Education	State/Local Public Health
Reduce Loss to Follow -Up by Targeting babies in NICU for early diagnosis.					

Targeting NICU Babies for Early Diagnosis

Action Steps	Responsible Actors
Develop screening protocol for NICU babies that transfer hospitals	State EHDI programs, NACHRI, AAP, AAA
Develop protocol for diagnostic testing of babies in NICU	AAP, AAA
Parent to Parent support during diagnostic testing	EHL advocacy organizations
Create web-based resource lists -diagnostic testing sites -PCPs to facilitate contact	State or local public health agencies e.g. Title V
Develop intervention protocols for use in NICU for babies identified with hearing loss	AAP, EI agencies

Targeting NICU Babies for Early Diagnosis

Action Steps	Responsible Actors
Survey centers that perform diagnostic testing/aid fitting prior to NICU discharge	NCHA, State EHDI Coordinators
Monitor EHDI process and outcome indicators separately for NICU graduates	CDC
Create a protocol to ensure correct identification of newborn's PCP for F/U prior to discharge from newborn hospital	AAP, AAFP, NACHRI, AHA, JCAHO
Perform a nationally representative survey of current communication methods between birthing hospitals and PCPs	CDC (AUCD), AHRQ, AAP
Create centers of excellence/ expertise in newborn diagnostic testing	AAA, State or Local Public Health Agencies (Title V)

Increase Timely Access to Effective EI by Qualified Providers (Moeller)

Action Steps	Responsible Actors
Increase support for training and innovative delivery models	Advocacy Groups, State/Local Education Agencies. Fed/State/Local Health programs
Collaborate on training modules	Dept Ed, MCHB
Create best practice guidelines for EI	All, with leadership from a workgroup of professionals.
Disseminate practice guidelines and provide technical assistance for implementation	NECTAC, NCHAM, Dept of Education
Develop valid tools for monitoring and reporting developmental outcomes	NIDCD, NICHD, CDC, AAP
Request increased support for interventions	Professional alliance of AG Bell, H&V, ASHA, CDC, Easter Seals, AAP, ITCA

Support Culturally and Linguistically Appropriate Family Resources (DesGeorges)

Action Steps	Responsible Actors
Collaborate to support a forum for key stakeholders	All Advocacy Groups-AND, AG Bell, H&V, ASDC, Others
Create proactive mechanisms for offering resources to families e.g. add to HIPPA-FERPA release form	Federal/ State/Local Medicaid/ SCHIP
Track data nationally on family resources/ offers of mentoring	Federal/ State/Local Medicaid/SCHIP. Dept. Ed.
Identify resources to ensure programs are culturally competent	National Center for Cultural Competence, CDC, HRSA, Advocacy groups
Support capacity of Family Resource Centers to address hearing loss	HRSA-MCHB, Advocacy groups
Public awareness campaign on EHDI	CDC, Advocacy groups with Public Relations/ Social Marketing Groups.

Expand and Improve Information Systems

(Dougherty)

Action Steps	Responsible Actors
Track and report individual and aggregate data across all states: agree on locus of responsibility for tracking.	CDC EHDI Systems All Stakeholders
Implement consent for sharing data across agencies at time of diagnosis Support IT infrastructure that includes health and education	Departments of health and education Family Advocacy Groups
Encourage family ownership of health/ed records Design IT systems with families in mind	Advocacy Organizations Federal/ State/ Local Public Health Agencies
Proactively link data with existing systems e.g. public health, metabolic screening and immunization registries, birth certificate.	National, state and local public health agencies.

Develop Measures (Dougherty)

Action Steps	Responsible Actors
Develop agreed care process and outcome measures based on professional organization recommendations	Professional societies, advocacy groups, federal agencies
Identify program characteristics associated with high quality care and use to create relevant structural measures of quality.	CDC, State EHDI Programs
Collect and submit measures for endorsement by the National Quality Forum	JCIH with CMS, National Quality Forum
Develop standards for identified data elements	CDC works with all stakeholders

Next Steps

- Full report presented to Office on Disability and all relevant Federal Agencies.
- Paper in preparation for peer-reviewed journal.





AHRQ Funding Opportunities

Health Care: Funding Announcements Subdirectory Page, Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Search Favorites

Address <http://www.ahrq.gov/fund/grantix.htm> Go Links

Find and apply for grant programs from Federal agencies

HIPAA Privacy Rule Information for researchers and patients on use of personal health data in research projects

All PAs are published in the *NIH Guide for Grants and Contracts* (<http://www.nih.gov/grants/guide/index.html>)

AHRQ Primary Announcements

AHRQ primary announcements are those for which AHRQ is the sole sponsor of the PA.

PA Number	Title
PAR-09-087	Mentored Research Scientist Research Career Development Award (K01)
PAR-09-086	Independent Scientist Award (K02)
PAR-09-085	Mentored Research Scientist Research Career Development Award (K08)
PA-09-071	AHRQ Health Services Research Demonstration and Dissemination Grants (R18)
PA-09-070	AHRQ Health Services Research Projects (R01)
PAR-08-270	Utilizing Health Information Technology (IT) to Improve Health Care Quality (R18) Technical Assistance Conference Call: Slides and Transcript (1/13/2009)
PAR-08-269	Exploratory and Developmental Grant to Improve Health Care Quality through Health Information Technology (IT) (R21) Technical Assistance Conference Call: Slides and Transcript (1/13/2009)
PAR-08-268	Small Research Grant to Improve Health Care Quality through Health Information Technology (IT) (R03) Technical Assistance Conference Call: Slides and Transcript (1/13/2009)
PAR-08-136	Researching Implementation and Change While Improving Quality (R18)
PA-06-448	AHRQ Small Research Grant Program (R03) Extension of Expiration Date
PA-06-409	AHRQ Individual Awards for Postdoctoral Fellows (F32) Delay in Transition to Electronic Submission of Applications Extension of Expiration Date
PA-06-378	AHRQ Grant Program for Large Conference Support (R13 and U13) Special Emphasis Notice: Important Considerations for Applying for Conference Grant Support from AHRQ
PA-06-118	AHRQ Grants for Health Services Research Dissertation (R36) Grant Extended to May 8, 2010
PA-06-074	Small Grant Program for Conference Support (R13) Transition Schedule to Adobe-based Forms for SF424 R&R E-Submissions Extension of Expiration Date Special Emphasis Notice: Important Considerations for Applying for

*National Institute on Deafness and
Other Communication Disorders
NIDCD/NIH (Donahue)*

- Many active NIDCD research grants in topic areas relating to HL in infants and children
- History of investigator initiated grants as well as set-aside money to fund special initiatives focusing on urgently needed information
- Audiology, speech pathology, early intervention and medical communities are actively engaged
- An adequate pool of both funding dollars and trained researchers is required to address future needs
- Often takes years to get answers, requiring patience and perseverance...

EHDI-Related Research

- Cochlear Implants and Hearing Aids
- Auditory, Speech, Language (spoken and sign), Cognitive and Psychosocial Development after Hearing Loss
- Device Development- Diagnostics and Rehabilitation
- Behavioral Assessment and Management
- Test Development
- Genetics and Hearing Loss
- Outcomes following Interventions

Special EHDI Initiatives

- Value and seek dialogue with scientific community and federal partners for priority setting
- Set aside money to develop and support special initiatives to obtain urgently needed information
- Seeking answers to the changing issues and questions before us

Outcomes in Children with Mild to Severe Hearing Loss

Current Funding Opportunity Announcement:
“Outcomes in Children with Mild to Severe Hearing Loss” (R01) expires July 2010.

Applications should be multidisciplinary and have a primary focus on determining the impact of intervention, child, and family factors on communicative, educational and social development outcomes in young children with mild to severe hearing loss.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-394.html>

Young Children with Mild to Severe Hearing Loss

Current Funding Opportunity Announcement:

“Young Children with Mild to Severe Hearing Loss” (R01 and R21) expires July 2010.

- Developmental research questions and/or the development of measurement tools for infants and young children with mild to severe hearing loss.
- <http://grants.nih.gov/grants/guide/pa-files/PA-07-399.html>
- <http://grants.nih.gov/grants/guide/pa-files/PA-07-400.html>

Research on Mild and/or Unilateral Hearing Loss

Current Funding Opportunity Announcement:

“Young Children with Mild to Severe Hearing Loss”
(R01 and R21) expires Nov 2009.

- Understanding of mild and unilateral hearing loss in infants and young children. This includes research on prevention, better diagnostic methods, and treatments for these forms of hearing loss that are often overlooked or minimized.
- <http://grants.nih.gov/grants/guide/pa-files/PA-07-038.html>
- NIDCD CONTACT: Dr. Dan Sklare sklared@nidcd.nih.gov

CDC EHDI and AUCD*

FY 2008: “Developmental Outcomes Feasibility Study”

University of Colorado (Yoshinaga-Itano & Gabbard)

The purpose of the National Early Childhood Assessment Project (NECAP) is to develop data management systems capable of collecting and reporting developmental outcomes of infants/children identified through the hearing screening programs

States that have are committed to collection of developmental outcome data include: Arizona, California, Colorado, Florida, Idaho, Indiana, Louisiana, Minnesota, New Mexico, North Carolina, Oklahoma, South Carolina, Utah, Wisconsin, and Wyoming

*** Association of University Centers on Disabilities**

CDC EHDI and AUCD

FY 2009 Research Topic of Interest (RTOI)

“Improving Early Hearing Detection and Intervention Data Reporting”

Purpose is to identify barriers and facilitators to accurate and consistent data reporting and evaluate ways that state EHDI programs can improve data reporting at the state level

Deadline to submit a Letter Of Intent (LOI) was
February 23, 2009

Conclusions

- Responsibility for transforming these Action Steps into real-life systems of care lies with all of us.
- NIH, AHRQ, CDC, MCHB and others can develop funding opportunities but stakeholders must apply for them and determine how to act on results.
- Prime movers in system change may be professionals, but may equally well be parents and family advocacy groups, and involve non-traditional e.g. public-private partnerships.