Baby Steps: Using a Regionally Customized Roadmap to Empower Families along the Journey of Screening through Early Intervention

Authors:
Emily Fields
Janet DesGeorges
Denise Davis-Pedrie
In the past 12 months, I have not had any financial interest or other relationship with provider(s) of the service(s) that will be discussed in my presentation.

This presentation will not include any discussion of pharmaceutical or devices.
Story from the field…

“In spite of the newborn screening triggering the identification, it was eight months before he had his hearing aids and 18 months old when he started speech therapy, when he was already showing a significant delay. I know that he had a definite advantage with the intervention he did have, but that knowledge should have turned into action much earlier. There is a world of professionals and organizations that could have guided, supported, and encouraged us that we were not made aware of for several years.”
What’s the Point?

- Starting Point! A one/two page visual document that very SIMPLY walks a parent through the 1-3-6 model.. not meant to be all the information a family needs
- Puts some control into a family’s hands
- Helps them to see what’s coming next
- Use as an educational tool with different parts/people involved in the system
...what is that they say?
Share liberally...
...Borrow blamelessly
...Steal Shamelessly
It all began with.... (NICHQ Collaborative Faculty Staff)

Universal Newborn Hearing Screening, Diagnosis, and Intervention
Learning about Hearing Loss -- A Roadmap for Families
Other State Road Maps…

- Nebraska
- Illinois
- British Columbia
- Hawaii
Colorado Infant Hearing Program – A Roadmap for Families

Child's Name: ____________________________
Child's Date of Birth: ______/____/____

Birth
- Home or Hospital Birth
- 1st Newborn Hearing Screen
  Date: ______/____/____

Screening Results
- Left Ear
  Did not pass
  Pass
  Not screened (missed)

Before 1 Month
- Outpatient Hearing Screen (or Rescreen)
  Place: ______/____/____
  Date: ______/____/____

Screening Results
- Right Ear
  Did not pass
  Pass
  Not screened (missed)

Before 3 Months
- Evaluation by a Pediatric Audiologist with experience testing children 0 – 6 months of age.
  (Babies over 4 mos. old may need sedation.)
  Place: ______/____/____
  Date: ______/____/____

Test Results
- Left Ear
  No hearing loss
  Hearing loss

- Right Ear
  No hearing loss
  Hearing loss

If a baby has a HEARING LOSS, the next steps are:
- Contact or referral to local Colorado Hearing Resource Coordinator (CO-Hear) & Early Intervention Colorado (Part C)
- Evaluation by an ENT (Ear, Nose and Throat doctor)
- Contact Colorado Families for Hands & Voices
- Learn about communication options and programs
- Discuss the use of Hearing aids with a Pediatric Audiologist, including information on loaner hearing aids
- Learn about assistive listening devices (such as FM systems, cochlear implants, etc.)

Before 6 Months
- Enroll in early intervention program that has experience serving children who are deaf and hard of hearing
- Regular visits with your Pediatric Audiologist
  “Children who participate in early intervention prior to six months can have age appropriate skills by preschool.
- Evaluations to discuss with your medical home:
  - Ophthalmologist (Eye Specialist)
  - Genetic Specialist
  - Other Medical Specialists (heart, development, kidneys, etc.)

Well baby checkup with health care provider at 2-4 days

Well baby checkup with health care provider at one month

Well baby checkup with health care provider at two months

Well baby checkup with health care provider at six months

Health Care Program for children with Special Needs
Hands & Voices
Individualized Information

Local and Regional Resources

Pediatric Audiologist: ____________________________
CO-Hear (Colorado Hearing Resource Coordinator): ____________________________
Health Care Program for Children with Special Needs (HCP) Regional Audiologist:

HCP Regional Office and Team Leader: ____________________________
Hands & Voices Regional Parent Guide: ____________________________
Part C Coordinator: ____________________________

Statewide Resources

• Health Care Program for Children with Special Needs: www.HCPColorado.org
• Colorado Home Intervention Program: http://hhic.colorado.gov
• Early Intervention Colorado, Services for Children Birth to Three: http://www.eicolorado.org/

National Resources

• www.babyhearing.org: Boys Town National Research Hospital informational site for parents
• Early Hearing Detection and Intervention Program, Centers for Disease Control website: www.cdc.gov/heardi
• National Center for Hearing Assessment & Management: www.infanthearing.org
• Hands & voices: www.handsandvoices.org
• Alexander Graham Bell Association for the Deaf/Hard of hearing: www.agbell.org
• American Society for Deaf Children, www.deafchildren.org
Ongoing Usage.....

- Spanish Translation
- Individualized for all 56 Hospitals
- Used as basis for statewide training with nurses and others
- Some Hospitals using it as the ‘written’ delivery of pass/refer
- Interactive Website for families and Physicians/Medical Home
- Regional EHDI teams (H&V GBYS, HCP, EI) onsite training