

# Parent and Stakeholder Collaboration in a Learning Community

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## LEARNING COMMUNITY (LC) PURPOSE

Increase the knowledge and engagement of pediatric health care professionals and families within the Early Hearing Detection and Intervention (EHDI) system to assure that Deaf or Hard of Hearing (D/HH) children are identified through newborn/infant hearing screening, receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy and social-emotional development.

Improve outcomes of children who are D/HH.

## STAKEHOLDER MEMBERS

- Pediatric Audiologist
- BEGINNINGS for Parents of Children Who are Deaf or Hard of Hearing
- Care Coordination for Children (CC4C) Program
- Children's Developmental Service Agency (CDSA) - Early Intervention
- Early Hearing Detection and Intervention Program (EHDI)
- Early Learning Sensory Support Program for Children with Hearing Impairments (ELSSP-HI) - Early Intervention
- Local Pediatric Practice
- North Carolina School for the Deaf (NCSD)
- NC Hands and Voices (NC H&V)
- Pediatrician and American Academy of Pediatrics (AAP) EHDI Chapter Champion
- Parents

## PARENT INVOLVEMENT

Six mothers of D/HH children participated on the Learning Community representing:

- American Sign Language (ASL) families
- Spoken language families
- families with babies born in NC
- families with babies born out of NC
- families with adopted children
- families with biological children



Photo credit: C&Y Branch

## HRSA UNHS GRANT TOPIC AREAS

### Priority Topic Areas Selected by LC

- Improving care coordination for children who are D/HH.
- Partnering with Title V Children and Youth with Special Health Care Needs (CYSHCN) programs on systems integration and family centered care coordination.
- Providing family-centered care that is culturally competent.
- Engaging family partners and pediatric clinicians in the EHDI System.

### Other Areas Covered

- Training regarding Joint Committee on Infant Hearing (JCIH 1-3-6) timeline recommendations.
- Risk factors for late-onset hearing loss.
- Peer to peer information sharing among participants.
- Developing collaborative leadership skills for members of family organizations.

### Ongoing Statewide Efforts

- Linking newborn hearing screening data to programs such as vital records, immunization, and blood spot screening.

## OPPORTUNITIES FOR IMPROVEMENT

### Activity Completed

- Comprehensive Resource List - increase visibility and accessibility of resources for providers and families.

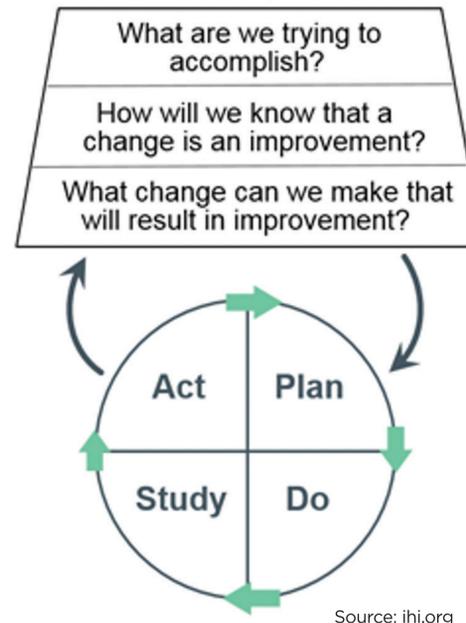
### Future Activities

- Provider education on NC resources (PCP, ENT, School Systems, etc.).
- Improve process of connecting families whose children were not born in North Carolina to available resources.
- Deaf Mentors and Role Models.
- EHDI System Navigator.

## KEY ELEMENTS OF RESOURCE LIST

1. Comprehensive, concise, parent-friendly, and representative of both spoken and visual resources.
2. Easy to navigate, user-friendly, and searchable, if possible.
3. Include brief description of each resource.
4. Display on accessible website (NC-EHDI website).

## Model for Improvement



Source: ihi.org

## PLAN-DO-STUDY-ACT (PDSA) TESTING

**Objective - Cycle 1: To share the redesigned resource list with parents and service providers and evaluate the content and format.**

The resource list was:

- Reviewed by two service providers and three mothers of children with hearing loss.
- Revised based on feedback (changed categories, added/removed resources, and revised descriptions).
- Shared with learning community members for final approval.
- Posted to EHDI Program Website. It will be reviewed on a quarterly basis.

## PDSA TEST QUESTIONS

### Cycle 1 (complete)

1. Do families/service providers find the resources on the list helpful?
2. Do families/service providers find the layout of the resource page user-friendly?
3. Would you share this resource page with other families that needed more information about hearing loss?

### Cycle 2 (Will take place 3 months after posting new Resource List)

4. Are more individuals accessing the resource page on the EHDI Program website?
5. How many service agencies posted the resource list link on their website?
6. How many parent groups posted the resource list link on social media?

## PDSA TEST FEEDBACK (CYCLE 1)

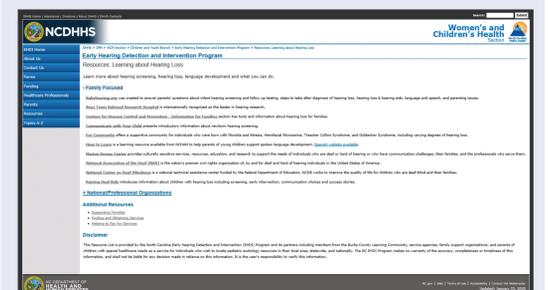
**Parent:** "There is a lot of valuable information there for folks to quickly answer questions they have or to find a starting place for an in-depth inquiry into a topic".

**Service Provider:** Love the website! This will be a great resource. Let me know when it launches and I will share the news with the teachers in my program. I can tell that a lot of work was put into this, and it shows! Thank you!

**Parent:** I am thinking that a brief description of what the resource offers would be helpful despite being very clear in the agency titles.

**Service Provider/Deaf Parent:** "There are deaf parents in NC that may have limited language competency to understand any type of website. I am wondering, will there be a video of a person who signs ASL and explains about resources on [www.ncnewbornhearing.org](http://www.ncnewbornhearing.org)?"

## SNAPSHOT OF NEW RESOURCE LIST PAGE



## DISSEMINATION STRATEGIES

- Send resource list to Pediatric Practice Managers; request posting to website and social media outlets.
- Partner with NC Pediatric Society and NC Academy of Family Physicians to send the resource list via newsletter or email.
- Partner with parents to send resource list via social media.
- Share resource list with key stakeholders and request they add the link to their websites.

## LESSON LEARNED

- Important to have representation from all stakeholder groups, especially parents.
- Conference calls are OK for planning and reviewing but in-person meetings are essential.
- Keep the ball rolling to maintain stakeholder engagement.
- Expect that progress will be slow but steady.
- Listen to your stakeholders and focus on what is salient to them.

## SUCCESSSES

- Networking time - making connections with local community partners.
- Degree of parent involvement.
- Breadth/depth of stakeholder representation.
- Consumer-driven outcomes.

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