

Participatory Action Research : Improving Follow Up Rates of Newborn Hearing Screening in Greater Cincinnati Area

Ryan Uy, MD; Erin Whitely, BA; Kimberly Walker; Susan Wiley, MD; Lisa Vaughn, PhD; Lisa Hunter, PhD
 Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

The Division of Developmental and Behavioral Pediatrics
 Cincinnati Children's Hospital Medical Center

The University of Cincinnati University Center for Excellence in Developmental Disabilities



Background

Newborn hearing screening (NHS) is a multifaceted system of education, screening, diagnosis, referral, treatment, care management, and ongoing evaluation of the effectiveness of all components.

Successful newborn screening systems rely on the collection, sharing and integration of data among the family, clinical care providers, and public health programs.¹

Although universal NHS has dramatically reduced the number of late-identified hearing loss in children, there are still barriers that prevent the timely follow-up of all babies.

Current national average for loss to follow up is 32% of those babies referred on the NHS².

Methods

- Participants included a group of ~30 stakeholders [Fig.2] to gather information about the NHS system in Cincinnati and the surrounding suburbs.
 - Ohio Maternal and Child Health - Regional Infant Hearing Program and Help me Grow
 - Ohio Department of Health
 - Women, Infant and Children (WIC) program, Hamilton County
 - Ohio Valley Voices – Oral school for Deaf children
 - St. Rita School for the Deaf
 - Hands and Voices
- Participants met together and broke into small groups where they provided ideas on the different issues impacting NHS and shared it to the whole group.

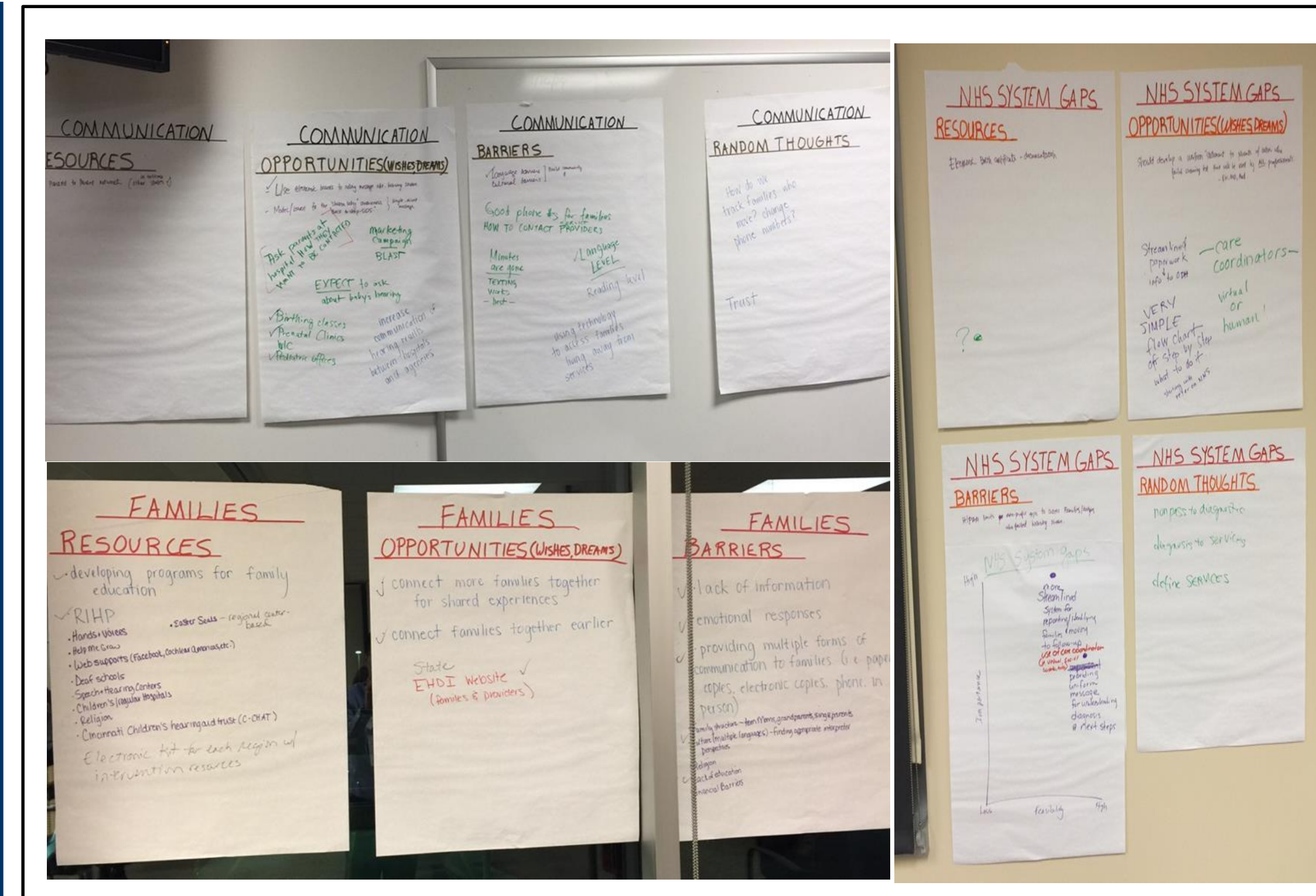


Fig. 3 – Prompt Boards

Next Steps

- Continue meeting with stakeholders to carry out action plans that are sustainable to effectively reduce loss to follow up rates in NHS.
- Create work groups that will continue to meet even after the GLA/PAR phase is over.

Goals and Objectives

- Determine gaps or weaknesses in the NHS system that contribute to loss to follow up.
- To use participatory action research (PAR) [Fig.1] to generate qualitative data about health beliefs and behaviors regarding utilization of NHS systems.
- Develop specific, sustainable projects to decrease loss to follow up rates in NHS at birth hospitals and requiring screening



Fig. 2 – Stakeholders' Meeting

Data collection

- Descriptive, qualitative data about barriers to follow up were collected using a Group Level Assessment (GLA) model during our Stakeholders' Meeting.
 - Prompt boards [Fig.4] were utilized during the meeting to capture participants' ideas.
- Small groups were created and participants came up with specific action plans [Table 1] on how to improve follow up rates.

Results

- “Distributed materials to families in an inconsistent fashion”
- “Should develop a uniform statement to parents with babies who failed screening test that will be used by ALL professionals (RN, MD, AuD)”
- “Lack of information and different emotional responses”
- “Language/cultural barriers (build communities to decrease these barriers)”
- “In denial, advice of relatives/friends, beliefs – minimizing severity”

Concept :	Flag Alert in EHR	Education for NBH Screeners	Hearing Screen Mobile Van
Description	Alert physicians when f/u has not occurred for failed screening	Standardized education method for screeners (quality, conveying test results)	Van that goes around town (targeting PCP offices) and offer screening/rescreening
Barriers:	- Working with staff or IT - Slow down clinic flow	- Motivation - Buy-in - Cost	- Intake process - Requires infrastructure, cost
Resources:		Help from ODH	Grant application
Concept :	Universal Tool for Screeners/AuD/RN/MD	Informational Video	F/U appointment scheduled prior to discharge
Description	Provide consistent message to parents about NBHS and results	Video to be shown in hospitals (patients' rooms) about NBHS	To ensure follow up
Barriers:	- Staff turnover - Different backgrounds and training	- Cost	- Absence of law mandating this
Resources:		ODH	Utilize case coordinator to facilitate implementation

Table 1

References

- Lloyd-Puryear MA, Brower A. Long-term follow-up in newborn screening: A systems approach for improving health outcomes. *Genetics in Medicine* Vol 12 (12): December 2010 Supplement.
- 2012 CDC EHD Hearing Screening & Follow-up Survey (www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)
- Baum F, MacDougall C, Smith D. Participatory action research. *J Epidemiol Community Health* 2006

Acknowledgements

- Cincinnati Children's Hospital LEND program for their assistance
- Families of Participants and Stakeholders
- Place Award from Cincinnati Children's Hospital
- Centers for Disease Control- Disability Research Center Development Grant
- Cincinnati Center for Translational Science and Technology
- LEND-AUCD and MCH Training Grant
- Dr. Daniel Choo, Ohio EHD Advisor
- Reena Kothari, Naomi Halverson, and Anna Starr, ODH
- Cindy Meale, Butler County WIC
- Betsy Buchanan, Hamilton County WIC

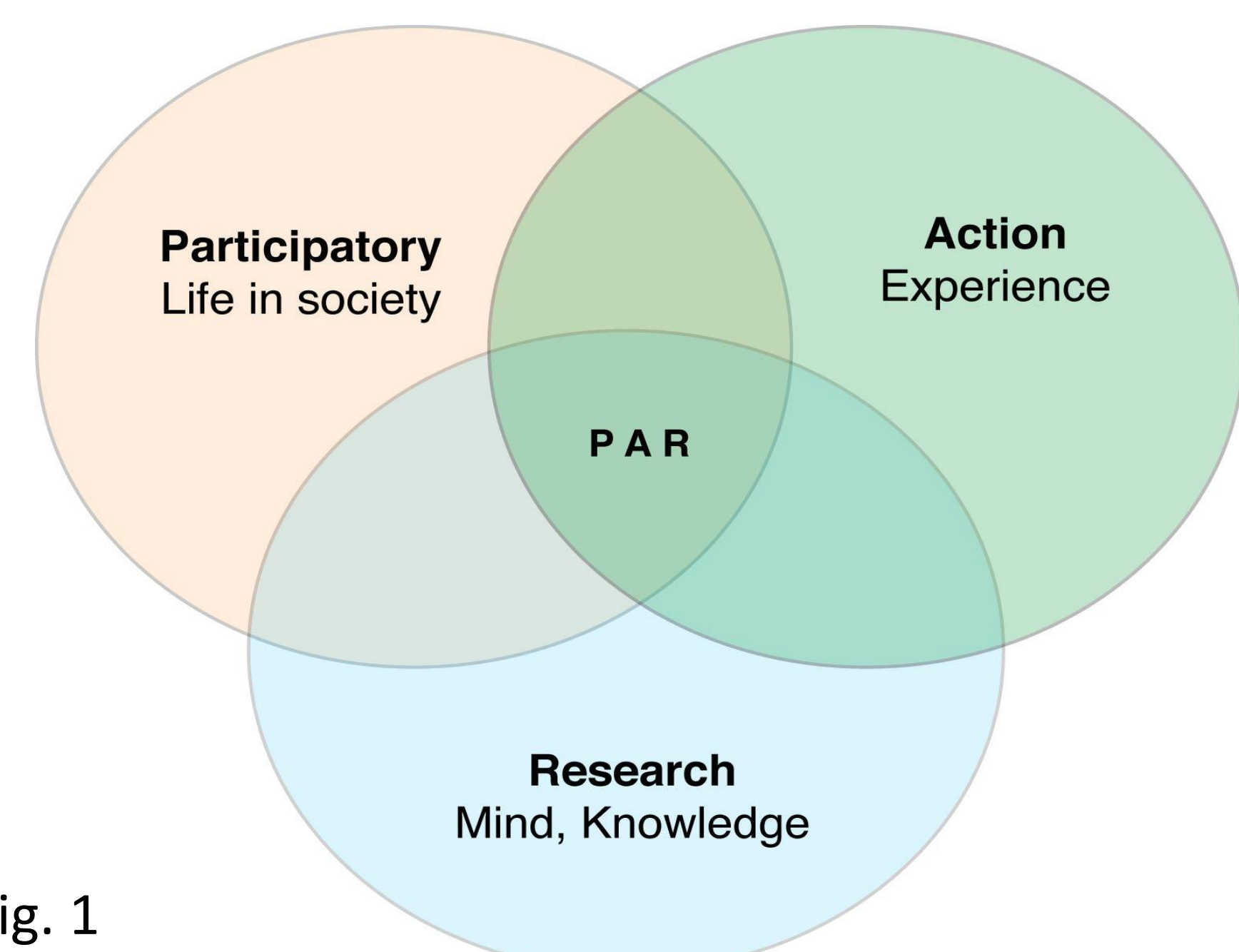


Fig. 1