



# EHDI and University Collaborations

LEVERAGING THE PARTNERSHIP TO ENHANCE PROGRAM IMPLEMENTATION AND OUTCOMES



# The Partnership

- ▶ Liza Creel
  - ▶ Assistant Professor, University of Louisville School of Public Health and Information Sciences
  - ▶ Commonwealth Scholar, Commonwealth Institute of Kentucky
- ▶ Cathy Lester
  - ▶ KY EHDI State Coordinator for past 6 years
  - ▶ Previously a social worker and social work adjunct instructor in Research Methods and Advanced Research I & II
- ▶ Julie Jacobs
  - ▶ Project Director, University of Kentucky, College of Public Health

# Liza's Background Story

- ▶ Prior work in Texas
  - ▶ Involvement in Regional Genetics Collaboratives
  - ▶ PhD Dissertation in Health Services Research
    - ▶ Focus on newborn hearing screening implementation within the NICU
- ▶ New job at University of Louisville
- ▶ Identifying new research opportunities
- ▶ Establishing a connection with the Kentucky Commission for Children with Special Health Care Needs

# EHDI Program Story

- ▶ Part of Kentucky's Title V agency, the Commission for Children with Special Health Care Needs
- ▶ Relatively small state, 53,000 births annually, and a small EHDI program (2 full-time staff, 4 part-time staff that didn't even make up a full FTE)
- ▶ KY has a solid EHDI-IS with extensive data available for analyzing
- ▶ KY EHDI has no epidemiologist support and staffing levels did not allow time for staff development to improve data analysis capacity.
- ▶ KY had the desire to do more with data, but no ability!

# Baby Steps – Orientation to Agency

- ▶ HIPAA – obtained signature on agency HIPPA form to allow orientation to data systems
- ▶ Sharing description of flow of data from hospital system (KY CHILD) to EHDI-IS (CUP)
- ▶ Demonstration of KY CHILD and CUP, and identification of relevant data elements
- ▶ EHDI Advisory Board – attended first meeting as observer
- ▶ Planning projects – initial projects arose from priorities identified at the Advisory Board meeting



# Key Facilitating Factors in Academia

- ▶ Association with Commonwealth Institute of Kentucky
- ▶ Salary support and protected research time
- ▶ Early career faculty member
  
- ▶ Translation to other university settings

# First Project

- ▶ Monitoring incidence of permanent childhood hearing loss (PCHL) in the KY population
- ▶ Identifying accurate sample
  - ▶ Original data set was subset of all births (only those with documented risk factors)
  - ▶ Measurement of incidence required data set will all births

# Additional Projects

- ▶ Risk factor surveillance
  - ▶ Role in supporting Advisory Committee work to:
    - ▶ Improve risk factor reporting
    - ▶ Support providers in follow-up for infants/children with a risk factor
- ▶ Hospital scheduling analysis
  - ▶ Testing hypothesis: Hospital scheduling of follow-up appointments improves likelihood an infant that refers for follow-up receives follow-up
    - ▶ Presentation at EHDI 2017
    - ▶ Manuscript



# Needs Assessment

- ▶ Summer 2016 – developed and launched stakeholder surveys to gain input on familiarity with the EHDI program, strengths of the program, and opportunities for continued improvement
  - ▶ Data collection now annual
- ▶ 2016 findings incorporated into proposal for HRSA funding
  - ▶ EHDI staff completed most of application for 2017 HRSA but benefitted greatly from Needs Assessment and Evaluation sections developed by Liza

# HRSA Grant Evaluation Contract

- ▶ UL SPHIS written in as evaluation partner for HRSA proposal
- ▶ Specific responsibilities include:
  - ▶ Launching a mixed methods evaluation to include qualitative and quantitative data collections (surveys and key informant interviews)
  - ▶ Analysis of quantitative data from the EHDI program
  - ▶ Preparation of instruments for measuring Learning Community outcomes
  - ▶ Conduct data collection and analysis of Learning Community outcomes

# CDC Grant Evaluation – Core and Expanded

- ▶ Collaborated on application
  - ▶ EHDl coordinator completed several sections
  - ▶ Liza completed evaluation and contributed to several other section
- ▶ CIK partnership offers resources for reporting to stakeholders
- ▶ Work collaboratively to complete CDC-required evaluation materials and incorporate measures into existing data collection efforts
- ▶ Liza attended the Kick-Off meeting in Atlanta as one of the 3 identified team members for the Expanded Activities

# Benefits to EHDI - Reliable Analysis and Interpretation of Data

- ▶ It is impossible to identify significance by “eyeballing” data
- ▶ Having a partner that is trained in statistical analysis allows the EHDI program to identify trends in the data that inform program initiatives
- ▶ Example – hospital scheduling – by analyzing follow-up data, we learned that having hospitals schedule follow-up appointments for families prior to discharge, those families were statistically more likely to get the needed follow-up. This changed our practice by working more emphatically with hospitals to strongly encourage this practice.

# Benefits to EHDI - Better Evaluation Efforts for Grant Reporting

- ▶ Grant evaluations are often reports of work accomplished without analysis of effectiveness
- ▶ Our evaluation plan now has additional efforts around surveys of 5 stakeholder groups (hospitals, families, audiologists, physicians, and EI providers)
- ▶ Example – Survey data was used in last HRSA report to support accomplishments on the work plan and elements of the Needs Assessment.



# Benefits to EHDI - Quality Improvement

- ▶ QI projects often start with “small tests of change” through Plan-Do-Study-Act (PDSA) initiatives
- ▶ Once these PDSA initiatives reveal valuable information, these initiatives grow in size and scope
- ▶ Data analysis from these allows the EHDI program to determine if the initiatives are responsible for significant positive changes
- ▶ Example - KY EHDI has had ongoing efforts to improve response to babies with risk factors for progressive or delayed onset hearing loss. Based on data analysis, KY EHDI Advisory Board is developing a protocol for physicians to use when working with infants with identified risk factors to improve monitoring of their hearing

# Benefits to University

- ▶ Partnerships between state and local communities
  - ▶ University goal of community collaboration
- ▶ Academic productivity
- ▶ Impact on important public health programs
  - ▶ Including efforts to encourage continued funding for the programs
- ▶ Impact on policymaking in the state

# Challenges – From Both Sides

- ▶ Data sharing – State government agencies require great caution in sharing data outside the program, much less outside state government
- ▶ Finding faculty with time
  - ▶ Role of students
- ▶ EHDI Program staff time – EHDI coordinators have multiple responsibilities in managing the EHDI program, from agency demands, CDC grant requirements, HRSA grant requirements and “other duties as assigned”. It can be difficult to set aside time to develop and nurture additional working relationships, even those that are productive and beneficial.

# Adding to the Fun

- ▶ Prior to the relationship with the University of Louisville, and Liza specifically, KY EHDI had an ongoing collaboration with the University of Kentucky (UK)
- ▶ KY EHDI provided data to UK regarding newborn screening results and subsequent follow-up results
- ▶ The data analyses that UK conducted yielded several papers on which the EHDI coordinator was a co-author

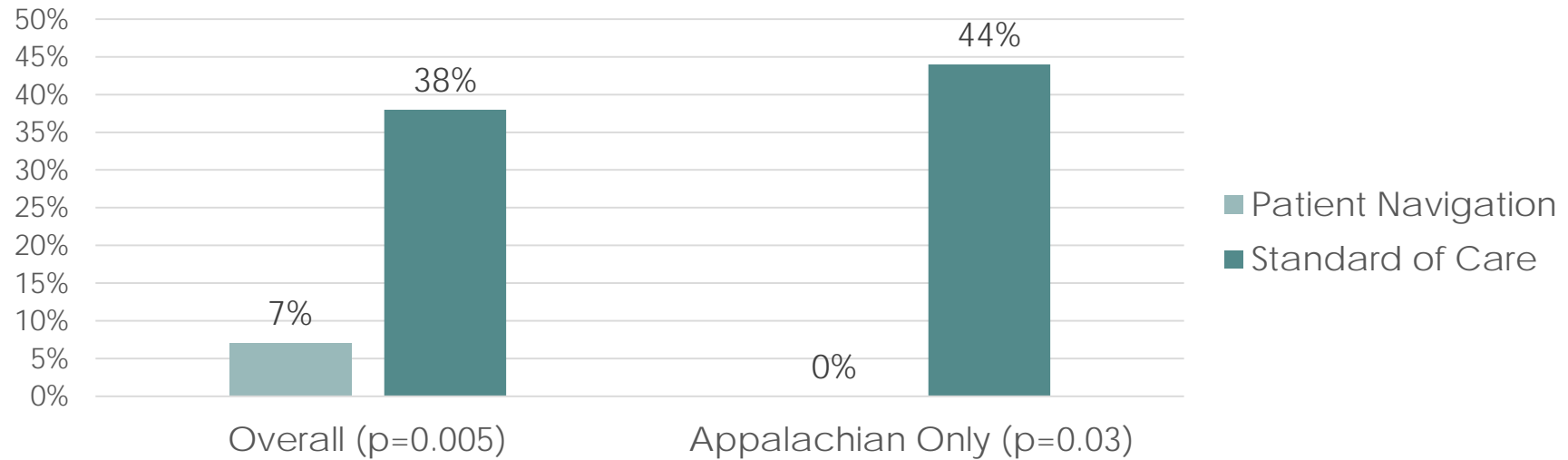
# Patient Navigator grant with EHDI patients

- ▶ Following the data sharing relationship, UK began a research project exploring the use of patient navigators to help families get through the process from a failed newborn screen through the subsequent diagnostic evaluation and possible diagnosis of hearing loss.
- ▶ The EHDI program, and the parent agency, the Commission for Children with Special Health Care Needs, assisted with the research by providing:
  - ▶ Referrals of patients and families
  - ▶ Data regarding follow-up compliance
- ▶ Appalachian and non-Appalachian participants were randomized to either “navigated” or “standard of care” conditions



# Patient Navigator – Results

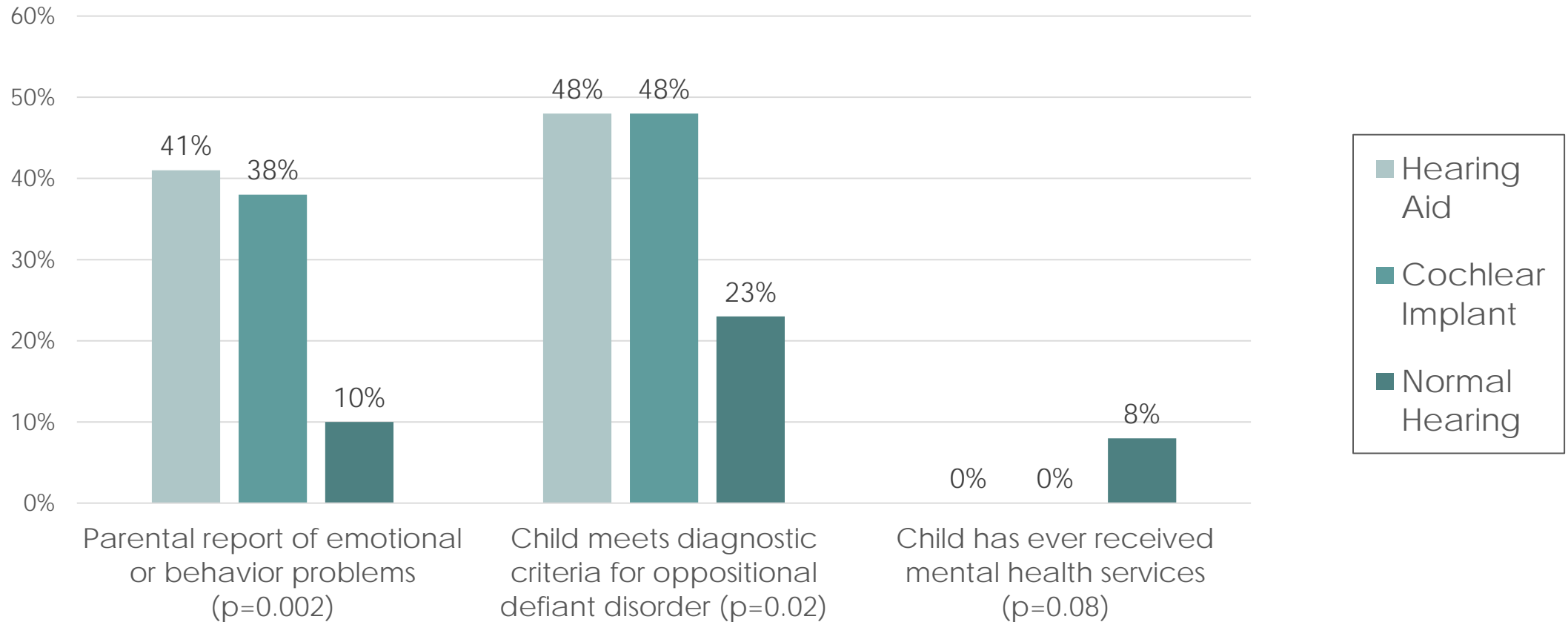
Audiological Diagnostic Testing Adherence:  
Percent Lost to Follow-Up at 6 Months



# Behavioral Problems in Children with Hearing Loss

- ▶ Aim 1: Compare disruptive behavior problems of 2-5 year old children
  - ▶ 29 children with hearing aids
  - ▶ 21 children with cochlear implants
  - ▶ 39 children with normal hearing
- ▶ Aim 2: Conduct a pilot randomized controlled trial of the “Family Check-Up” behavioral training intervention with 12 parents

# Behavioral Problems in Children with Hearing Loss- Results



# UK and EHDI become UK, UL, and EHDI



- ▶ Early in the relationship between EHDI and UL, an introduction was made to UK researchers, Dr. Matt Bush, Dr. Tina Studts and Julie Jacobs.
- ▶ This introduction yielded an even more productive collaboration as Liza brought new skills to the group with her work in cost effectiveness studies.
- ▶ The group bonded over beignets and began planning world domination, at least in the area of infant hearing loss.

# UK Collaboration with Current UL/EHDI Research

- ▶ As part of the work done on behalf of the EHDI Advisory Board, Liza was analyzing the impact of hospital scheduling of diagnostic audiology appointments on the compliance with follow-up recommendations
- ▶ After the first joint meeting, UK joined in the discussion
- ▶ Grant writing together
  - ▶ Building on each others areas of expertise



# R01 – Patient Navigator

- ▶ UK began the application process for a National Institutes of Health “R01” grant
- ▶ This project will test the effectiveness of patient navigation using 10 state-supported clinics administered by Kentucky’s Commission for Children with Special Health Care Needs (CCSHCN)
- ▶ The study design also includes assessments of implementation factors and of the cost-effectiveness of patient navigation
- ▶ Both EHDI and U of L were involved in the application and will be involved once the grant is funded

# VI<sup>2</sup>P – Child Behavior

- ▶ Value of Innovation to Implementation Program (VI<sup>2</sup>P) is an internal grant within the University of Kentucky to adapt an evidence-based behavioral intervention (the “Family Check-Up”) to the needs of families with pre-school aged children with hearing loss
- ▶ Through the use of a Community Advisory Board, interviews with families, and focus groups of key informants, the intervention will be developed and piloted with a small group of families recruited from the state’s Title V agency, the Commission for Children with Special Health Care Needs

# R01 – Child Behavior

- ▶ Our 2<sup>nd</sup> NIH R01 application builds on the VI<sup>2</sup>P project
- ▶ Using the intervention developed and pilot tested in the previous project, a randomized controlled experiment will be conducted using 10 CCSHCN audiology clinics (5 intervention clinics & 5 control clinics)
- ▶ 15 families in each of the 5 intervention clinics will receive the annual “Family Check-Up” parenting support program for 4 years
- ▶ The EHDI program again will provide referrals of families and clinic data related to enrolled participants in all 10 clinics
- ▶ Liza will conduct cost analyses

# Wrap-up

- ▶ Partnerships between the EHDl program and academic partners leverages resources and expertise
- ▶ Several key factors facilitate successful collaboration
- ▶ Margaritas