

Follow Up and Support for Families: Creating a Family Centered Loss to Follow Up System

Anne Banger
Karen Hopkins
Tonya Ng
Holly Richards

Maine EHDI

- Anne Banger
Follow-Up Coordinator, Maine Newborn Hearing Program
- Karen Hopkins
Director, Statewide Education and Family Services
- Tonya Ng
Parent Consultant, Maine Newborn Hearing Program
- Holly Richards
Program Manager, Maine Newborn Hearing Program

History of Maine EHDI



2005

First year full hearing screen data was collected in Maine

	2005
Screen	94%
Follow-Up	34%
Part C	10%

Importance of Parent Role Identified

- Parent Consultant Position Created
- Funded by HRSA Grant



2007

Parent Consultant Hired

- Parent
- Contract position
- Part-time
- Home-based office
- Role
 - Family support following diagnosis
 - Start Hands & Voices in Maine



2007

Law changed

▶ Mandated Audiology Reporting

- Anyone performing screens or diagnostics through age 3
- Reports submitted via web-form or manually



Data

	2005	2006	2007
Screened	94%	97%	98%
Follow-Up	34%	34%	50%
Part C	10%	21%	30%



2009

Law changed

- Hospitals mandated to schedule follow-up appointment



2010

Follow-Up Coordinator Position Created

- Parent, full-time contracted position
- Role
 - Contact PCP and Audiologist on refer

	2005	2006	2007	2010
Screened	94%	97%	98%	98%
Follow-Up	34%	34%	50%	68%
Part C	10%	21%	30%	35%

2011

New Parent Consultant Hired

- Focus shifted to include follow-up with parents

	2005	2006	2007	2010	2011
Screened	94%	97%	98%	98%	98%
Follow-Up	34%	34%	50%	68%	71%
Part C	10%	21%	30%	35%	32%

2012

New Follow-Up Coordinator Hired

- Focus on proactive case management

	2005	2006	2007	2010	2011	2012
Screened	94%	97%	98%	98%	98%	98%
Follow-Up	34%	34%	50%	68%	71%	73%
Part C	10%	21%	30%	35%	32%	48%

2014

Guide By Your Side Program

- Program Coordinator
- Four Parent Guides
- Paid Hourly positions
- Funded by HRSA grant
- Embedded into Maine's early intervention process



2017

Deaf/Hard of Hearing Guides Hired

- Eleven Deaf/Hard of Hearing Guides
- Paid Hourly positions
- Funded by HRSA grant
- Embedded into Maine's early intervention process



When Baby Refers on Newborn Hearing Screening



By one month of age

Screening facility

- Required to schedule follow-up appointment
- Complete and fax Maine EHDI program referral form to PCP and Maine EHDI office



By one month of age.....

- Maine EHDI program
 - Follow-up Coordinator contacts screening facility for any missing information on Maine EHDI program referral form
 - Follow-up Coordinator contacts PCP
 - Parent Consultant contacts family



By three months of age....

- Follow-up appointment...
 - Follow-up Coordinator
 - Contacts Audiologist if no report
 - Contacts PCP if no follow-up
 - Parent Consultant
 - Contacts family if no follow-up
 - Contacts family if hearing loss confirmed
 - Collaborates with Early Intervention



By six months of age....

- Parent Consultant
 - Follow-up support
 - Collaborates with early intervention
- Follow-up Coordinator
 - Contacts PCP and Audiologist as needed
- Enrolled in Early Intervention
 - Part C
 - Early Childhood and Family Services (ECFS)
 - Memorandum of Agreement– Part C and ECFS

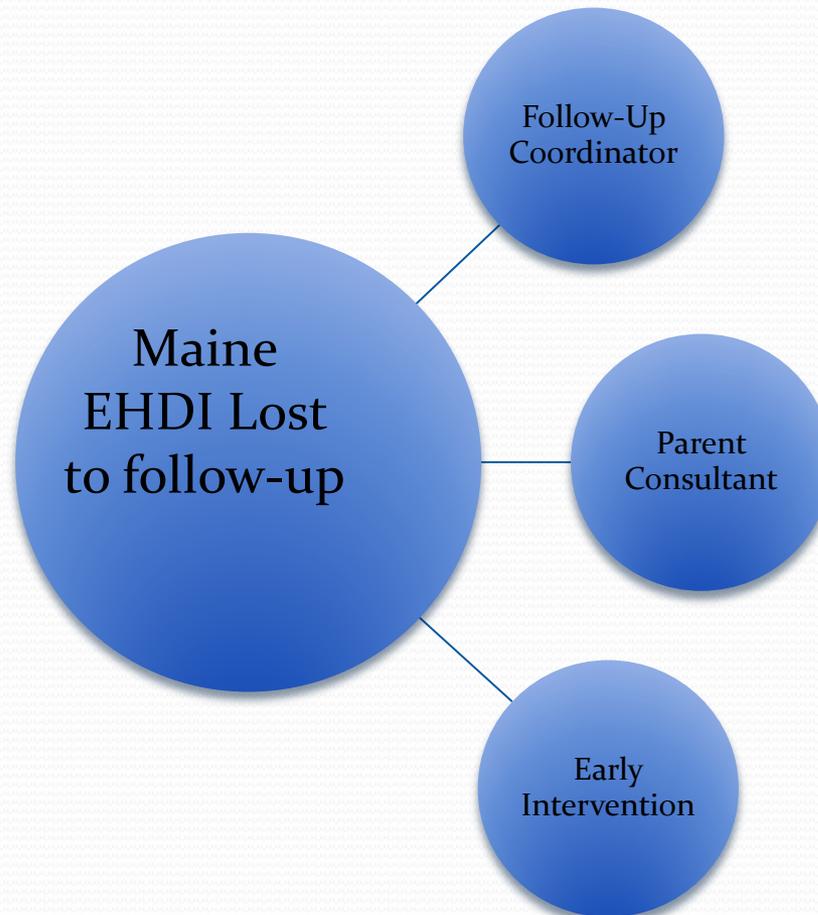


What we have learned

- What works
 - Parent Involvement
 - Clear data system
 - Three-pronged approach
 - Collaboration between Follow-Up Coordinator, Parent Consultant and Early Intervention



Maine EHDI Three-Pronged Approach



What we have learned

- Challenges...
 - Lack of Resources
 - (fiscal and personnel)
 - Getting Information
 - Lack of training
 - Consistency



How Maine EHDI benefits from parent involvement

- Parent-to-parent support
 - Support in the Follow-Up Process
 - Support in the Early Intervention Process
- Parent Voice to Professionals
 - Screening Facility, PCP and Audiologist
- Parent Voice in EHDI awareness programs
 - Screening facilities
 - Staff programs
 - Early Intervention
- Improved Data



The data says it all



	2005	2006	2007	2010	2011	2012	2016
Screened	94%	97%	98%	98%	98%	98%	98%
Follow-Up	34%	34%	50%	68%	71%	73%	77%
Part C	10 %	21%	30%	35%	32%	48%	70%

Thank you!

- **Karen Hopkins**
(207)781-6335
karen.hopkins@mecdhh.org
- **Anne Banger**
(207)274-1790
annemnhp@icloud.com
- **Tonya Ng**
(207)329-0804
tonya.mnhp@gmail.com
- **Holly Richards, MPH, CHES**
(207)287-4623
holly.richards@maine.gov

