



Hands & Voices Collaboration with Hospital Screening Programs to Address Loss to Follow Up

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Guide By Your Side is a program of Hands & Voices



- To empower parents to make their own decisions that are right for their child and family
- To encourage and assist families of children who did not pass screening to return for critical follow up
- To provide EARLY, comprehensive, unbiased information and support to families of children with confirmed hearing loss



Components of GBYS

Follow Through (Pre Dx)

- at referral on inpatient hearing screening
- at referral on outpatient or 2nd hearing screening

Direct Parent Support (Post Dx)

- immediately after identification
- ongoing as requested by family

Representation at the Systems Level

- EHDI Advisory Committee
- EHDI outreach activities

FT Parent Guides have:



- formalized on-going training and affiliation with H&V.
- knowledge of state EHDI system, referral process and options for follow up.
- sensitivity to range of emotional responses that families experience.
- knowledge of joys and challenges of raising a child who is deaf or hard of hearing.

FT Parent Guides contact families and :



- share with the families the importance of follow up **from a perspective of someone who benefited** from NBHS.
- encourage families to move forward; reinforce consistent message of importance of getting to next appointment without causing anxiety.
- answer questions; direct audiological and medical questions to appropriate professional.



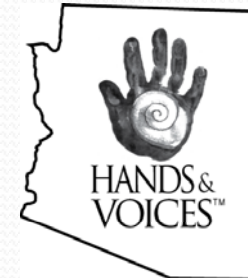
- ask if baby's next appointment is set.
- facilitate the process of follow up: finding diagnostic centers, helping make the calls, explaining what to expect, overcoming language and transportation barriers.
- discuss steps with a family, not to take the steps for them.
- help families discover that **they** can help **themselves**, not to take that responsibility for them.

Arizona - Follow Through



- Hospitals are assigned a FT Guide.
- FT Guides collect information from hospitals on infants who don't pass screening
- FT Guides provide hospitals with FT cards.
- FT Guides call families.

GBYS FT Postcard



Mom, I just had my hearing screened and I need to have my ears re-checked in two weeks.



It is very important to bring me back to the hospital or to an Audiologist. I might have a hearing loss. Someone may be calling you to answer questions and help get my ears checked. If you don't want someone to call you, please call 1-866-685-1050.



Arizona Department of Health Services is partnering with Guide By Your Side to assist families through the screening process. A Parent Guide will be contacting you. If you prefer not to be contacted, please call the Program Coordinator at 866-685-1050.

GBYS Program Coordinator



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Collaborations

- Arizona Department of Health Services
- The EAR Foundation of Arizona
- Arizona EHDI
- Arizona Hands & Voices



Wisconsin - Follow Through



- Hospitals are assigned a FT Guide.
- FT Guides provide hospital staff with talking points: “Let’s Talk About the Guide By Your Side Follow-Through Program”
- FT Guides provide hospitals with FT cards
- FT Guides contact families



GBYS FT Program Note Card

"Mom, I just had my hearing screened and I need to have my _____ ear/s re-checked in two weeks."

"Please don't worry. This is only a screening but the doctor says that it is very important that you bring me back to the Hospital or to an Audiologist in a week or so. They also said that there is someone you can talk to if you want to learn more or need help getting my ear/s re-checked."

GBYS Follow Through Coordinator



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Collaborations

- Wisconsin Dept. of Public Instruction
- Wisconsin Dept. of Health and Family Services
 - WI Sound Beginnings (WSB) (EHDI program)
 - WI Birth to 3 Program
 - Office for the Deaf and Hard of Hearing
 - Regional Centers for Children with Special Health Care Needs
- Wisconsin Families for Hands & Voices
- WI Personnel Development Project (University of WI)



Indiana - Follow Through

Role of the Parent Consultant



- Works collaboratively with EHDI staff to ensure:
 - that families of children who refer from UNHS due to a “did not pass” or “passed, but at risk for hearing loss” results receive contact (letters, phone calls)
 - Contacts families within 1 week of receipt of an EARS alert to ensure that audiological follow-up is scheduled or in process
- Uses the EHDI Alert Response System (EARS) to document all contacts with families and professionals



- Shares information on navigating through the process from a parent's perspective



- Links families to audiology services, EI and other services that may be needed and fall within the domain of short-term EHDI follow-up

- Participates in outreach activities conducted by the EHDI program which target consumers and professionals (i.e. EHDI Family Conference, Early Intervention forums, EHDI trainings)

Did not Pass Follow up Protocols



	Step Name	Sequence	Instructions	Response	
	DNP - Call Parent (immediately)	1	Call parent to encourage follow-up, provide FS phone number, and provide EHDI number for additional assistance as needed.	Phone	X
	DNP-Send 1st Mother and Physician Letters (immediately)	2	Go to Response Center. Select 1st letter Did Not Pass. Save letter to batch.	Letters	X
	DNP-Send 2nd Mother letter (45 days)	3	No follow-up, DAE, or reports have been received by EHDI. Select 2nd letter.	Letters	X
	DNP-Make Phone Call to Parent (45 days - same time as 2nd letter)	4	Contact parent to determine if testing is complete or scheduled. If no response, reassign to audiologist	Phone	X
	DNP-Make second call to PCP (90 days)	5	No f/u results have been received at EHDI program. Select phone call and record notes.	Phone	X
	DNP-Send SPOE Email (120 days)	6	Email SPOE contact to determine if f/u has been completed	Email	X
	DNP-Review file and set status (when child is one year of age)	7	Review file and attempt one last family contact if appropriate. If no contact occurs, classify LTF/D. If parent refusal, note on CHIP and close file.	Phone	X

GBYS Program Coordinator



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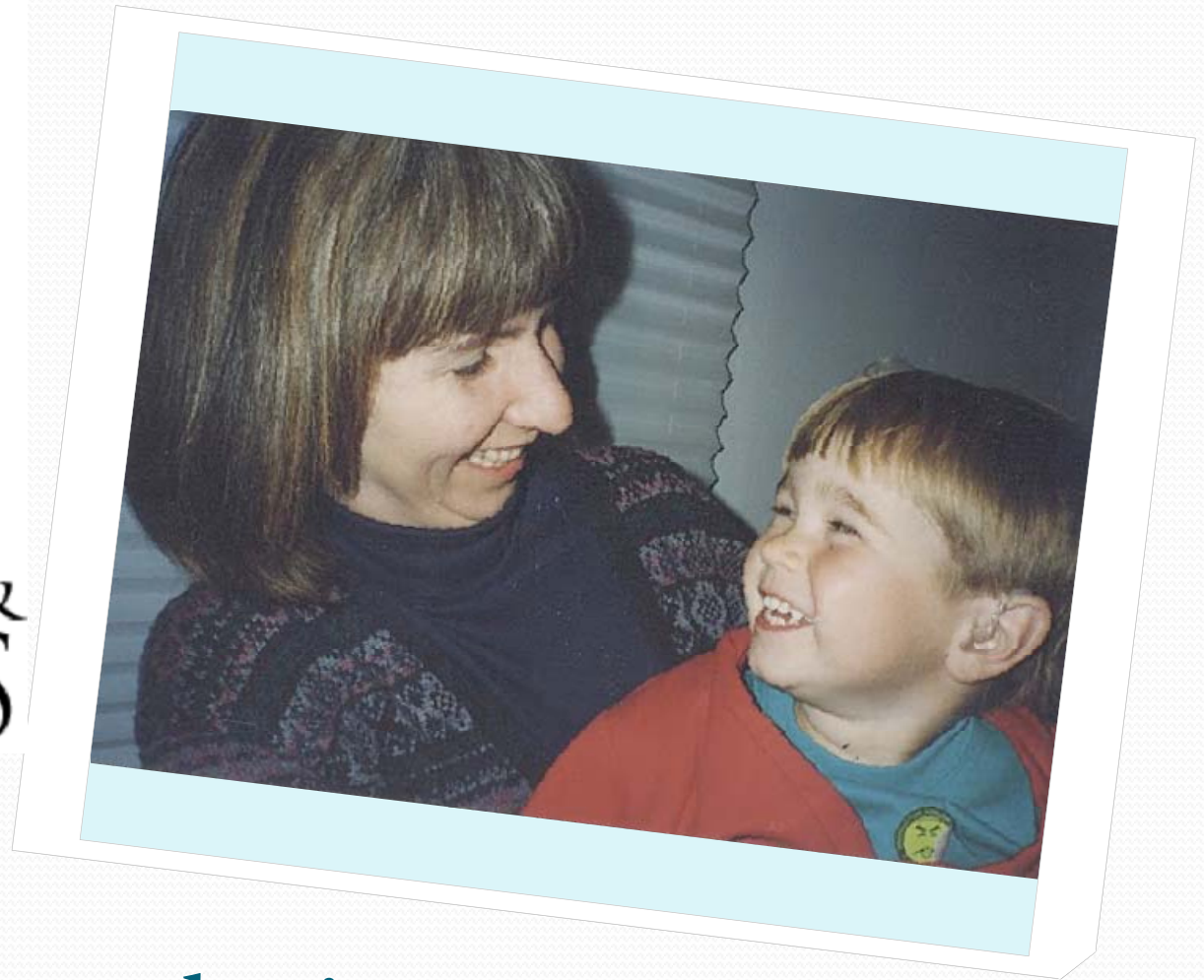


Loss & Found

- DVD developed by Hands & Voices
- Can be shown to families when an infant doesn't pass newborn screening



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