

# **EHDI and Guide By Your Side: Very Early Family Support**

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# The Story: EHDI and GBYS

- Increasing # of families began to contact the EHDI program with questions and a need for direction
- Staff could answer some questions, but observed that parent-to-parent emotional support and guidance re: next steps was needed
- EHDI Parent Consultant hired-LTF/D improved, but recognized need for even earlier and greater support
- EHDI and Hands & Voices partnered to offer GBYS to:
  - 1) Enhance very early family support across the state
  - 2) Decrease loss to follow-up
  - 3) Assist families in accessing services









# Implementation of GBYS

- January-August 2009: GBYS Parent Coordinator hired to work at EHDI
  - Developed Indiana program plans and documents
  - Aligned GBYS service regions with EHDI Regional Consultant regions across State
  - Hired Parent Guides through a rigorous interviewing process
  - Conducted Guide training
- Sept 1, 2009: GBYS Program Launch
  - 12 Parent Guides across the State
  - 30 Families have been matched with a Parent Guide

# Implementation of GBYS








- Guide Training:
  - Supporting families without Bias
  - Encountering Emotions
  - Role of the Parent Guide
  - HIPAA training
  - Policies, Procedures & Protocols
- Program Evaluation:
  - Bi-annual review of the program with EHDI staff
  - Parent Guide Satisfaction Survey – completed by family
  - GBYS – Guide Input Survey – completed by Guide

# EHDI & GBYS Protocols

	Step Name	Sequence	Instructions	Response	
	<b>DX HL-Confirm DAE results (immediately)</b>	1	<b>Upon receipt of DAE, audiologist reviews results. Batch Parent Tool Kit Letter. Assign next alert to Parent Coordinator</b>	Letters	X
	<b>DX HL-Phone call (immediately)</b>	2	<b>Contact family to review EHDI and resources. Offer GBYS. Complete ELF and intake form if family opts into GBYS. If family doesn't opt into GBYS, refer to EHDI Dx Hg Loss Protocols.</b>	Phone	X
	<b>Match with GBYS Parent Guide (immediately)</b>	3	<b>GBYS Parent Coordinator contacts appropriate Parent Guide and provides family contact information. Set next alert for 90 days after initial phone call with family.</b>	Phone	X
	<b>Parent Guide Contact Family (48 hrs)</b>	4	<b>Parent Guide contacts family and schedules first face-to-face session.</b>	Phone	X
	<b>2nd Parent Coordinator contact with family (90 days after initial call)</b>	5	<b>Parent Coordinator calls family to confirm that GBYS services are in place and working well. Parent Coordinator sets another alert for 90 days.</b>	Phone	X
	<b>GBYS Completes 6 Hrs with family</b>	6	<b>GBYS Parent Guide completes six hours of time with family, submits session notes, reviews Parent Tool Kit information including parent support organization contact information, and has family complete and return the Parent Guide Satisfaction Survey.</b>	Phone	X
	<b>Final Parent Coordinator contact with family (90 days after 2nd contact)</b>	7	<b>Parent Coordinator calls family inquire about GBYS services, answers questions, ensures that ongoing support and ei are in place. If Parent Guide Satisfaction Survey has not been completed, do this via phone with family.</b>	Phone	X
	<b>Finalize Case</b>	8	<b>Review file, ELF form, notes, etc., and determine if additional follow-up is needed. Finalize and close file.</b>	Finalize	X

# GBYS & EARS

## EHDI Long-term Follow-up (ELF) Form

<b>Name of Informant:</b>	
<b>Role of Informant:</b>	--Select-- ▾
<b>Last Updated:</b>	
<b>Last Updated By:</b>	
<b>Brief EHDI explanation provided?</b>	<input type="radio"/> Yes <input type="radio"/> No
<b>Guide by Your Side</b>	
<b>First contact:</b>	<input type="text"/> 
<b>Participating:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown
<b>Enrolled:</b>	<input type="text"/> 
<b>First Visit:</b>	<input type="text"/> 
<b>Completed:</b>	<input type="text"/> 
<b>Enrolled in First Steps?</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown
<b>Date Enrolled in FS (use approximate if specific date is unknown):</b>	<input type="text"/> 
<b>ED Team Eval</b>	
<b>Scheduled:</b>	<input type="text"/> 
<b>Occurred:</b>	<input type="text"/> 
<b>Signed Reciprocal Release:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown
<b>Technology Used:</b>	<input type="checkbox"/> Hearing Aid <input type="checkbox"/> Cochlear Implant <input type="checkbox"/> FM System <input type="checkbox"/> Other (specify in comments)
<b>Fitting of amplification:</b>	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unsure about pursuing <input type="radio"/> Not Yet Received <input type="radio"/> Left Ear <input type="radio"/> Right Ear <input type="radio"/> Both <input type="radio"/> Loaner <input type="radio"/> Personal

# GBYS & EARS

## EHDI Long-term Follow-up (ELF) Form

SPOE		--Select--
EI Services Received:		<input type="checkbox"/> Audiology <input type="checkbox"/> Speech/Language/Hearing Therapy (First Steps) <input type="checkbox"/> Speech/Language/Hearing Therapy (Private) <input type="checkbox"/> Developmental Therapy (First Steps) <input type="checkbox"/> Deaf/HOH Parent-Infant Program (State) <input type="checkbox"/> Deaf/HOH Parent-Infant Program (private) <input type="checkbox"/> SKI*HI Program <input type="checkbox"/> Occupational Therapy (First Steps) <input type="checkbox"/> Occupational Therapy (private) <input type="checkbox"/> Physical Therapy (First Steps) <input type="checkbox"/> Physical Therapy (private) <input type="checkbox"/> Other
EI Service Frequency (#/period):		0 / --Select--
<b>Enrolled in NECAP</b> <b>NECAP Reports</b> <b>Other Diagnosis/Health</b>	<b>Genetic Eval and Counseling:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown <input type="radio"/> Recommended
	<b>ENT Eval:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown <input type="radio"/> Recommended
	<b>Vision Eval:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown <input type="radio"/> Recommended
	<b>Primary Household Language:</b>	<input type="radio"/> English <input type="radio"/> Spanish <input type="radio"/> ASL <input type="radio"/> Other (Specify in Comments)
	<b>Mother Hearing Status:</b>	<input type="radio"/> normal <input type="radio"/> Hard of Hearing <input type="radio"/> Deaf
	<b>Father Hearing Status:</b>	<input type="radio"/> normal <input type="radio"/> Hard of Hearing <input type="radio"/> Deaf
	<b>Child's Primary Communication Methodology:</b>	--Select--
	<b>Connection with Family Support Organization:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown <input type="radio"/> Recommended
	<b>If yes, please specify:</b>	<input type="text"/>
	<b>Children with Special Healthcare Services info. Received:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown <input type="radio"/> NA
	<b>Parent Toolkit Received:</b>	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown
	<b>Religious Waiver Received Date:</b>	<input type="text"/>
	<b>Child Moved Out of State:</b>	<b>State moved to</b> <input type="text"/> <b>Date state notified by ISDH</b> <input type="text"/>

# Possible Parent Guide Roles & Activities

Work as liaison between families and Part C Intake/Service Coordinators

- Assist families in preparation for the IFSP process
  - Blank IFSP
  - Discover family goals and outcomes
- Discuss
  - Communication opportunities
  - Use of Part C Matrix to choose provider
  - Questions to ask providers
  - Importance of working with quality providers
- Attend IFSP meetings
- Investigate unique service delivery options for
  - Rural families
  - Spanish speaking families
  - Provider Availability
  - Children with other developmental needs



# The Guided Family Notebook: A Snapshot



## Indiana Hands & Voices Guide By Your Side Guided Family Notebook

*Welcome to the Guide By Your Side Program! This family notebook was created to empower families of children who are deaf or hard of hearing to “captain” their child’s team. The materials are designed to help families learn about their child’s hearing loss, early intervention services (First Steps), communication opportunities, how to work with professionals, and much more.*

### **Family Picture!**

**We encourage you to place a picture of your child or family here. This notebook is for you. Personalize it as much as you would like. We are honored to be a part of your family’s journey!**

# GBYS in the EHDI Program: Benefits from the EHDI Perspective

## Full Integration of Parent Partners into EHDI Program

- Provide “parent perspective”
- Assist refinement of procedures and protocols
  - Timeliness of follow-up
  - Bias Checks
  - End User Needs
- EHDI Family Conference
- Identification and training of statewide parent leaders
- Improved Data Sharing
- Improved services to special populations
- Achievement of Family Support Goals & Objectives
- Marketing
- Advocacy
- Public policy

# GBYS in the EHDI Program: Benefits from the EHDI Perspective

## Support, Empower & Encourage Parents on Behalf of EHDI

- Increased level of comfort and willingness to share information during follow-up process
  - Not Passing UNHS
  - Diagnosed Hearing Loss
- Training regarding decision making
- Self Advocacy & improved communication with professionals
- Improved transitions – Part C and Part B
- Referral for additional services, agencies & support organizations

# GBYS in the EHDI Program: Benefits from the Parent Perspective

- Parent led programming
- Statewide parent contacts
- Unique type of support only another parent can provide
- **Early** support to parents after confirmation of hearing loss
- Unbiased and timely resource dissemination and support
- Process for families to discover their strengths and their child's strengths
- Support for families entering the Early Intervention system and other services (i.e. medical)
- Family Guided Notebook materials
- Opportunity for continued support through Hands & Voices Chapter

# Collaborative Activities

- Presentations to SPOE offices
- EHDI Family Conference
- Parent participation on the NICHQ team
- Indiana Family Resource Guide
- Participation on the EHDI Advisory Committee
- Trainer forums
- EHDI Strategic Planning process
- Discussions about Data Management
- Refinement of the EHDI Long-Term Follow-up (ELF) Form

# And Why?



# For More Information .....

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