Keeping “Family” in the Individual Family Services Plan for Deaf or Hard of Hearing Children
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- My Background
- Point of contact for parents and stakeholders requesting Guide services
- Sees to the day-to-day operations of TXGBYS
Texas Guide By Your Side is a parent & family support program that embodies the mission of *Hands & Voices*, which is to provide support in an unbiased manner to families with children who are deaf or hard of hearing.

- Part of a nationally coordinated program that has been tried and tested over time
- 22 Programs and 6 Start Ups around the country and Canada.

[www.txgbys.org](http://www.txgbys.org)
Today’s Presentation Overview

- Background/Guiding Documents
  - IDEA Special Considerations as they relate to Part C
  - JCIH EI Supplement Best Practice Guidelines
  - Protective Factors for Parents
- Categories of Family Outcomes for the IFSP
- How do we practically incorporate this into the IFSP?
  - Examples
  - Tools (provided on handout)
What’s unique?

- 95% of all children who are deaf or hard of hearing are born into hearing families (Mitchell & Karchmer, 2004)

- 90% of these families have no background in deafness or connections to the deaf community (Center for Demographic Studies 1984)

- “The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives.” (D. Luterman, 2006)
Hearing Loss is Simple – right?

- No two audiograms are the same
- You can encounter a huge variety of types and causes of hearing loss
- There is a variety of assistive technology out there
- There is a large variety of communication choices and combinations of choices
- No two families are the same
- Individualized planning is not simple and no one person can be an expert in it all; we have to know who to involve and work together
Families are the Focus, but...

“What works for your child is what makes the choice right!”

- But how do families know where to start and how to evaluate if it’s working?
- Parents don’t know what they don’t know
- How can we help them become knowledgeable, confident and participatory?
The team MUST consider:

- Language
- Communication mode
- Direct communication with peers
- Direct communication with professionals
- Academic level
- FULL range of needs
From IDEA, Part B – Special Considerations to Part C

- How does this relate to the IFSP?
- Consideration of individual needs
- Communication – what’s the big deal?
  - Learning
  - Social Skills
  - Behavior
  - JCIH correlations
Goal 1: All Children Who Are D/HH and Their Families Have Access to Timely and Coordinated Entry Into EI Programs

Recommendation: Develop a mechanism that ensures family access to all available resources and information that is accurate, well-balanced, comprehensive, and conveyed in an unbiased manner.
Goal 9: All Families Will Have Access to Other Families Who Have Children Who Are D/HH and Who Are Appropriately Trained to Provide... Support, Mentorship, and Guidance

Rationale: Families rank family-to-family support as one of the most helpful forms of support for the family.\textsuperscript{27,74} Parents/families reporting participation in social networks with other parents/families of D/HH children had less isolation, greater acceptance of their child, and improved interactional responsivity.\textsuperscript{75} (Hintermair, M., 2000)

Recommendation: Identify collaborative channels to create sustainable and compensated family-to-family support services.
Goal 11: All Children Who Are D/HH and Their Families Have Access to Support, Mentorship, and Guidance From Individuals Who Are D/HH

Rationale: Families who have many contacts with adults who are D/HH exhibit a strong sense of competence with regard to raising their child who is D/HH.\textsuperscript{75} (Hintermair, M., 2000)

Recommendation: Develop and implement guidelines that address providing families with access to D/HH individuals who can provide family support
Self-Efficacy and Social Networks of Families with Deaf/HH Children:

(Hintermair, 2000)
Research suggests that children who have special needs experience three to four times higher risk of maltreatment.

Addressing the development of protective factors can decrease the child’s risk for maltreatment and improve overall health and well-being of children and families.
Six Protective Factors

- Research has shown that these protective factors are linked to a lower incidence of child abuse/neglect and improved well-being:
  - Nurturing and attachment
  - Knowledge of parenting and of child and youth development
  - Parental resilience
  - Social connections
  - Concrete supports for parents
  - Social and emotional competence of children
Who are the players?
What’s the focus?
What’s the format?
Where do we start? (Next slide)
How do we incorporate additional Family Services and Family Outcomes in the IFSP?
Determining Strengths and Needs of the Child and the Family (Assessment)

"A family-directed assessment must be conducted by qualified personnel in order to identify the families' resources, priorities and concerns and the supports and services necessary to enhance the family's capacity to meet the developmental needs of the family's infant or toddler with a disability.

The family-directed assessment must-
(i) Be voluntary on the part of each family member participating in the assessment;
(ii) Be based on information obtained through an assessment tool and also through an interview with those family members who elect to participate in the assessment; and
(iii) Include the family's description of its resources, priorities and concerns related to enhancing the child's development."
Possible Categories of Outcomes

- **Services:**
  - Family Education
  - Specialized Skills Training

- **Outcomes:**
  - Communication
  - Self-Advocacy
  - Safety
  - Support/Self Efficacy
Decisions should be arrived at through a process.

- “Informed Choices” resources
- CDC Decision Guide to Communication Choices
- Communication Considerations A-Z

AI Teachers, GBYS Parent Guides and D/HH Guides can help parents explore this outcome.

*Family will work with TXGBYS Parent Guide and/or D/HH Guide to explore communication choices using the CDC Decision Guide to Communication Choices*
Communication Category Cont’d

- During and after a family makes an initial decision regarding communication, national, state and local resources should be identified and incorporated into outcomes. These are a partial listing of many resources available to families.
  - AG Bell
  - American Society for Deaf Children
  - National Cued Speech Association
  - Hands & Voices
  - John Tracy Clinic / Correspondence Course
  - NCHAM, etc...

*Family will contact abc resources to enhance their knowledge of xyz communication approach(s).*
Decisions, Decisions, Decisions ...

- Families’ decisions are often based upon their views of the world, their experiences, and their goals for their children and their individual family situations (Sass-Lehrer, 2002).

- This can change over time or depending on receptive/expressive abilities, changing environment, etc.

- Due to all the information parents are asked to process, we need to continually support and re-introduce materials and resources and help families explore and re-visit outcomes and services. The goal is not to make one decision before 3 yrs., but to create the habit of observing and reviewing the progress of the child. These skills will serve the parent/child in the long run and carry over into the IEP process. (Lisa Crawford, ERCOD Statewide Parent Liaison)
Referrals to programs / services can serve as outcomes

Family will contact Family Signs Program to explore virtual sign language instruction in language of their choice.

Family will contact Shared Reading Project to begin individualized services/instruction on how to create a love of books and read to your child using a manual language.
Self-advocacy skills are key for the child as they get older. The long term goal is to have the child lead the process.

As the child’s role expands the parent’s role changes and eventually decreases. The birth to 3 process is just the beginning.

In the meantime, the parent needs to learn advocacy skills, too.
The parents (and the child to the extent developmentally possible) need to be knowledgeable about:

- The child’s hearing loss
- The child’s use of technology
- How the child prefers to learn
- What their rights are within the law
- How to collaborate with professionals
Self-Advocacy Outcomes

Family will keep a journal and report on observations and examples of when baby Joe seemed to engage more with visual input, with auditory input and/or sensory/kinesthetic input.

In preparation for transition to Part B, Parent will participate with their GBYS Parent Guide in a guided review of [H&V Advocacy for Deaf and Hard of Hearing Children](#)

Family will work with Audiologist, AI teacher and Parent Guide to be able to accurately describe baby Joe’s audiogram and what his hearing levels are.

Family will learn hearing aid maintenance and use ling sounds to check Joe’s hearing aids on a daily basis.

Baby Joe will point to his ear and nod when he hears or point to ear and shake his head ‘no’ when the hearing aid is not working.

Family will work with GBYS D/HH Guide to identify appropriate assistive technology for home such as flashers for the smoke alarm, door bell and phone, captions on TV, etc.
C. Safety Category

- Protective factors (slide 16) help parents to find resources, supports, or coping strategies that allow them to parent effectively, even under stress.

- The use of parent to parent contacts and contact with deaf/hard of hearing adults has demonstrated strengthening of these protective factors.
Safety Outcomes

The child will give clear nonverbal, signed or spoken “no” to uncomfortable interaction through role play and real life activities followed by appropriate parent response to that “no.” including an explanation when interaction is necessary for health or safety of child (e.g., medical visits, hygiene).

The family will understand their role in child safety by a guided review with a GBYS Parent Guide of Parent Plan for Child Safety Hands and Voices.

Parents can describe physical and emotional signs of suspected abuse or neglect in a very young child and parents will understand the methods to report suspected abuse or neglect for any child.

Parents will explore and break down barriers to acceptance and nurturing of their deaf or hard of hearing child using support from a GBYS Parent Guide or D/HH Guide.
This is an over-arching category that links to all of the background information/research as well as other categories for IFSP outcomes introduced today.

**self-efficacy** (self'-e·fē·kē), adj. positive subjective assessment of one's ability to cope with a given situation; sense of personal power.

Self-efficacy plays a critical role in how we think, feel and behave.

Self-identity and self-concept for both parent and child are included in this category.
Support and Self-Efficacy Cont’d

- Parent support: general disabilities, through vendors or national organizations
- D/HH specific parent support organization: TXH&V and TX GBYS Program – support and information is offered in an unbiased manner
  - Parent Guides
  - Deaf/Hard of Hearing Guides
The Family is at the Center

- **Supported families** are emotionally healthy, and ready to face their responsibilities.

- **Informed families** have the resources to make good decisions, take ownership of decisions and outcomes, and are better partners with professionals in the process.

- **Modeling by other families** – family’s learn best by seeing other families in action.
WHAT PARENTS SAY:

“Texas Hands and Voices and their Guide by Your Side program have been VERY beneficial to our family from the moment we got the diagnosis that our daughter was deaf. They provide parent to parent support and paired us with another parent that has walked this journey before.”

(parent, Tiffany Savage)

WHAT PROVIDERS SAY:

“As a provider who works every day with families of deaf and hard of hearing children, I lean heavily on Texas Hands and Voices GBYS program to help make sure families have the critical support they need from other families. The feeling of isolation as a parent of a deaf child can be overwhelming, and GBYS addresses it immediately and thoroughly. The executive staff at Texas H&V is a very passionate and committed group of parents, and it has been a real pleasure to collaborate with them!”

(provider, Dr. Rachel St. John, Director, Family Focused Center on Deafness, Children’s Med. Center Dallas and UT Southwestern)
Support/Self-Efficacy Outcomes

The family will request a parent guide and/or Deaf/HH Guide from TXH&V GBYS Program.

The family will “like” the TXH&V Facebook page and participate in monthly chat events on Facebook.

The family will seek out and attend an event for families of d/hh children.

The family will seek out and attend a Deaf community event.
FAMILY outcomes may not meet the same prescribed criteria as other child-focused developmental outcomes.

Outcome should still provide details as to:

- Which staff / provider outside ECI
- How/where they will work together with a family
- Methods used (such as supported coaching and guided research)
- Steps to take between visits (family ‘homework’)
How to Refer to GBYS — *GBYS is here to support the Service Coordinator, the AI Teacher, and the family.

- On-line form to request services. Parents can self-refer. Professionals can also request services for staff or families they serve.

  English  [http://GBYS.formstack.com/forms/request](http://GBYS.formstack.com/forms/request)

  Spanish  [http://GBYS.formstack.com/forms/requestSP](http://GBYS.formstack.com/forms/requestSP)

- For professionals referring in the TEHDI/OZ esP database select: Professional Contacts -> Parent Group -> Texas Hands & Voices
Our Texas Guides

**DEAF/HH Guides:**

- Pamela Farley  
  Austin area
- Brian Rapp  
  Tyler area
- Chely Davidson*  
  Tyler/Nacogdoches
- Cori Smith  
  DFW area
- Carolyn Colley  
  Houston area
- Jon Leach  
  Houston area

* culturally Hispanic
Our Texas Guides

PARENT GUIDES: * denotes Spanish speaking Guides

- Terry Myers* El Paso
- Linda Lartigue* San Antonio
- Jamie Gordon Corpus Christi
- Lisa Bates DFW area
- Tiffany Savage DFW area
- Denisse Gonzalez* DFW area
- Susie Gonzalez* Houston area
- Tina Proctor* The Valley
- Jennifer Peterson Austin area
- Melissa Duron* Austin area
- Brandie Via Amarillo
- Katie Rapp Tyler area
Texas GBYS website: [www.txgbys.org](http://www.txgbys.org)

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The Guide talked to us like hearing loss was normal. I want to be like that. I just knew after talking with the Guide that everything was going to be okay."
We appreciate all you do for families in Texas and look forward to collaboration on any level...

Thank you for your time!!