

Hands & Voices Guide By Your Side Frequently Asked Questions and Guiding Principles

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Section 1: GBYS Program Description

1. What is Guide By Your Side?

Hands & Voices Guide By Your Side (GBYS)TM is a replicable family support program that embodies the mission and vision of Hands & VoicesTM, which is to provide unbiased support to families with children who are deaf or hard of hearing. GBYS does this through specially trained parents of children who are deaf or hard of hearing. These parents work as "Guides" directly with families who have just learned of their child's hearing condition, or who have older children and are in need of the unique support that comes from someone else who has walked this path him/herself and can share from direct experience and wisdom. GBYS programs can also include an option for Deaf/Hard of Hearing Guides (DHH Guides) who are deaf or hard of hearing adults and specially trained to provide support to families. GBYS has been created to be a flexible program that will meet the unique family support and outreach needs of your state/province.

2. How does a GBYS program work?

GBYS programs are grounded in the Hands & Voices values described while being adapted to the particular focus of an H&V chapter and state/territory system in which they exist. Chapters along with funding agency(ies) partners determine the goals of the program based on the needs identified in the state/province. Your GBYS program may consist of one or more of the following elements:

- Provide timely parent-to-parent support at the time of confirmation of a hearing condition.
- Offer specific support and resource dissemination about deafness/hearing loss in addition to general Part C service coordination system and support and/or Part B school age services depending on the age of the identified child.
- Reduce the risk of loss to follow up by timely connection of GBYS Parent Guides to families with babies who do not pass/refer on the newborn hearing screening.
- Influence and improve the systems designed to serve families and their children who are deaf or hard of hearing by providing a recognized role for GBYS Program Coordinator and Guides.
- Assure continuity to families by providing support throughout a child's life, especially at times of transitions; GBYS is not limited to a specific age range.

Provide not only Parent Guides, but trained Deaf or Hard of Hearing (DHH)
Guides to families with newly identified babies, young children, or to seasoned
parents with teenagers who are deaf or hard of hearing. Exposure to DHH adults
can provide families and DHH children with invaluable perspectives that come
from personal experience.

3. What kind of specialized knowledge and skills will the GBYS Guides have?

- Experiential knowledge of joys and challenges of raising a child who is deaf or hard of hearing
- Sensitivity to the range of emotional responses that families experience
- Information about early intervention and educational program options
- Specialized parenting skills that emphasize meeting the unique needs of a child who is deaf or hard of hearing
- Unbiased information and emphasis on the support of the family in the decision-making process for their child and family
- Local, state, provincial, national resources specific to children who are deaf or hard of hearing
- Knowledge of the state/provincial EHDI system
- Formalized GBYS training from and on-going affiliation with Hands & Voices

Section 2: FAQs about Program Implementation

1. Can GBYS be implemented without a Hands & Voices Chapter?

No, GBYS is a licensed and copyright-protected property of Hands & Voices. Hands & Voices has the sole authority to grant use of GBYS programs to Hands & Voices chapters that meet the criteria for its operation as appropriate; demonstrated support for H&V/GBYS Guiding Principles and active H&V membership. The name Guide By Your Side cannot be used except as authorized, and it cannot be represented separately from Hands & Voices. H&V chapters working in concert with state/province agencies to offer GBYS may include reference to their state/province in the program title, i.e., "Colorado Hands & Voices/GBYS." All GBYS programs must complete a formal application and approval process as described in the GBYS Operations Manual.

2. How is H&V /GBYS program model different from other forms of family support?

At the foundation of GBYS is our Hands & Voices value of peer support, and a parentdriven agenda. There is a comfort level that happens very naturally between parents who can relate to each other's experience of coping with their child's hearing condition, and facing the challenges of navigating a service system that was created and implemented by professionals. This process can be confusing to the uninitiated, and the benefit of having someone who's "been there, done that" is inestimable. Assuring that the quality of the interaction upholds our mission of unbiased support is the purpose of required training for our Parent Guides and DHH Guides to be appropriate in their GBYS roles.

As a parent-driven, parent/professional collaborative organization, Hands & Voices has a proven track record of success with family support, and our GBYS program operationalizes our special brand of support at the systems-level.

3. How do we start a GBYS program in our state/province?

The GBYS Operations Manual provides specific, comprehensive directions for program application and start up. However, the following provides a brief and broad description of the program and what is entailed in the start up process.

- **a. CONSIDERATIONS**: The following are questions to consider when thinking about the implementation of a Guide By Your Side Program and the necessary capacity to support it.
 - 1. Funding: Do you have funds to pay the GBYS Program staff, program expenses, and program activities?
 - 2. Sustainability: Do you have the infrastructure to hire program staff and sustain this program over time?
 - 3. Collaboration: Do you have formal ties between your H&V chapter, state/province agencies, and other stakeholders needed to facilitate trainings, referrals?
 - 4. Parent Leadership: The GBYS Coordinator (must be an H&V parent of a child who is DHH) must demonstrate leadership capacity; this is also true for the Parent Guides. The H&V chapter may have people like this within its ranks, or recruitment of the same may also be necessary.
 - 5. Quality Control: Do you have a way to continuously monitor and evaluate the GBYS program? All Guides must be held to the Hands & Voices mission and philosophy. The Hands & Voices chapter is responsible for program support and oversight so needed infrastructure is required.

b. START UP STEPS:

- 1. Bring your stakeholders together to review and discuss Hands & Voices/GBYS Guiding Principles.
- 2. Prioritize parent support goals and objectives for your state/province.
- 3. Review potential GBYS components and discuss which may be applicable for your state/province.
- 4. Identify a GBYS Program Coordinator who is a trained H&V parent, or a parent who will become trained and join Hands & Voices. This person is the GBYS liaison between the local H&V chapter, and/or H&V HQ, and funding agency(ies).
- 5. Decide from where/how the program will administered.
- 6. Identify budgetary issues and project sustainable funding.

7. Contact H&V HQ offices to notify them of an effort for GBYS start up in your state/province; access GBYS Operating Manual and application: http://www.handsandvoices.org/gbys/secure/index.html

Chapters will be required to submit an application to implement the GBYS Program. Hands & Voices HQ has a program approval committee who reviews all applications and provides a response. After application approval, H&V/GBYS will provide required training and technical assistance to your chapter as you move forward with implementation. Fees apply.

4. What are the benefits of being part of the Hands & Voices HQ program?

The benefits to starting GBYS are that you will be training parent leaders, incorporating DHH perspectives, and embedding parent/professional collaboration into your EHDI/Part B/C and family support systems. This will increase both the effectiveness of state/province EHDI Systems and their capacity to serve families. Research acknowledges the role of parent-peer connections. (Åsberg, Vogel, & Bowers, 2007; Bradham, Houston, Guignard, & Hoffman, 2011; Brown & Remine, 2008; Dalzell, Nelson, Haigh, Williams, & Monti, 2007; Eleweke, Gilbert, & Bays, 2008; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Fitzpatrick, 2010; Hardonk et al., 2013; Jackson, Wegner, & Turnbull, 2010; Jackson, 2011; Jamieson, Zaidman-Zait, & Poon, 2011; Larson, Munoz, DesGeorges, Nelson, & Kennedy, 2012; Lederberg & Golbach, 2002; Muñoz, Blaiser, & Barwick, 2013; Poon & Zaidman-Zait, 2014; Sipal & Sayin, 2012).

Hands & Voices is utilizing an evidenced based Conceptual Framework of Parent to Parent Support for Parents of Children who are Deaf or Hard of Hearing in their training. In a literature review of 39 peer-reviewed articles published from 2000 to 2014, Henderson, Johnson and Moodie describe the importance of parent-to-parent support in helping to guide parents on how to advocate on behalf of their child and access special education and other services. Peer parental support systems boost parental morale and confidence when looking toward the future at points of transition. Parents are better positioned to support the goals chosen by the child through meaningful collaboration. The findings of this dual-stage scoping review and electronic Delphi study provide a conceptual framework that defines the vital contribution of parents in Early Hearing Detection and Intervention programs.

http://aja.pubs.asha.org/article.aspx?articleid=1915171

Why re-invent the wheel? Hands & Voices has a strong, credible reputation for balanced, sensitive, and meaningful family support. Implementing a program like H&V/GBYS gives your state/province the advantage of replicating a successful proven model. Plus, when GBYS Parent Guides or DHH Guides fulfill their budget-allotted contact with families, the local Hands & Voices chapter remains as a source to refer families for networking, information and on-going support that upholds the values of Hands & Voices GBYS.

5. What will Hands & Voices provide to states/provinces?

- **a.** Access to skilled trainers and GBYS curriculum.
- **b.** Web-based and on-site training:
 - Technical assistance for program planning, implementation and administration
 - On-site GBYS training and presentation materials for GBYS Coordinator and Guides
 - On-going training opportunities through the annual leadership conference and virtual training
- **c.** Opportunity to train state/province stakeholders in Hands & Voices GBYS and Supporting Families Without Bias at a session in the morning of the first day of onsite training. (the rest of the 2 day initial training is closed to just the program staff)
- **d.** GBYS Operations Manual, which will include information about:
 - State/province requirements to H&V's HQ office
 - Memorandum of Understanding
 - Expectations for H&V Chapter leadership
 - Overview of essential GBYS training requirements
 - Curriculum Overview
 - Administrative recommendations & models
 - Program Goals & Objectives
 - Hiring guidelines and qualification requirements for guides
 - Ongoing training & meeting forum suggestions
 - Potential program activities
 - Program policies, procedures and paperwork
 - GBYS Program Coordinator job description
 - Examples of Guide interview questions
 - Guide position descriptions
 - List of specialized skills
 - Applications
 - Sample referral forms and other templates
 - Sample confidentiality guidelines and consent form

6. How much does it cost to have the initial training?

The GBYS Basic-Training Package (which includes required courses) features two H&V trainers and curriculum. Cost is based on number of days (two generally required) and customized training needs as identified. Sample agendas and basic training recommendations are available upon request, however budgets usually range from \$5000-\$6000 (including travel and expenses).

Hands & Voices Guide By Your Side Program Guiding Principles

GBYS programs are grounded with Guiding Principles while being adapted to the priorities and administrative structures of the Hands & Voices chapter and the state/provincial system in which they exist. GBYS is a deaf and hard of hearing categorically specific program. The following Guiding Principles were developed in order to create a consistent set of standards by which every GBYS program should adhere:

Principle 1. Parent Leadership is required; Deaf/Hard of Hearing specific focus is maintained.

- The GBYS Program Coordinator must be a qualified parent of a child who is deaf or hard of hearing.
- All Parent Guides are parents of children who are deaf or hard of hearing.
- All GBYS Parent and DHH Guides include diverse communicators and lived experiences with unbiased attitudes.
- All GBYS Program Coordinators, Parent Guides, and DHH Guides are members of the Hands & Voices local Chapter.

Principle 2. Collaboration is essential.

- GBYS parent leaders and professional partners share peer-level status as collaborators in this family support endeavor.
- Strong, formal relationships exist between GBYS agency/program partners and Hand & Voices.
- All parties agree that the Hands & Voices chapter has philosophical and functional ownership of the GBYS program and documented by M.O.U. signed by all collaborators.
- Hands & Voices HQ promotes collaboration amongst all GBYS programs through a structure of quarterly virtual meetings and facilitating a closed online forum for discussion and sharing of resources.

Principle 3. All GBYS programs will abide by the values of the H&V organization.

- Parent leadership is actualized through program decision making.
- Professional collaboration is an essential element of the program.
- Full range of communication & service options are equitably presented.
- Exposure to Guides who represent diverse models of communication that exemplify the Hands & Voices slogan, "What works for your child is what makes the choice right."
- Flexible program administration designed to meet individual state/provincial needs.
- Full and effective communication access included in all aspects of the program.

Principle 4. Cultural representation and sensitivity included as core program values.

- Trainings are not held on days of cultural, religious, or ethnic holidays.
- Program works in collaboration with existing state/province cultural advocates and organizations.
- Materials strive to be available in the language of the GBYS Guides and families whom they serve.
- Programs are encouraged to have Guides who can represent the cultural needs/population specific to their state/province.
- The GBYS Program seeks to institutionalize cultural and linguistic competence in policies, structures, practices, procedures and dedicated resources.
- Deaf Cultural values are acknowledged and respected.
- Sensitivity to the diverse life experiences of all Deaf and Hard of Hearing Adults are honored and respected.

Principle 5. Uncompromised commitment to supporting families according to their unique needs, priorities and values.

- Regardless of geographical location, socio-economic status, communication method or mode, educational choices, or life choices, all families will be offered GBYS family Support.
- Family Support will be provided through GBYS that is consistent with Hands & Voices mission, vision and philosophical alignment.
- GBYS programming will ensure flexibility and be family driven based on the needs of the individual families served.

Principle 6. Cohesion and commonality benefit GBYS programs.

- GBYS programs in each state/province will share a common mission, vision, culture, and stake in each other's success that:
 - o Is consistent with Hands & Voices values.
 - o Shares in a relationship and in communication with one another.
 - o Offers continuous training and quality improvement.
 - o Is accountable for evaluation of family satisfaction and outcomes.
- Hands & Voices Chapters with GBYS Programs will ensure Cohesion Indicators are followed and minimally reviewed annually and evaluated through the GBYS Program Annual Health Assessment.

Principle 7. State/provincial agencies, program partners, and the Chapter have a responsibility for committed and sustainable funding.

- GBYS Parent Coordinator, Parent Guides and/or DHH Guides are paid for their time, including training.
- Flexibility for rate and type of compensation consistent with standard business practices and determined by the H&V Chapter.
- Chapter administration of the GBYS program is included in the annual budget through either a paid chapter position and/or an administrative fee.
- Reasonable expenses are to be considered and included into the budget.

- Program Coordinators attendance to the H&V Annual Leadership Conference will be supported and included in the program budget. Consideration for Guides attendance will be given as well.
- Program Coordinator and Guides Chapter membership dues are included in the program budget.

Principle 8. GBYS Guides are provided initial and on-going training plus support for their participation in Hands & Voices Chapter activities and monitored through the H&V Leveled Recognition Program.

- H&V GBYS basic training curriculum is required at initial training including;
 - o Hands & Voices Organizational and GBYS Program Overview.
 - o Supporting families without bias and how to share personal stories in unbiased manner.
 - o How to share information and resources for the full continuum of communication and educational options.
 - Preparation for providing appropriate emotional support and acceptance of every family's choices around communication options and other life choices.
 - Role playing common questions asked by parents served through GBYS and how to handle questions a Guide may not have an answer.
 - o Confidentiality standards and practices considerations.
 - Functional understanding of formal systems and services available to families and their children in the state/province where they live as well as National resources.
 - o Regular and on-going communication within the GBYS program for Guides to exchange information, insights and inspiration.
 - o Annual Self-Evaluation and personal goal setting is required.
 - On-going training is monitored annually through the Leveled Recognition Program.

For information about the *Guide By Your Side* Program, contact: GBYS@handsandvoices.org