

Unanswered Questions from Family Engagement Webinar, held 9/2/16

1. **Question:** Louisiana mentioned attending pediatric conferences to educate them about hearing loss and referrals- how did you get invited to that or how did you go about getting there to speak with them?

Response:

- a. LA- Our LA Chapter Champion, Dr. Thira Choojitarom has been able to secure at least a 15-minute slot on the lunchtime agenda for a few years. This past year Dr. Choo arranged for Dr. Rachel St. John to be the keynote speaker. Following her presentation, she introduced the LA EHDI Follow-up Coordinator and Program Manager who were available to answer state specific questions.
- b. WY- WY EHDI asks the Hands and Voices Chapter to identify families to whom they would like to offer the opportunity to travel to the National Hands and Voices Conference and/or the Annual EHDI conference. Expenses are paid by EHDI. Depending upon families that are available, from one to six families have been sent at a time. However, it is much more likely that it will be one or two families instead of more than two. If Hands and Voices does not have someone they can identify, then the EHDI staff and EI providers are provided the same opportunity to offer the opportunity to families.
- c. CO- The CO AAP Chapter Champion is going to get the EHDI state team on the agenda. We hope to do a pre/post questionnaire to measure knowledge gained. In addition we are considering putting information into the CO AAP newsletter to provide better education.

In addition, as an attempt at “just-in-time” education, the CO-Hears as first representatives to meet families in the EI system occasionally send a letter informing physicians about the entrance of a child into EI with a description of services offered to encourage physicians to seek diagnostics and early intervention earlier for other children in their practice while the topic may be most relevant to them. We hope to systematize this procedure through the EHDI database in our state.

2. **Question:** Wyoming- Will you please review and expound upon what your paid parent does as a H&V employee?

Response:

- a. LA- Our parents are not H&V employees; they are paid through LA EHDI. Parents are involved in all aspects of the EHDI process 1) contacting families of infants who are lost to follow-up after failed newborn screening, 2) providing parent-to-parent support after diagnosis and through the family’s journey, and 3) providing training to other parents and professionals (e.g., physician offices that rescreen, LSU audiology students, grand rounds for physician residents, annual LA pediatric conference, early intervention providers, statewide conferences, EI providers). Parents also coordinate regional H&V activities for families across the state.
- b. WY- Kim Reimann is the WY Pediatric Audiology Clinic Coordinator. She also presents to doctors at Grand Rounds when she can. She helped author Hearing Health Information (HHI) in combination with an EI/SLP and another parent. This information was distributed to

medical personnel (Pediatricians, Family Practice, PA's, DO's, ENT's). These are just some of the work Kim does to further the engagement of medical personnel and parents of child who have a child who is d/hoh. We also send money to WY Hands and Voices for the Executive Director to use at her discretion...It can go to salaries, newsletters, travel, etc., etc.

- a. CO- The CO Guide By Your Side meets with referred families to discuss parent support, share resources in a specific area of the state, connect families to each other, and offer ongoing connection to H&V as children grow, enter preschool, and beyond. They will also provide support at IFSP & IEP meetings to ensure that Part C and school districts are meeting the needs of the child (birth through age 21). They host local events for parents, from formal workshops on topics from pragmatic language to IDEA, or informal gatherings to give families an opportunity to interact with each other and identified Deaf and hard of hearing role models. Parent guides also serve on regional EHDI team meetings and create/update resources to share with families through our quarterly newspaper, monthly e-news, or published resource guides (a general Guide for new families, or the Parent Funding Toolkit, or the Bridge to Preschool transition booklet are three of the most popular resources.) Guides serve either regionally or as specialty guides. Current specialty guides are placed at the state school for the deaf, a Spanish speaking guide, and a guide who has a child with Microtia/atresia/unilateral loss.

3. **Question:** Can Colorado reiterate what they said about the Evidence based practice model for family support?

Response:

- a. LA- Parents provide details of their meetings, workshops, presentations, contacts with families and professionals, etc. through monthly activity reports.
 - b. WY- We are able to “count” things that have been done, i.e. number of educational materials shared with how many people, etc. We send a survey to each family who attends the Pediatric Diagnostic Clinic “run” by Wy EHDI. BUT measuring (and using Evidence Based practice) has been “not so much” up to this point. We are planning to improve that component of our work if the FOA is funded.
 - c. CO- We are involved in a project group tasked with creating family learning outcomes based on the model shared of parent-to parent support in the last slide of our section, supporting a rubric of measurable outcomes we feel would assist in the development of a learning parent into a supporting parent, at least at a level where a parent has a sense of competence and well-being around caring and meeting the needs for their child who is deaf/hard of hearing. See Henderson, Rebecca, “Parent-to-Parent Support for Parents of children who are Deaf or Hard of Hearing: A Conceptual Framework” (2015) Electronic Thesis and Dissertation Repository. Paper 311
4. **Question:** Can you share the letter Wyoming uses to encourage families to go to follow up appointments? And what term does your state use for a

child who needs a diagnostic work up after a newborn screening? Refer?
Do not pass?

Response:

- a. LA- Will post on VLC. We state “Your baby's hearing test in the hospital at birth showed that he/she needs more testing.”
 - b. WY- Will post on VLC. We say both, “referred on the screening” or failed on the screening...no rule to follow.
 - c. CO- Currently the parent letters come from the CO Dept. of Public Health. However, we are looking into those letters coming from H&V instead. Will post on the VLC
5. **Question:** I think I saw that Wyoming EHDI uses FaceTime to engage with parents and EI? Can you talk a little more about how that works?

Response:

- a. WY- It is along the same lines as tele-therapy. Our EI support person (SLP/Susan Fischer) connects with EI providers and parents to determine their needs/wants and then schedules a time for them to meet via Face time to discuss their questions. Susan mentors EI providers and parents on an on-going basis via this venue...also going to meet person to person from time to time. The service is offered to all families and EI providers when a child is diagnosed and can continue as long as there is interest (expressed as active engagement) by the family and or the EI provider.
- b. CO- We are just starting to offer SKYPE or Facetime or Zoom for families who live far from Guides where travel is not practical,

though we try hard to recruit Guides from a wide geographic area to better meet the needs of the whole state.

6. **Question:** How do you recruit guides?

Response:

- a. LA- Initially, a GBYS statewide training was offered to any parents interested in learning about GBYS. Parents were provided a childcare/transportation stipend, hotel expenses were paid for families who did not live within driving distance, and meals were provided. From that group of about 20 parents, we were able to learn more about potential applicants and measure their interest. Potential parent guides were then interviewed by our EHDI parent consultant and a member of our EHDI staff. From that initial training group, 4 parent guides were hired, and as our GBYS program has grown, 3 additional parent guides have been hired.
 - b. WY- We do not have guides.
 - c. CO- We ask for recommendations from all of our collaborative partners for new parent candidates, and consider those we have met through GBYS efforts as well. We also post “ads” on our Facebook pages and through eblasts, but we find the best candidates come through parents we have already met or referrals from providers.
7. **Question:** For the states that have direct referral to GBYS, do you refer ALL families w DHH kids or just the ones LTF/LTD (i.e. those not taking the next step)

Response:

- a. LA- In Louisiana every child with a confirmed hearing loss is referred to a GBYS Parent Guide, and the designated single point of entry for Deaf/HOH kids into early intervention, the Parent Pupil Education Program (PPEP) through LA School for the Deaf (LSD). Two of our Parent Guides also send letters and make phone calls to families of infants LTF, and fax PCP's of those infants.
 - b. WY- We ask permission of all families with children identified with hearing loss to allow us to refer them to WY Hands and Voices. I do not know of anyone who has not given permission to be referred to Hands and Voices. But then sometimes I "don't know everything that is going on!!!".
 - c. CO- Currently the referral comes after the identification by an audiologist or entrance into the EI program. A few families find us through the internet or parent roadmaps on their own, or are referred by teachers of the deaf as well. An improvement we want to make is to have a referral directly from our EHDI database to Hands & Voices with an MOU between CDPHE (health dept.) and the University of Colorado (where the HRSA grant lives), and we are also looking at an "opt-out" system to better capture referrals to the majority of parents.
8. **Question:** How do the parent guides work with the early intervention providers?

Response:

- a. LA- In LA our parent guides currently meet twice a year for a face-to-face meeting with the PPEP Outreach Teachers to discuss family

needs and share information (PPEP Outreach Teachers have a signed Release of Information for each family). We have added a training component to these face-to-face meetings. Our Lead ASTra Advocate provided training on the IEP process and next month will provide training on IFSP. Additionally, our parent guides and EI providers maintain contact to be able to better assist our families.

- b. WY- We do not have the GBYS program.
- c. CO- The parent guides work directly with the Colorado Hearing Resource Providers (CO-Hear). Sometimes they will meet the family together as a team. The parent guides seek to invite families to participate in ongoing events, receive the newspaper on a quarterly basis, and otherwise stay connected with the parent group long-term. The Colorado Home Intervention Program and H&V regularly co-host events to help families meet each other, and parent guides serve on the Colorado Home Intervention Program advisory committee, while a CO-Hear also serves on the H&V board of directors.

9. **Question:** How are your programs notified of children with newly diagnosed hearing loss?

Response:

- a. LA- When a child is diagnosed with hearing loss, the audiologist submits a follow-up services report to LA EHDI, and within 48 hours, the child is referred to a GBYS parent guide, and PPEP.
- b. WY- Audiologists, EI providers, families. No 'set' process. We follow all kids who have failed their birth screening so we hound people for

results. The audiologists licensed in WY received an advisory letter from the Licensure Board educating them to report all children (infants, toddlers and preschoolers) identified with hearing loss to the WY EHDI program. We have not seen too much of a change in reporting since that happened. We are trying to get it into the Rules and Regs attached to our legislation so it has more “teeth”.

- c. CO- The diagnosing audiologist inputs the results of the evaluation directly into the EHDI data system, which is populated by the electronic birth certificate of babies who have missed or did not pass a second screen. That triggers a referral to the CO-Hear Coordinator. The CO-Hear then meets with the family and asks if they would like parent support. If so they refer them to Hands & Voices and the respective GBYS.

10.Question: To all the presenters: How do you evaluate your family support programs (in other words, quality? impact? timeliness? impact on families reaching 1-3-6 milestones?) Please share quantitative and/or qualitative measures you use.

Response:

- a. LA- Our EHDI Tracking Coordinator tracks all babies with permanent childhood hearing loss from screening through diagnostics and entry into EI. Specifically, we track date of 1) referral to EI, 2) entry into EI, 3) referral to a GBYS parent guide, and 4) GBYS initial family contact. Achievement of 1-3-6 goals are also tracked. Additionally, beginning with our 2015 births, this quantitative data is captured in our LA EHDI Information System, which streamlines reporting and tracking. We

do not currently have a method to measure the qualitative impact of family-to-family support. We plan to address this over the next 3 years.

- b. WY- Our 1,3 6 numbers are measured, of course. These numbers reflect family engagement and support in an indirect fashion...if the family is not engaged then the child typically does not meet the 1/3/6 guidelines ...BUT, again, we have not had much setup to DIRECTLY measure the effects of family support. We hope to do more of this if the FOA application is funded!!
- c. CO- H&V sent out parent surveys to determine how well they are meeting the needs of families. In addition, H & V is now keeping track of the time from referral to the date a family was contacted by a parent guide. We are going to add fields to the EHDI IS so the parent guides can add this information and be able to more accurately identify how many families receive support, when and how. Random surveys after GBYS contact are in the plans for next year.

11.Question: Do any of these programs include a deaf person/professional meeting the family early on?

Response:

- a. LA- Meeting a Deaf mentor is available through LA School for the Deaf, but there is no systematic procedure in place to ensure that this is offered. We plan to address this over the next three years.
- b. WY- We offer the Shared Reading Program via an agreement with CSDB (ASL-Gallaudet) as well as an English Word Order reading program to families (limit of seven families receiving this program at

a time). These programs are taught by Deaf individuals or adults who use CI.

- c. CO- Colorado is very fortunate that there are Deaf/hard of hearing professionals involved in every aspect of the EHDI system. A family may have a Deaf audiologist, or meet a Deaf early interventionist or a Deaf mentor right in their hospital clinic after identification.

Deaf/hard of hearing mentors also sit on the Colorado Infant Hearing Advisory Committee and regularly give input to the EHDI system, most recently in the language used in an updated brochure. There is currently a Deaf/Hard of Hearing mentor program called the Partner Project. While small, these mentors are oriented to their role, benefit from learning about one another's stories, come from diverse backgrounds, have different levels of hearing loss and experiences with equipment usage, and are prepared to reach out to families and school programs to share their experiences for the benefit of young children. Families are encouraged to meet many different types of role models regardless of how their child might choose to communicate currently. Our state school for the deaf also has a large library of role model videos that families and school programs can view on their website.

12.Question: If so how are deaf mentors funded and do they Do any of these programs include ASL tutoring to the families?

Response:

- a. LA- Deaf mentor services and ASL instruction services are offered through the LA School for the Deaf.

b. WY- See question 11 with WY answer

13.Question: I just quickly checked the CO Roadmap, is there a certain reason why each region has its own roadmap? Would the procedure maybe be different for each region?

Response:

- a. LA- We are currently working on revising the LA roadmap. If audiology facilities are listed on the back, this would be the only regional difference.
- d. CO- Because CO has such large diversity between urban, rural, and frontier communities we felt it best to customize so families receive local resources to help them navigate their system best as possible. This is in keeping with the public health goals to make entry into the system as seamless as possible for families.

14.Question: How are your state's EHDI programs funded?

Response:

- a. LA- Federal Grants
- b. WY- Federal Grants and State Trust and Agency funds
- e. CO- Currently only with CDC and HRSA funding. We will be looking at going back to legislation for sustainability in funding and more define statutory regulations to ensure follow-up from screening through early intervention including parent support.

15.Question: Could these speakers clarify - are these parent surveys/evaluations sent by the EHDI program or by Hands & Voices?

Response:

- a. LA- The surveys sent are from both EHDI and Guide by Your Side.

- b. WY- The survey we send to parents about our clinic comes from a parent who works for EHDI...so BOTH.
- c. CO- CO had funding from CDC over 10 years ago to send out extensive surveys to parents. There was not specific parent component other than they could check if they received those services. Many parents commented that meeting another parent was the most helpful early in their journey. I will post these on the VLC.

16.Question: How do you help parent support providers emphasize and respect parent choice when there is a movement to push parents to use ASL, emphasizing that any other choice can result in language deprivation?

Response:

- a. LA- We believe firmly in parent choice. Families given complete, unbiased information about all modes of communication will make the decision that works best for their family and child.
- b. WY- Good question. WE do not have the answer. We think respect for others and the choices they make is a great approach for ALL areas of life...not just communication modes. If people (parents, providers, doctors, lawyers, merchants, etc.) are not able to respect other opinions then we feel it is an issue with that person needing/wanting "control". That is a personal characteristic that is changed "from the inside out". We would try to hire people who appear to have less need to control others. HOWEVER...we at WY EHDI discuss and "own" or "admit to" our own levels of wanting/needing control--because we all have SOME level of that characteristic. We are all VERY good about helping other staff "see"

their control issues!!! Admitting we all have some level of control “issues” opens the door to conversation about “who is in control”...and of course, for children with hearing loss it is the parent(s) who have the control. Knowing that, we try to provide information and encourage parents to contact other parents (and professionals) to help them make an informed decision about communication modes. We are very upfront about our own biases with the parents (builds trust). We tell them it is our responsibility to help them find information and people who can guide them in their choices. But it is their responsibility to choose the communication mode for their family. We are pretty good about letting them know that nothing is cast in stone and that IF the initial communication mode they choose does not seem to be resulting in the progress and communication they want to see...well then it is time to reconsider the modes and try again and again and again. Hands and Voices is clear about saying whatever works for your child/family is **WHAT WORKS**.

- c. CO- We strongly believe that the CO-Hear Coordinators, the GBYS, and the Partner Project mentors deliver unbiased information. They receive an initial training to understand how to share information in an unbiased way with ongoing updates and case studies to supplement that training. The agencies only hire these professionals if they are committed to unbiased information. Guides and early interventionists suggest that “a year’s growth in a year’s time” should be the measure by which families decide if a particular approach or

option is meeting their child's needs, and to ask questions if a child is not gaining in language development each month.

17.Question: Louisiana mentioned attending pediatric conferences to educate them about hearing loss and referrals- how did you get invited to that or how did you go about getting there to speak with them?

Response:

- a. LA- Same question as #1
- b. WY- same question as #1
- c. CO- GBYS is set up as an application process, including a budget, initial training, and a statement of support from the various related agencies in a state. If there are questions about that model, they can be addressed to the HQ GBYS Program Director, at lisa@handsandvoices.org.

18.Question: How do the parent guides work with the early intervention providers?

Response:

- a. LA- Same question as #8
- b. WY- We do not have GBYS

19.Question: In the absence of having an official GBYS program, can we pay for a parent to go through their training?

Response:

- a. LA- This question may be best answered by Hands & Voices headquarters, specifically Lisa Kovacs, Director of Programs [lisakovacs@handsandvoices.org].

b. WY- Wyoming does not have GBYS program, but we sure would be interested in having a H&V parent go through the training. If someone has an answer, please share!