B -3 Programs of Various Communication Modes Collaborating to Serve Families

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Plan for Today

• Overview of Services in Western WA
• History of Collaboration
• Similarities in our programs
  – Best Practices
  – Need for Specialists
  – Other Similarities
• Differences among our programs
• Beneficial Outcomes
• Action Steps
• QA
Overview of Services in Western WA

• FRC services available to all families who have an infant/toddler who qualifies for early intervention

• 3 non-profit agencies providing specialized instruction for families who have a infant or toddler diagnosed as deaf of hard of hearing in the Puget Sound region
3 Agencies in Western Wa

- Hearing, Speech and Deafness Center, Parent-Infant Program: ASL/English Bilingual Approach

– Family Conversations, Seattle Children’s Hospital: Combined Communication (Spoken language and SEE)

– Listen and Talk, Parent-Infant Program: Listening and Spoken Language
History of Collaboration

King and Snohomish Counties
Challenges before 2000

• Referrals to agencies appeared to reflect the existing professional relationships versus provision of unbiased information.
  – “Audiologist told us to contact Program A”
  – “…Contacted Program B on our own and then got [a] doctor…”
  – “FRC only recommended Agency C.”
  – “The most difficult was that they were both* positive agencies.”
• *There were 3 agencies.
Challenges before 2000

• Families received FRC support *after* they enrolled in a specialized program for families impacted by hearing loss.
• Only 2 of the 3 specialized programs were designated by King County as a provider for FRC and Part C services.
• Families didn’t have equal access to funding and services.
Evolving Systems

• 1996-99: Program-Affiliated FRC services for families enrolled in that specific program.

• 1999-2000: Program-Affiliated FRC services for families enrolled in a different program.

• 2000-2003: Independent FRC services for families enrolled in the program without program-affiliated FRC services.

• 2003-Present: Independent FRC services for families who were enrolled in any program.
Concerns
Program-Affiliated (D/HH) FRC Services - Concerns

• Do families receive accurate information about all communication approaches?
• Is it fair to families when professionals affiliated with a specific approach and program are responsible for sharing information about other programs?
• Would a family avoid changing programs because they feel obligated to stay with the FRC and provider with which they presently work?
FRC Services - Other Agencies Concerns

• Anecdotal records show that FRCs without specific training in the needs of children who are d/hh and related systems result in:
  – Not accessing available funding for hearing aid technology.
  – Not accessing/Delayed access of loaner FM bank.
  – Not receiving information about preschool options/specially designed service at transition.
Survey Tool

• A family survey was created to capture the experiences of those who had exited Part C services.
• County DDD representatives with appropriate permission to contact families placed calls to conduct an interview.
Parent Survey

1. When your child was identified with a hearing loss, did someone tell you what to do next and who to contact?
   Yes____ No____

   Did someone tell you about any of the following programs?

   Family Conversations?
   (also known as ECHI)______
   Listen and Talk______
   Parent Infant Program______

2. Did someone explain the educational and therapy services available to your child?
   Yes____ No____

   Did someone explain what an Individual Family Service Plan is?
   Yes____ No____

   Did someone explain your rights as a parent?
   Yes____ No____

   Did someone explain Family Resources Coordination?
   Yes____ No____

3. What was helpful to you about the information shared with you?

   If it was not helpful, what did you do?

4. Please indicate how information about the three programs was shared with you:

   Brochure
   Listen & Talk
   Family Conversations
   Parent Infant Program
   F.R.C.
   Video
   Met families
   Visit

5. a. What agency was your F.R.C. from?
   _______________________
   b. Did you change F.R.C.'s at any point? Yes____ No____
   c. If so, why?
   _______________________

6. Was someone with birth to three services available to listen to your to your concerns and questions regarding choosing a program?
   Yes____ No____

   If so, who listened? F.R.C.____ Service Provider/Teacher____ Other programs____
   Audiologist____ Other____

7. Was the I.F.S.P. process clearly explained to you? Yes____ No____

8. Did you feel that your concerns and priorities were addressed during the I.F.S.P. process?
   Yes____ No____

9. Were you prepared for your child's three year old transition out of birth to three services?
   Yes____ No____

10. If your child received birth to three services at more than one agency, were those services well coordinated?
   Yes____ No____

11. Were you aware of the choices available for your child after the transition?
    Yes____ No____

    Check the choices that you were aware of:
    Public School Developmental Preschool
    Public School Program for children with hearing loss
    Private School Program for children with hearing loss
    Regular community preschool
    Other____

12. Who do you think was helpful during the transition process?
    Your birth to three provider? Yes____ No____ NA____
    Your school district? Yes____ No____ NA____
    Other birth to three provider? Yes____ No____ NA____
    F.R.C.? Yes____ No____ NA____

13. How old was your child when you learned that he or she had a hearing loss?
    0-6 months____ 7-12 months____ 13-18 months____ 19-24 months____ 25-30 months____ 31-36 months____

14. How old was your child when you began working with an F.R.C.?
    0-6 months____ 7-12 months____ 13-18 months____ 19-24 months____ 25-30 months____ 31-36 months____

15. How old was your child when your family began working with one of the three birth to three programs? 0-6 months____ 7-12 months____ 13-18 months____ 19-24 months____ 25-30 months____ 31-36 months____

16. Please add any comments that you would like to share around accessing F.R.C. services beginning with your child's initial identification with a hearing loss through the transition out of birth to three services.

17. Please share any experiences or suggestions you may have regarding the birth to three services that your child and family received.
Survey Highlights

• Families received printed information about different programs.
• Program-specific information presented by FRCs varied.
• Connections to other families during the decision-making process was infrequent.
• Families felt like they were “on their own”.
• FRCs without specific focus on children who are d/hh needed information about supports available for children and families impacted by hearing loss.
Moving Forward

• King County established an independent FRC Model, relying on staff at an agency separate from the audiology clinics and providers of Part C services to provide service coordination.

• Survey results and established Best Practice Guidelines were reflected upon as the model was developed.

• All 3 Seattle-area agencies for families with children who are d/hh participated in the development of the model.
Rationale
Independent FRC

• Families have unbiased support as they talk directly to specific programs about the approaches before enrolling.

• Professionals share accurate information about and respect for the different communication options.

• Families know they have choices
Independent FRC

• Families have timely access to available funding and supports

• The model supports the flexibility for families to change programs if needed or desired by the family while minimizing the potential impact on relationships between families and providers
Implementing the Model
Initial Steps...

• 1-3-6 Goal

• At the point of diagnosis, the audiologist shares information about Part C and FRC services, providing contact information of the Independent FRCs.

• The audiologist contacts the Independent FRCs
Early Intervention Services
FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING | KING, PIERCE, AND SNOHOMISH COUNTIES

The Parent-Infant Program (PIP) educates and empowers families to communicate with confidence. We utilize a bilingual educational approach with American Sign Language (ASL) and English (or the spoken language of the family, if not English) to instill early, unrestricted access to language because timing is critical. Early access to language builds a foundation for a lifetime of learning. We coach families on strategies to encourage early communication and strengthen bonding. We support the use of hearing aids and cochlear implants. In addition, we provide families’ access to Deaf role models and connections to the Deaf community. Our services include: Home visits (focusing on ASL and spoken language development), Parent Education & Support Groups, Celebrate Reading Nights, Bilingual Kids’ Club Playgroup, ASL instruction, the Shared Reading Project, and a Resource Library.

Listen and Talk’s mission is to help children who are deaf or hard of hearing communicate and learn through listening and spoken language. No sign language is used. Parents are the primary facilitators of their child’s listening and spoken language development. Our credentialed staff members coach parents to enable their child to rely on hearing as the primary way of developing listening and spoken language. Our practice is guided by the Principles of LSLS Auditory-Verbal Therapy, an evidence-based practice which promotes early diagnosis, 1 to 1 family-focused therapy, and state-of-the-art audiological management and technology, such as cochlear implants, hearing aids, FM systems, and bone-anchored hearing aids. Providers implement ongoing formal/informal diagnostic assessments to develop targets, monitor progress, and evaluate effectiveness. Program goals focus on the development of listening, thinking, and conversational skills while preparing children for early inclusion into their neighborhood school and for later ventures as independently as possible. The ultimate goal is for the child to have access to a full range of academic, social, and occupational choices throughout life. We also support families in their use of their native language, if other than English. Music and Movement Classes and Parent-Toddler Groups supplement family sessions. We also offer Family Groups specifically addressing needs related to Unilateral (one-sided) hearing loss and provide many opportunities for families to meet other children and adults who are deaf and hard of hearing and who communicate through listening and spoken language.

Family Conversations uses a combined communication approach to help all families build strong parent-child relationships. Families are supported and coached to explore a variety of tools to find the most effective way to meet their goals for their child(ren). These tools include: amplification technology (hearing aids, cochlear implants, and FM systems), listening and spoken language strategies (including music and singing, language and literacy strategies including Library Kits, and visual communication including Signing Exact English). Parents learn and practice methods and strategies to share their personal values and culture with their child(ren) through language. A Communication Specialist meets regularly with a family in the child’s natural environment supporting the family’s learning through daily routines and play. Family Conversations Group is an opportunity for children and parents to meet one another. The Little Conversations Group is designed to support language, speech, literacy and social development. The Parent Conversations Group allows adults to meet and discuss issues important to them regarding raising a child who is deaf or hard of hearing.

There are three early intervention programs in the community dedicated to helping families who have a child who is deaf or hard of hearing. Each program is committed to helping children reach their language and learning potential. The programs differ in the type of communication system used to help the child and family develop. Families and other caregivers are encouraged to visit each of the programs prior to making a decision in which program to enroll.

Detailed information, contacts, and links to websites for each program are provided on the back of this sheet.
Please note...

- **Families are not forced to contact each agency, but it is encouraged.**
- **In situations such as the diagnosis of UHL, only 2 agencies serving families with children who are d/hh will be potential service providers.**
Details

• Data management systems must recognize that FRC services and other services will include providers from different agencies.

• Original documents (permission to evaluate, release of information, etc.) may be in different locations.

• Communication between the FRC and providers is critical.
Program Similarities

All three programs strive to meet and exceed Best Practices for providing services to infants and toddlers who are deaf or hard of hearing and their families.
Best Practice

• Supplement to the Joint Commission on Infant Hearing 2007 Position Statement (March 2013)

• Washington Department of Health “Best Practice Guidelines in Early Intervention for Children with Hearing Loss”
JCIH 2013

Joint committee member organizations included representatives from:

- Alexander Graham Bell Association
- American Academy of Audiology
- American Academy of Otolaryngology-Head and Neck Surgery
- American Academy of Pediatrics
- American Speech-Language-Hearing Association
- Council on Education of the Deaf
- Conference of Educational Administrators of Schools and Programs for the Deaf
- National Association of the Deaf
- Directors of Speech and Hearing Programs in State Health and Welfare Agencies
- Contributors from several other organizations.
“There is evidence that earlier identification of children who are D/HH, accompanied by timely and appropriate interventions, can result in language, communication, cognitive and social-emotional skills that are consistent with children's cognitive abilities and chronological age.”
JCIH Goals:

• All Children who are D/HH and their families experience timely access to service coordinators who have specialized knowledge and skills related to working with individuals who are D/HH.

• Dissemination of information without bias
JCIH Goals:

All Children Who are D/HH from Birth to 3 years of age and their families have EI providers who have the professional qualifications and core knowledge and skills to optimize the child’s development and child/family well-being.
Best Practice Guidelines in Early Intervention for Children with Hearing Loss

It is recommended that all infants be screened for hearing loss by one month of age, receive diagnostic audiologic assessment by three months of age if necessary, and be enrolled in early intervention services by six months of age if the child is identified as having a hearing loss. Studies have shown that children identified with hearing loss who receive intervention prior to 6 months of age often meet or exceed the receptive and expressive language scores of their hearing peers. This protocol was developed by a workgroup comprised of parents, early intervention specialists, audiologists, members of the deaf community, and DOH staff, with extensive knowledge and expertise in early intervention services for children who are deaf or hard of hearing.

1) Early Intervention (EI) for children with hearing loss is family focused:
   - Families have access to EI services provided by specialist(s) with specific training in working with birth-to-three-year-olds with hearing loss, in addition to other specialists that may be needed, as identified in the Individualized Family Service Plan (IFSP) (e.g., physical therapists, speech-language pathologists).
   - Families may access these specialized services via a variety of supports including outreach by specialized program staff, outreach by other families, and distance technology.
   - Services will be delivered and resources made available in the parents' primary language.
   - Services are provided and resources are available in the family's chosen method of communication and educational approach including American Sign Language (ASL), Signed English (SE), Auditory-Oral, Auditory-Verbal, Cued-Speech, etc.
   - During the early period of information gathering and decision making, families are assisted by a person who can present and discuss unbiased information about communication options, respects family choices, and allows parents to make an informed decision.
   - Care focuses on family strengths and follows the family's vision and priorities.
   - Services include all members of the family and their circle of support, as requested by the family.
   - Care is developmentally appropriate for the child.
   - Families, EI providers, and the child's medical home collaborated to provide the child with hearing loss access to communication with the important people in their lives ("relationship-focused EI").
   - Families choose where to meet with EI providers, their Family Resources Coordinator (FRC) and other providers.
   - Brothers and sisters of children with hearing loss have access to age-appropriate information, support and instruction.
   - Children with hearing loss and their hearing siblings have opportunities to interact socially with other siblings of deaf and hard of hearing (DHH) children, young children, youth, and adults who are DHH.

2) EI providers and other professionals working with this population have specialized expertise and training:
   - FRCs with initial contact to families have specialized training in effective practices for infants/toddlers who are DHH and related family issues. They provide support and information in an unbiased manner.
   - EI providers working with DHH children and their families receive initial and ongoing training in DHH education, child development, early childhood education, and technology.
   - EI specialists who are trained to work with children who are DHH (including consultants who are deaf) participate in outreach to, and consultation with, other EI providers and medical professionals.

3) Families with DHH children enrolled in EI receive appropriate information, evaluation, services, and support. Components include:
   - How to link with appropriate Part C systems, including on FRCs and other EI services, to ensure access to a variety of services, including EI services that may be needed by the child (e.g., physical therapy, vision services).
   - Information about family networking and support services, including support in dealing with the emotional impact of diagnosis (i.e. parent support groups, individual and family counseling).
   - Information regarding communication options for DHH individuals, Deaf Culture, and available specialized services and assistive technology.
   - Support and family assistance in exploring and selecting a communication approach, recognizing that this choice can change over time.
   - Variety of support models for children/families in learning the communication approach of their choice.
   - Ongoing audiological services and monitoring of hearing aids/cochlear implants if requested by parents.
   - Assistance in helping the child learn to effectively wear and use assistive devices, and to develop residual hearing if requested by parents.
   - Opportunities to gain support and information from a variety of individuals who are DHH, and other parents of children with hearing loss (e.g., parent mentoring program).
   - Information specifically for families relocating to, or moving out of, Washington State.

4) IFSP Meetings and Ongoing Evaluation of Child:
   - Participants in the IFSP meetings will include, but are not limited to, family members, EI providers, specialists in DHH, audiology, FRC, any other health care/service provider requested by the family.
   - The EI team administrators and coordinates regular assessments appropriate for children with hearing loss to document progress of child toward developmental milestones and IFSP outcomes.

5) Other Services:
   - Infants identified with hearing loss are referred to an Ear, Nose and Throat (ENT) for evaluation and appropriate medical and/or surgical care if indicated.
   - Families are informed of genetic services, and if requested, provided with a referral to genetic evaluation within three months of diagnosis.
Why the need for D/HH Specialists?

- Extensive training, experience and expertise: the impact of hearing loss, the development of sign language, accommodations for listening/visual environments, auditory and speech acoustic foundations needed for listening and spoken language development, etc.
- Specifically trained in the development of language for children who do not hear typically.
Specialists

- Staff have master’s degrees and specialized certifications
- Ongoing continuing education to keep current
- Connections with a community of families
- Connections with Resources
- Community connections including D/HH adults
Specialists around the State

Goal: Collaborations among specialized providers, CDHL and local service providers to make specialized resources available state-wide.

- Build capacity within communities while providing specialized services for DHH children and their families
Additional Program Similarities

• Provide sessions in the natural environment
• Use a coaching model
• Staff participate in the same training opportunities
• Provide opportunities for families to connect with other families and/or adults who are d/hh
• Provide parent education
Program Differences

- Mode of Communication
- Specialized Expertise
- Organizational Differences
Benefits

• Team meetings with all 3 programs
• Shared trainings
• Break down the walls of secrecy.
• Participate in county/state/national/community meetings and activities as a unit ……..
• Families feel more comfortable and able to ask questions which reduces stress
• Sharing resources, space and knowledge
Local Action Steps

• King County - Examples
  – Attitude
  – Created independent model
  – Agency collaboration to create materials shared with families.
  – Training for FRCs
  – Share info with different agencies

• Your Community
  – ____________________________________________
  – ____________________________________________
  – ____________________________________________
  – ____________________________________________
References

• EHDDI documents, Best Practice Guidelines
  http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-019_EHDDIIntrvProto.pdf

• Supplement to the Joint Committee,

• Center for Childhood Deafness and Hearing Loss
  www.cdhl.org

• Hands and Voices www.wahandsandvoices.org

• Guide By Your Side-Christine Griffin
  gbys@wahandsandvoices.org
- **Listen and Talk**
  8610 8th Ave NE
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- **HSDC/Parent Infant Program**
  1625 19th Avenue
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- **Seattle Children’s Hospital/Family Conversations**
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