

# Delivery of Unbiased Information about Intervention Options: An Independent Coordination Model

EHDI Conference

March 1, 2010

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# Plan for the Day

- History
- Details about WA
- Concerns
- Rationale for Independent FRC
- Implementation
- QA



# Learning Objectives

- Identify concerns when relying on initial coordination of services provided through an intervention program or agency associated with a particular communication modality.
- Describe the rationale for providing initial service coordination through an independent agency that does not offer early intervention services for families impacted by hearing loss.
- List 3 action steps to ensure that families in their local community have accurate, unbiased information about communication options/early intervention programs.



# History & Details



# Services Available in WA

- FRC services available to all families with an infant/toddler who had special needs.
- 3 agencies providing specialized instruction for families impacted by hearing loss in the Puget Sound region
  - ASL/Bi-Bi
  - Simultaneous Communication (SEE)
  - Listening and Spoken Language



## King Co. Challenges in 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 recommended *Agency C*.”
  - “The most difficult was that they were both\* positive agencies.”
    - \*There were 3 agencies.





# King Co. Challenges in 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 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.





## Please note...

- Families always have the right to receive coordination services from an FRC from a different agency.
- Over time, each agency phased out service coordination for families enrolled in their programs for children who are d/hh.



# 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?

	yes	no	Who told you?
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:

	Listen & Talk	Family Conversations	Parent Infant Program
Brochure	___	___	___
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? \_\_\_\_\_  
\_\_\_\_\_

5. 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?

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.



## Washington State Department of Health

# 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 audiological 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 Exact English (SEE), 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 final 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 complete 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 (D/HH) children, young children, youth, and adults who are D/HH*.

**Early Intervention (EI)** in Washington State are services and supports designed to meet the developmental needs of a child 0-3 with a delay or a disability and the needs of the family related to enhancing the child's development.

The term **deaf** is used to describe persons who have a hearing loss greater than 90 dB HL. It also may be used to refer to those who consider themselves part of the Deaf community or culture and choose to communicate using American Sign Language instead of spoken communication.

**Hard of Hearing (H/H)** is the term used to describe those with mild to severe hearing loss.

**The Individualized Family Service Plan (IFSP)** is an ongoing planning process and document designed to meet the changing needs of children and families enrolled in early intervention. Federal guidelines require that the initial IFSP be completed within 45 days of referral.

**American Sign Language (ASL)** is a visual language with unique form, function, and social usage. It is the language of the deaf community and the third most common language used in the USA.

**Unbiased** means free from all prejudice and favoritism.

**Relationship-Focused Early Intervention** is concerned with the prevention of developmental problems and the promotion of social-emotional well-being. With prompt support, families and children develop mutual engagement and elaborate, satisfying, barrier-free 2-way communication early in life.

A **Family Resources Coordinator (FRC)** assists families with children birth to three, in accessing resources from the point of identification of a concern through the development of the Individualized Family Service Plan, early intervention services and transition to preschool special education or other services.

### 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 D/HH and related family issues. They provide support and information in an unbiased manner.
- EI providers working with D/HH children and their families receive initial and ongoing training in D/HH education, child development, early childhood education, and technology.
- EI specialists who are trained to work with children who are D/HH (including consultants who are deaf) participate in outreach to, and consultation with, other EI providers and medical professionals.

### 3) Families with D/HH children enrolled in EI receive appropriate information, evaluation, services, and support. Components include:

- **How to link with county/state Part C system, including an FRC and other EI services, to ensure access to funding a variety of services, including other 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 D/HH individuals, Deaf Culture, and available specialized services and assistive technology.**
- **Support and careful assistance in exploring and selecting a communication approach, recognizing that this choice may 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/or use assistive devices, and to develop his/her residual hearing if requested by parents.**
- **Opportunities to gain support and information from a variety of individuals who are D/HH, 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 be limited to, family members, EI provider specializing in D/HH, audiologist, FRC, any other health care/service provider requested by the family.
- The EI team administers 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.

Assistive Technology may include relay telephone services, telecommunication devices, closed-captioning, hearing dogs, visual and/or technical devices.

### Additional Resources:

For more information on hearing loss, please visit

[http://www.seattlchildrens.org/programs/listings/newborn\\_hearing\\_screening/default.htm](http://www.seattlchildrens.org/programs/listings/newborn_hearing_screening/default.htm)

This publication was supported by a cooperative agreement number UR3/CCU018872 from the Centers of Disease Control and Prevention (CDC) and grant number 6H61MC00084 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of either CDC or HRSA.





# Rationale



# Independent FRC

- Families would know they have choices.
- Families would have unbiased support as they talked directly to specific programs about the approaches before enrolling.
- The model supports the flexibility to change programs if needed/desired by the family while minimizing the potential impact of relationships between families and providers.
- Emphasizes sharing accurate information about and respect for the different communication options.
- Ensures timely access to available funding and supports.



# 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, who are employed by Seamar.



# Service Coordination for Families

- Families are contacted, usually by phone, directly by an FRC with the support of a language interpreter if needed.
- A home visit is scheduled with the FRC.
- Printed information about all 3 programs is shared with families.



## Early Intervention Services for Children who are Deaf or Hard of Hearing

### Introduction

There are three birth-to-3 programs in the community dedicated to helping families who have children who are deaf or hard of hearing. Each of these programs is committed to helping the children reach their language and learning potential. The programs differ in the type of communication system that they help the child and family develop. Below is a brief summary description of each program. Families and other caregivers are encouraged to visit each of the programs prior to making a decision on which program in which to enroll. Contact information for each program is provided on the back of this sheet.



Seattle Children's  
HOSPITAL • RESEARCH • FOUNDATION

### Family Conversations

Family Conversations is a Total Communication Early Intervention program based out of Seattle Children's Hospital in eight counties throughout western Washington. Family Conversations is committed to working with families to enhance the parent-child relationship. Families are taught to use both visual communication (Signing Exact English, speech reading and gestures) and auditory/listening skills simultaneously to establish clear communication with their child. Specialists meet weekly with each family in the child's natural environment. Regional Family Support Groups for children and parents are available and are designed to help families learn about issues in raising a child who is deaf or hard-of-hearing. The specialized curriculum used is designed to enhance, language, speech, literacy and learning. Families learn methods and strategies to share their personal values and culture across the literacy continuum while building language and relationships. Family Conversations strongly support the use of hearing aids, cochlear implants and FM systems.



Hearing, Speech  
& Deafness Center

The Parent-Infant Program (PIP) at the Hearing, Speech & Deafness works with the child's entire family to strengthen family communication and cohesiveness through learning speech, listening, sign language, cued speech and other communication methods depending on the child's and family's needs. The 57 year old program provides for a weekly structured playgroup, to help children learn American Sign Language (ASL), spoken English supported by Cued Speech, and other communication strategies. In addition, specialists visit the home twice a month to work with families in the child's natural environment and train in the Shared Reading Project equipping families to build literacy in children with hearing loss. Additional services are available which include ASL classes, weekly support groups for adult family members and siblings, and Speech Language and Audiology services and assistive technology.



Listen and Talk is committed to helping children with hearing loss and deafness develop spoken communication. No sign language is used. The Listen and Talk Parent-Infant Program consists of two parts: Auditory-Verbal Therapy and Parent -Toddler Play Groups. To make learning to listen and speak as natural as possible, Listen and Talk's Early Intervention Specialists act as coaches, teaching the child's family/caregivers how to work with their child in a natural, playful way. Families gain an understanding of the process of listening and talking. Then, through modeling and practice they continue to teach their child to respond to and interpret sound in a meaningful way. These sessions build a foundation upon which language learning will continue throughout a child's daily life. Listen and Talk's Parent-Toddler Group gives children, families and professionals another chance to learn from each other. Listen and Talk also offers Family Groups specifically addressing needs related to Unilateral Hearing Loss.





# Families Exploring Options

- Family's preference for how to connect with programs is decided.
- The FRC notifies all agencies that a family is exploring their options via email.
- Contact information is faxed to the agencies at the same time.
- Each agency is responsible for follow-up with the family.





# 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.*



# Timelines

- Initial IFSPs are written within the 45-day Timeline.
- If the family is still exploring their options and the 45-day Timeline is expiring,
  - Extenuating circumstances are noted by the FRC.
- This model has not resulted in an inability to stay in compliance with federally mandated timelines.



# 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.



# Funding

- The agency providing independent FRC services is housed within a county-supported agency with a contract specifically for those services.
- The county sets reimbursement rates for service providers, separate from the reimbursement rate for service coordination.
- County contracts detail the services an agency provides for eligible families.



# Q & A



# Local Action Steps

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



- Your Community



– \_\_\_\_\_

– \_\_\_\_\_

– \_\_\_\_\_



A large, bright yellow sunburst graphic with many sharp rays, centered behind the text.

**THANK YOU**



# References and Contact Info





- <http://www.doh.wa.gov/cfh/mch/Genetics/ehddi/default.htm>
  - EHDDI documents, i.e. Best Practice Guidelines
- Listen and Talk  
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