

The Cycle of Support: Supporting Families through EHDI and Beyond

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Financial Disclosure



In the past 12 months, I have not had any financial interest or other relationship with provider(s) of the service(s) that will be discussed in my presentation.

This presentation will not include any discussion of pharmaceutical or devices.

Presentation Overview



1. Learning Objectives
2. Where Families Find Support
3. Learning/Communication Types
4. Types of Families
5. Family Dynamics
6. Tools
7. Parent Evolution
8. Obtaining Parent Perspectives
9. Take Home Messages

The Importance of Parent Involvement



- Research indicates that the single-most important factor in predicting successful outcomes of newly identified deaf/hh babies in early intervention is **the active participation of their parents.**
(Yoshinaga-Itano, Coulter & Thomson, 2000)
- **Benefits of Parent involvement** include higher reading scores, higher grades on homework, improved attitudes towards school, improved relationships between parents and teachers.
(Donahoo, 2001)

Observations about Changing Needs of Parents



- 10 years ago, families had to personally attend workshops to get information or to find support from other families
- Today, families have access to information without leaving their home
- Families are far more complicated and heavily scheduled
- Our charge is to make sure that parents get accurate, comprehensive information/support for all choices in as many ways as possible



Learning Styles



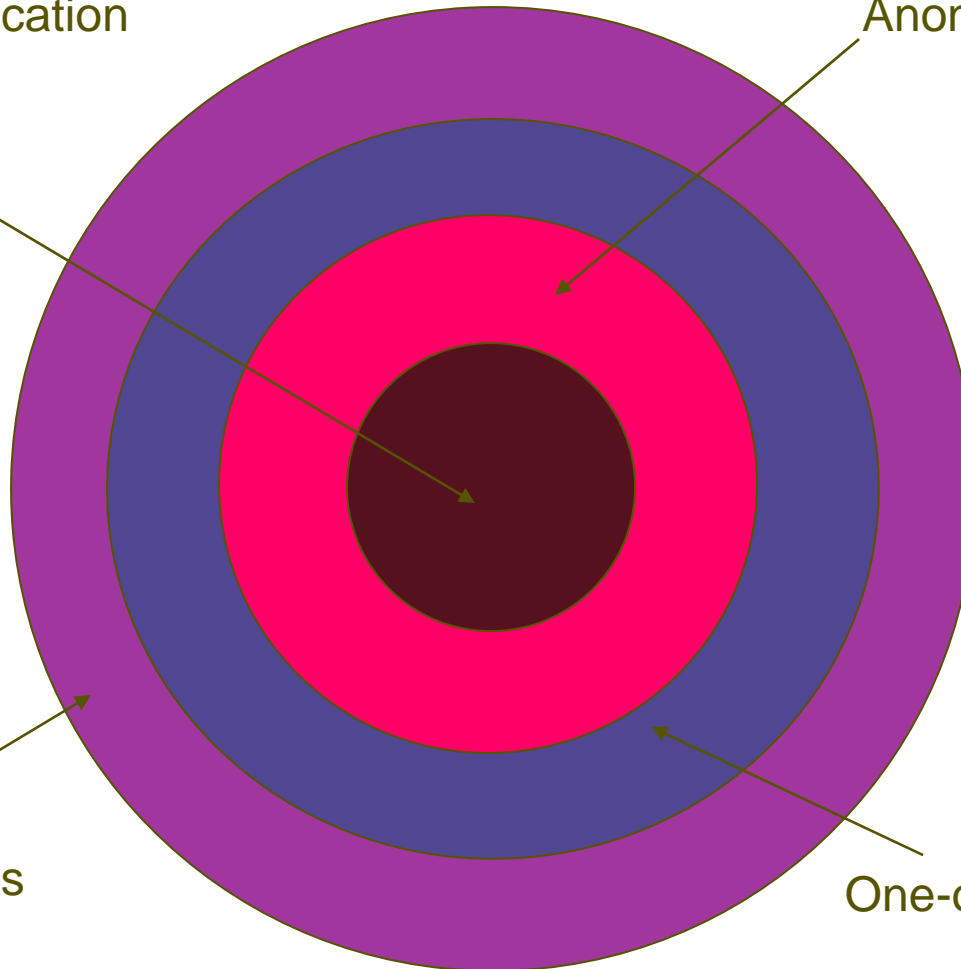
- Visual
- Auditory
- Tactile

Communication Types



Passive Communication

Anonymous Interactions



Group Interactions

One-on-one Communication

Types of families



- Newly diagnosed
 - Lots of questions
 - Emotional
 - Over/Under informed
- Experienced
 - Invested time
 - Invested money
 - Researched
 - Everything is “okay” or “going good”
- Other
 - Low SES
 - Geographic restrictions
 - Cultural Considerations

Family Dynamics



- What families look like today
 - Grandparents
 - Nannies/Child care providers
 - Single parents
 - Same sex parents
 - Teen parents
- How much support do you provide?
- How do you feel about their family dynamic?

Passive Communication Tools



- Newsletters
- Mass Email Alerts
- Web Sites
- Fact Sheets
- Roadmaps
- Care plans
- Parent Welcome Letters
- New Parent Packets
- Resource guides

Anonymous Communication Tools



- Chat Rooms
- Bulletin Boards
- Email
- List serves
- Blogs

One-on-One Communication Tools



- Phone communication between H&V GBYS Parent Guides and parent
- Email communication between Parent Guides and parent
- Facilitated phone/email contact between parents
- In person meetings between Parent Guides and parents
- Facilitated in person meetings between parents

Small Group Interaction Tools



- Small group interaction at a setting familiar to the parent
 - Parent group at a school, church or cultural center
- Small group interaction at a setting unfamiliar to the parent
 - Host organization's site
 - Public Place

Large Group Communication Tools



- Social Events
- Educational Workshops/Conferences
- Retreats
- Regional Family Activities/Socialization Days
- Coffee Chats

The evolution of a parent



- Parent led, centered, involved, directed...
For their own child
- Parent-to-Parent...
For each other
- Parent participation through advocacy...
In the System

The evolution of parent support



- The “F” in IFSP
- Support off the cliff – *“Godspeed in Part B”*
 - EHDI 1-3-6...part C...Part B...transition to work/school...*paying their own cell phone bill*
- Who’s the driver?
 - 1. Parent driven/child passive
 - 2. Parent driven/child input
 - 3. Parent driven/child driven
 - 4. Child driven/parent input
 - 5. Child driven/parent passive



Obtaining the Parent perspective



- Active model of how parents grow in the role as ...**activist**, advocate, **challenger**, change-agent, **collaborator**, community developer, educator, facilitator, **framer**, innovator, **life-long learner**, listener, **mediator**, negotiator, participant, **TEAM MEMBER**, role model, **SUPPORTER**, **visionary**....
 - Wanting to be involved for all the right reasons
 - Accessing resources to learn leadership
 - Learning from other parent leaders
 - Innovative, creative, positive improvements

Take Home Messages



- Families with children newly identified as deaf/hard of hearing may have intense needs
- **Families' needs continue long past the initial identification**
- Family support systems need to incorporate children who are identified later and children past identification
- Tools exist to provide comprehensive and effective family support

Contact Information



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