

It's Time for your Family Support Check-up

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Why all the talk about Family Support?

- Families report feelings of dissatisfaction with the support they receive.
- Families frequently state that they do not believe they were given all the facts
- Systems need to recognize the importance of supporting families, and concur on what that support looks like



Why all the talk about Family Support?



- A father said he was puzzled by terms... When he was told about an FM trainer, he expected some kind of fitness instructor
- Hearing parents cannot rely solely on support from their hearing family...having a child with hearing loss changes a lot of what you think you know!

What Research and Experience Tell Us About Family Support

- Family choice and decision making occur at all levels of family involvement in the intervention process.
- Families report high need for emotional support



Why Is Family Support Important to EHDI Programs?

- ◇ Reduce Loss to follow-up.
- ◇ Provide a link between diagnosis & intervention.
- ◇ 95% of children with hearing loss are born to hearing parents.
- ◇ Creates a important mechanism for evaluating program effectiveness.
- ◇ We're not doing a very good job of it!

Where Families Find Support

- Formal Parent Support Groups
 - Δ Deaf Specific
 - Δ General Disability
- Informal Parent Support

Parent-to-Parent

- Mentor
- Role Model

Adults Who Are Deaf/ Hard of Hearing

family

Information

- Internet Websites
- Brochures
- Books
- CDs/DVDs/Videos
- Resource Guides
- Curricula

Professionals

- Service Coordinator
- Parent Educator
- Early Interventionist
- Audiologist
- Medical Home/ Physician
- Speech/Language Pathologists
- Teacher
- Hospital Staff
- Communication Instructor/Specialist

Existing Communities

- Family
- Friends
- Neighborhood
- Places of Worship/Spiritual

Where Families Find Support

- Existing Communities

Consider: Do we acknowledge pre-existing support, and how do we support families in sharing what they are learning with their existing communities?



Where Families Find Support

Professionals

Consider: How are professionals trained to provide support to families?



Where Families Find Support



- Parent-to-Parent and Deaf/HH Adults



Consider: How can the parent-to-parent connection and access to Deaf/HH adults be imbedded in a system so that all families can have the opportunity for support from these entities?

Where Families Find Support

- Information

Consider: How does an EHDI system maintain the quality and quantity of information to families?





Where to begin?

Three Critical Questions

1. What does our EHDI program want to accomplish as a whole?
2. How will supporting families help us reach our goals?
3. Is everybody "on the bus"?



Key Elements to Consider



1. Clearly defined goals and objectives
2. Carefully identified and well-trained staff
3. Collaboration between community resources
4. Evaluation and Continuous Quality Improvement

Clearly Defined Goals and Objectives



- Be able to clearly articulate the reasons for delivering support in the way you have chosen....
- Baby steps...what to target first???

NCHAM Goals Bank for EHDI Teams

Sample Goals, Objectives and Activities for State Teams

- **Topics Covered:**
 - **NBHS**
 - **Audiological Evaluation**
 - **Early Intervention**
 - **Lost to F/U; Lost to Documentation**
 - **Family Support**
 - **Periodic Childhood Screening**
 - **Professional Development**
 - **Program Infrastructure**
 - **Data Management**
 - **Quality Enhancement/Continuous Improvement/Evaluation**
 - **Collaboration**

Sample Goal: Increase the percentage of families who participate in 1 to 3 identified aspects of Family Support

Objective 2: Seek appropriate parent representation on identified state groups.

Activities:

- 2.1** Make a list of committee/boards in which it would be advantageous to have a parent and/or adult with hearing loss on
- 2.2** Appoint these identified individuals to these committee/boards (i.e., State ICC, Local ICC, EDHI, Advisory Boards for Part B, Part C, governor)

Objective 6: Determine the current needs of families in your state.

Activities:

- 6.1** Administer a survey to identify the kinds of support families with young children need to help them
- 6.2** Conduct focus groups
- 6.3** Add a parent needs survey component to each IFSP meeting (every six months)
- 6.4** Provide script to Service Coordinator related to the survey

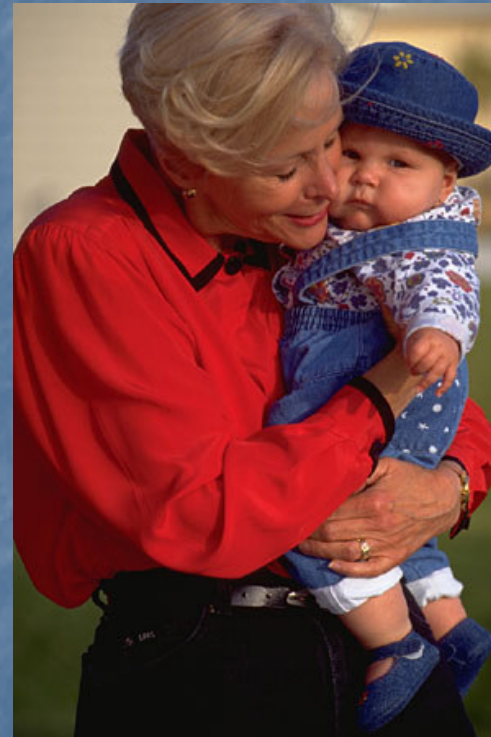
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Carefully Identified and Well-Trained Staff

- Programs needs to decide what educational, professional and personal experiences are needed by the persons who will be providing family support... "nice is not enough"
- Parents as staff consultants can provide an important perspective.



How do we prepare staff?

Sample Goal: Improve outcomes of babies, toddlers and young children with hearing loss through a formulated plan of continuing education by (date) focused on enhancing the knowledge and skills sets of providers.

Objective 2: Identify state training needs for the personnel serving this population.

Activities:

- 2.1 Survey state providers regarding their needs for serving this population**
- 2.2 Post training opportunities on the state website**
- 2.3 Work in partnership with state organizations in providing the training needed as identified (i.e., state meetings, webinars/web-events, conferences, workshops, etc.)**
- 2.4 Create a list of providers who specialize in provision of services that are part of UNHS and EHDI follow-up (i.e. LSLS Cert AVT, LSLS Cert AVEd, SLP, pediatric audiologists, Teachers of the Deaf, hospitals, CI programs, parent classes on sign language)**

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Collaboration Between Community Resources

- Families are complex and no one approach can meet the multiple and varied needs of each family.
- Trying to create a continuum of services for children and families in a community. Partner with existing parent organizations to build capacity.
- Support is more effective when linked to a broader system of care.
- The more stakeholders invested in your efforts, the greater reach and effectiveness the program will have.

How do you engage all the stakeholders?

Objective 1: Develop a Communication and Outreach Plan between the EHDI program and stakeholders.

Activities:

- 1.1** Survey state providers on how they want information shared
- 1.2** Submit articles to state organizations for publications in their newsletters, journals, etc.
- 1.5** Create and post a blog on the state website
- 1.6** Present at grand rounds, university training programs, state association meetings, etc.
- 1.7** Create state outreach program to parents, physicians and providers with designated speakers sending the same message (i.e., speak at birthing classes)
- 1.9** Create state outreach program to various charitable organization (i.e., Lion's club, Kiwanis, Sertoma, League, etc.) with designated speakers requesting support for state identified needs (i.e., printing materials in Spanish, conducting trainings to providers, loaner hearing aid program, etc.)

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Evaluation and Continuous Quality Improvement

- Allows stakeholders, including families, to know if and how support is being implemented and the extent to which it is meeting objectives.
- Encourages “end-user” feedback from formal and informal channels to assure the program is effective for families from their point of view.
- Effective support programs use info to refine and improve their processes.

...everyone thinks I should know what to do because we have two other kids, but what I really need is some positive feedback to know that I am doing things right...

How to evaluate family **support** efforts

- **Early Hearing Detection and Intervention Program Checklist**
 - checklist to determine how well EHDI programs are meeting JCIH recommendations
 - The categories based on JCIH2007 key updates
 - “No” = review of that program component is needed suggested

<http://www.asha.org/members/aud/access-aud-online/AAUD1107>

Family Support Principles

- Staff & families work together in relationships based on equality & respect.
- Staff enhance families' capacity to support the growth & development of all family members.
- Families are resources to their own members, to other families, to programs, & to communities.
- Programs affirm & strengthen families' cultural, racial, & linguistic identities.
- Programs are embedded in their communities.
- Programs advocate with families for services & systems that are fair, responsive, and accountable.
- Practitioners work with families to mobilize formal & informal resources to support family development.
- Programs are flexible & continually responsive to emerging family & community issues.
- Principles of family support are modeled in all program activities.

(C. J. Dunst citing Family Support America)

As part of a collaborative team, we have the responsibility to meet the challenge of working with families with
caring, compassion and expertise.

Perigoe, 2004



The Family Support Code:

- To honor the right of a family to make choices for this child.
- To strive to connect families with diverse information sources so those choices are comprehensively well informed.
- To provide support and information without a spin, a skew or a hidden agenda.
- To enable and empower the family to take the lead in this entire process.



(www.handsandvoices.org)