

# Investing in Family Support: Taking it to the Next Level

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Beginnings

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EHDI Indiana

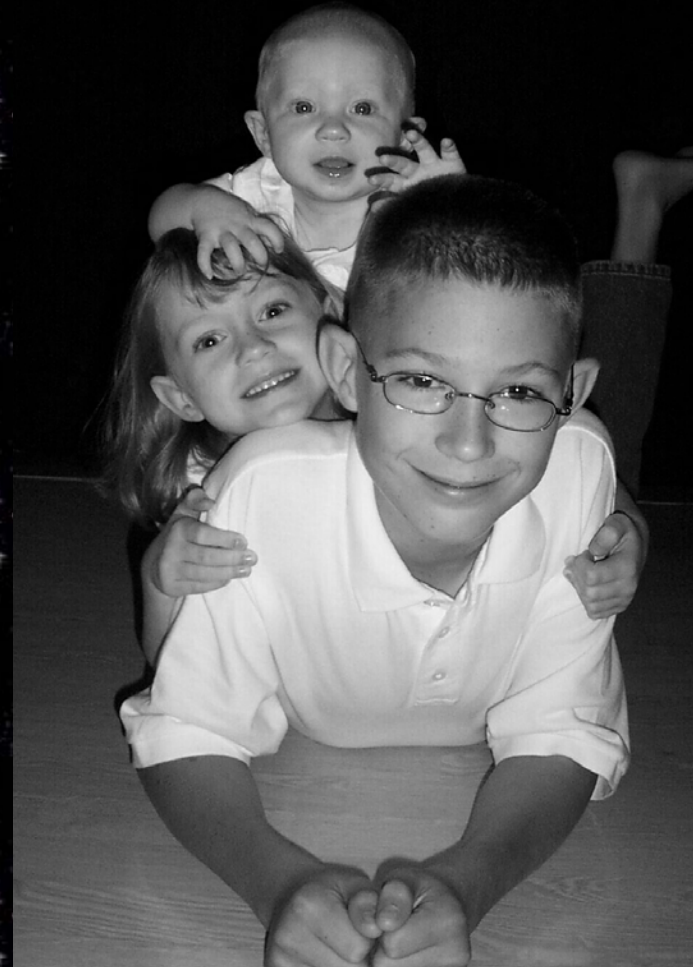
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Hand & Voices National

**EHDI 2008**



# Family Support...

## A New "Star" in the Service Constellation

- "Family Support" is discovered!
  - In research
  - By the JCIH and others
  - To the relief of parents
- Mapping this "new" area of service
  - The Diagram of Family Support
  - How Professionals Facilitate Support
- The Role of Family Support in the System
  - NCHAM
  - Investing in Family Support: IFSC1, 2, 3

## Researchers agree: Support Helps

- Mothers who reported high social support were rated as better adjusted despite degree of hearing loss or life stress.
- Social support accounted for 43% of the variance in mother's reported negative life stress.

*(Calderon, R., & Greenberg, M. 1999)*

- Social networks with other parents of children who are deaf were associated with less isolation, acceptance of their child, and improved interactional responsiveness
- Parents who had contact with deaf adults reported less depression, less isolation, and increased interactional responsiveness to their child.

*(Hintermaier, M., 2000)*

## The Joint Committee on Infant Hearing Agrees!

"The most important role for the *family of an infant who is deaf or hard of hearing* is to **love, nurture, and communicate** with the baby. From this foundation, families usually develop an urgent desire to understand and meet the special needs of their infant. Families gain knowledge, insight, and experience by accessing resources and through participation in scheduled early intervention appointments including audiologic, medical, habilitative, and educational sessions."

**"This experience can be enhanced when families choose to become involved with parental support groups, individuals who are deaf or hard of hearing, and/or their children's deaf or hard-of-hearing peers. (p. 902)"**

# MCHB: Show me the family support!



**UNHSI Future Directions:** "Currently, family-to-family support services are particularly underdeveloped. These services lack funding or adequate participation from families to make them successful. UNHS Programs may need to reach out to other existing family support services in their states as program models and potential partners in development. "

(Mathmetica Policy Research Final Report, p. 60, HRSA 2007)

# Families agree...

## but want to be proactive, not just reactive

- Recognize our “birthright” as experts in our own child & the parents legal rights to choose communication modality
  - Part C. 303.25 NATIVE LANGUAGE-(a) Native language, when used with respect to an individual who is limited English proficient, means the following: (1) The language or mode of communication normally used by that individual, or, in the case of a child, the language or mode of communication normally used by the parents of the child, except as provided in paragraph (a)(2) of this section. (2) In all direct contact with a child (including evaluation of the child), the language or mode of communication normally used by the child in the home or learning environment.(b) For an individual with deafness or blindness, or for an individual with no written language, the term native language means the mode of communication that is normally used by the individual (such as sign language, Braille, or oral communication).

Source: Hands & Voices National

# Families agree...

but want to be proactive, not just reactive

Share all information without bias or manipulation

- Expose us to DHH parenting role models and mentors
- Don't judge.
- Partner with us, but prepare us for autonomy, not dependency

# Where Families Find Support



- Originally conceptualized by the planning team for IFSC1
- Aim was to provide a visual tool
- Serves as the foundation for ongoing planning about family support
- Fluid, evolving, interactive



# 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

# Parents Have Existing Communities of Support...right?

- Ninety-five percent of all deaf children are born to hearing families (Mitchell & Karchmer, 2004)
- 90% of these families have no background in deafness or connection to the deaf community. (Center for Demographic Studies, 1984)

# Existing Communities



Families

Friends

Neighborhood

Places of  
Worship

Co-Workers

The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives."

(D. Luterman, 2006)

The emotional response to the child's hearing loss is independent of the degree of loss.

(D. Luterman, 2006)

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# Others Who Are Deaf/Hard of Hearing

Role Models

Mentors

Children/Teens/  
Adults



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# Professional to Parent Support

Service Coordinators

Parent Educators

Early Interventionists

Audiologists

Medical Home/Physician

Speech-Language Pathologists

Teachers

Hospital Staff

Communication Instructor/Specialist





Help parents  
and child

Have  
knowledge to  
impart

Specialized



Parents need help to make sense out of everything that is happening.

A photograph showing an adult's hand holding a child's hand. The adult's hand is on the left, wearing a white ribbed sleeve. The child's hand is on the right, smaller and more delicate. The hands are clasped together in a supportive grip. The background is a solid, muted green color.

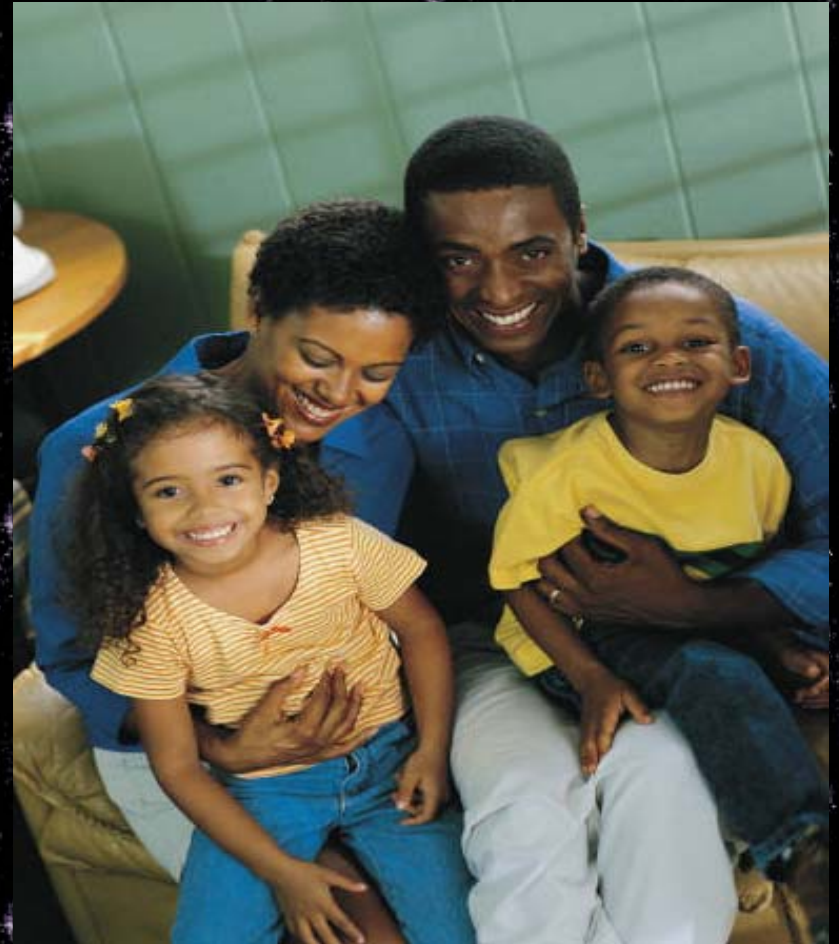
Since 1987...

family-centered  
emotional,  
informational,  
and technical support



# Family Support

- Home Visits
- Emotional Support
- Advocacy
- Consultation
- In-Service
- Classroom Observations
- Information
- Assistance accessing services





- Explanation of hearing tests and hearing loss
- Communication options
- Educational rights and procedures

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# Information as 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

# Providing Information as Family Support

- ~20 million people speak **poor** English; 10 million speak **no** English
- ~66 million patient/professional encounters occurred **across language barriers** in 2002
- ~330 **languages** are spoken or signed in the US, not including the 550+ recognized Indian tribes
- <60% of the population has English as a **first language**

(US Census Bureau 02, OMB 02)

# What I won't tell you today...

- Materials should be:
  - Culturally competent
  - Native language
  - Family friendly
  - Unbiased
  - Multi-media
  - User friendly
- This is challenging enough--but you already knew that, didn't you?!?!



# But, did you know...?



- 85% of what we know we learn by listening
- However, 75% of the time we are distracted, preoccupied or forgetful
- We have ~50% recall immediately after talking with someone
- We listen at 125-250 words/minute and think at 1000-3000

# Learning Styles

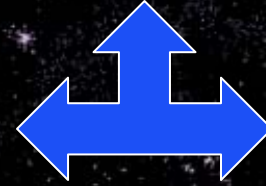
- Convenience Sample of 93 parents of D/HOH
- Preferred Learning Styles (could choose more than 1):
  - 34 selected Reading Booklets/Info Sheets
  - 86 selected One-to-One Discussion
  - 44 selected Hands-on

# What we learned...

- Parents have different learning styles; It is our responsibility to modify and adjust to meet their informational needs...
- One size doesn't fit all!



Where to begin?



# 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???

# 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?

- Professionals

Consider: How are professionals trained to provide support to families? How can we support professional development needs?

- Information

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

# Where Families Find Support

- Parent-to-Parent

Consider: What opportunities are available to facilitate parent-to-parent connections? How can we build upon those?

- Deaf/HH Adults:

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

# Key Elements to Consider



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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"
- Highly Qualified Provider, huh?



# How do I view my role in the EHDI system?

- Diagnostician?
- Coordinator?
- Therapist?
- Early Interventionist?
- Counselor?
- Data Collector?
- Family Supporter?



# Audiologists are not prepared ...who else isn't?

- 12% of training programs offer coursework in counseling  
(McCarthy et al, 86 and '94)
- 45% report feeling ill-prepared to counsel  
(Martin et al, 92)
- Expressions of psychological aspects of HI by parents were responded to with technical information 88% of the time  
(English et al, 99)



# Key Elements to Consider



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# Collaboration between Community Resources

- Families are complex and no one method can meet the multiple and varied needs of each family.
- Creating a continuum of services for children and families in a community.
- Support is more effective when linked to a broader system of care.

*...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*

What resources are readily available?



What does the Continuum look like in your state????

# Home-Grown Examples

- Swimming Teacher
- Free Community Sign Classes
- Pockets and Bows
- Sibling Workshops

*....she never left my house without telling me,  
"You are doing an important job. It is very hard  
work and you are doing it well". I always waited for  
her to say that...*

# Key Elements to Consider



1. Clearly defined goals and objectives
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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.

*"Our Parent advisor taught us to read an audiogram, care for hearing aids, develop our daughter's hearing ability, make everyday routine opportunities to learn language. Our Deaf Mentor took away our fear of what our daughter's life might be like, guided us into the Deaf world, helped us understand Deaf Culture, taught us to effectively use ASL. We would have been cheated if we hadn't had the benefits of both of these wonderful people in our lives."*

*Diane and Ron, parents of a daughter with hearing loss*

“In EI, parents choose the destination and how to get there. They may choose the scenic back roads or the interstate. EI should be like *American Automobile Association*—give info on how to get to the destination, as much or as little information, maps, guidebooks as the family wants...they may change their minds about where to go or how to get there—they may choose not to drive at all but to hire a chauffeur or take a train.”

Marnie Campbell, Kansas



# A Systems Based Approach

- Can a system really support a family?
  - Barriers in the system
  - Positive aspects of the system
- How does a system support a family?
  - Information
  - Direction
  - Monitoring and follow-up

# Family Support Within the System

- What do families want from “the system?”
  - ✓ A clear “in road”
  - ✓ Easy navigation through the system
  - ✓ To talk to someone who understands their situation
  - ✓ Workable solutions: These must consider barriers to participation in family support (I.e. stipends, mileage reimbursement)



# Family Support within the System

- What kinds of information do families need and want?

✓ Answers to specific questions:

- What do we need to do next?
- How are we going to pay for this?
- Who can help us with what we need to do?
- Now that I've landed in Holland instead of Italy, what am I going to need to know for the journey?
- "I want to be left alone. No, I don't. Yes, I do. No, I don't.....Okay, I'll talk with you. Well, maybe I'll just listen."



# Family Support within the System

- Family Support in the Indiana EHDI Program
  - ✓ Parent Consultant (follow-up)
    - A Touchstone Approach...
      - "Just touching base..."
      - About 10-15 questions guide the conversation
      - "Can I call you again in a few months to see how it's going?"

# Family Support within the System

- Family Support in the Indiana EHDI Program
  - ✓ Parent Toolkit (letter, Family Resource Guide, Brochures)
  - ✓ New website- Consumer focus
  - ✓ Annual Family Conference
  - ✓ Teleconferences and regional meetings
  - ✓ Encouragement to contact Family Support Organizations

# Family Support within the System

Why do Indiana families need Family Support Organizations?

- Learn about resources
- Additional support for the journey
- Participation in events that support needs and wants....content-specific teleconferences, conferences and meetings, family camps
- Decreased chance of "conflict of interest" in family arenas
- Connection in the wilderness

# Family Support within the System



- Indiana Family Support
  - ✓ Indiana State Dept of Health "Community-Integrated Systems" encourages involvement of family members on committees for their unique perspective as "users of the system"
  - ✓ EHDl Program considers parents/other family member involvement in programmatic aspects to be a non-negotiable, part of "what we do"

# Family Support within the System

- Future Directions

- ✓ Indiana Family Support Committee-born  
October 2007 in Nashville, TN
- ✓ Survey families on Family Support Organization  
Involvement
- ✓ Work with Indiana Outreach for Deaf and  
Hard of Hearing Children, First Steps, Hands and  
Voices, other Family Support Organizations to provide  
increased support to Indiana families, especially during  
times that families deem "most critical" to them

# Remember...

Family choice and decision making occur at all levels of family involvement in the intervention process.

- BE a STAR—

Take Family Support to the next level!



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





Join us for IFSC3!  
Raleigh, NC      October 5-7



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