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MCHB/NHS Present:

Why EHDI Programs Need
to Include Family Support

Wednesday, August 30, 2006
1:00-3:00pm Eastern

Moderator:
Patti Martin

Family Quality of Life: From Surviving to Thriving

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*Families, in all their rich and
confusing complexity, hold
within themselves the greatest
possibilities of nourishing each member.*



Family Quality of Life

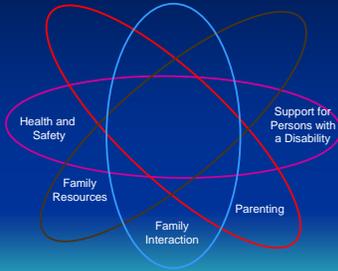
- The degree to which the family members' needs are met
- The extent to which they enjoy their time together
- The extent to which they are able to do things that are important to them.

Poston, Park, Turnbull, Mannan, & Marquis, 2003



A Dynamic Model of Family Quality of Life

- ◆ Family domains provide the context within which individual members form a collective family unit.



Beach Center, University of Kansas

Risk & Resilience

- Risks
- Resilience



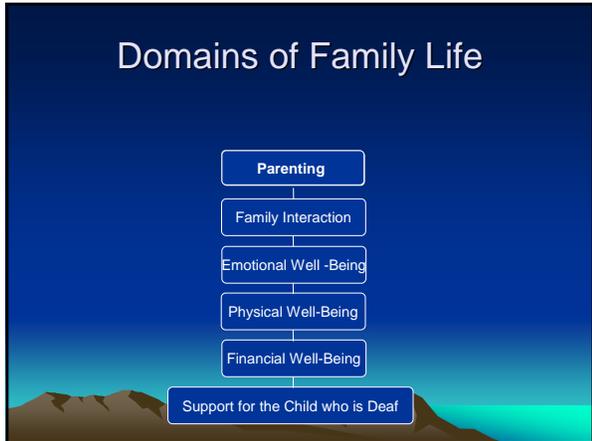
Thriving Families

Improved outcomes



Support for the family





Parenting

Definition: Refers to activities that adult family members do to help children grow and develop.

Sample Items

- Adults in my family have time to take care of the individual needs of every child
- Family members help the children learn to be independent
- Adults in my family teach the children to make good decisions

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Family Interaction

Definition: Focuses on the relationships among family members.

Sample Items

- My family members talk openly with each other.
- My family enjoys spending time together.
- My family members show that they love and care for each other.

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Emotional Well-Being

Definition: Refers to the feeling or affective parts of family members and family life.

Sample Items

- My family members have friends or others who provide support.
- My family has the support we need to relieve stress.
- My family members have some time to pursue their own interests.

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Physical/Material Well-Being

Definition: Refers to the resources available to the family to meet its members' needs.

Sample Items

- My family feels safe at home, work, school, and in our neighborhood.
- My family gets medical care when needed.
- My family members have transportation to get to the places they need to be.

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Support for Special Needs

Definition: Focuses on support from family members and from outside of the family provided in order to benefit the family member who is deaf.

Sample Items

- My family member with special needs has support to achieve goals at school or in the work place.
- My family member with special needs has support to achieve goals at home.
- My family has a good relationship with the people who provide services and supports to our family member with a disability.

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Characteristics of children

- N = 207 (80% return rate)
- Age of child at time of survey
 - Range: Birth to 72 months
 - Mean: 44 months
 - SD: 16.58 month

Results: Satisfaction with family life

- Overall, families were generally satisfied
- Emotional well-being
 - Lowest mean for family satisfaction by domain

Health/Financial Well-being	4.38	.65
Emotional Well-being	3.65	.94
Family Interaction	4.27	.76
Parenting	4.33	.79
Support for Child	4.22	.79

5 items of family life with *least* satisfaction

Time to pursue interests	3.34	1.3
Stress relief	3.35	1.2
Support from local agencies	3.83	1.3
Inclusion in community	3.88	1.1
Finances	3.95	1.0

Impact of Deafness on Family Life

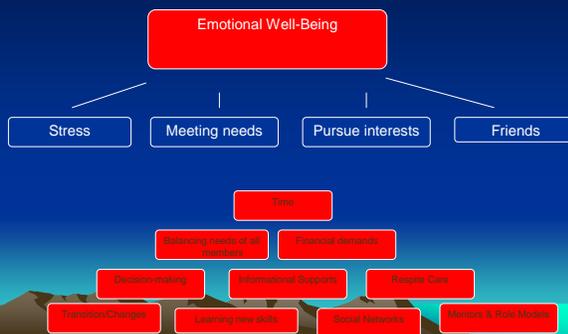
The largest impact of deafness was also in the area of emotional well-being

Health/Financial Well-being	2.17	1.06
Emotional Well-being	3.02	1.28
Family Interaction	2.36	1.21
Parenting	2.82	1.31

Top 5 items of *MOST* impact of deafness

Time to pursue individual interests	3.34	1.3
Support for special needs of all children	3.10	1.5
Time for needs of all children	3.12	1.6
Stress	3.05	1.5
Information needed to make decisions	2.95	1.56

Possible influencing factors



Family Involvement

Thriving Involved Families

Improved Family & Child Outcomes

Calderon (2000); DesJardin (2003); Fantuzzo, McWayne, Perry, & Childs (2004); Moeller (2000).

How are families involved?

Involved in decision making	4.87	.64
Determine goals	4.75	.59
Consistent in use of hearing aids/ CI	4.74	.64
Involved in selecting service providers	4.59	.92
Inform providers about child	4.53	.73
Integrate strategies into everyday activities	4.50	.77
Ask questions to seek out information	4.40	.82

Reported Involvement (contd.)

Practice skills outside sessions	4.32	.96
Attend team meetings or educational mtg	4.08	2.2
Accompany child to special appointments	3.87	1.0
Seek out and read informational resources	3.85	.93
Observe therapy sessions	3.63	1.36
Participate in sessions	3.52	1.35
Socialize with other parents of D/HH	3.00	1.45

* 20% of parents report they have never met with other parents of children who are deaf or hard of hearing

Differences in Involvement By Age

Indicator	Under 36	36-60	>60 mo
Observe Therapy	4.09	3.72	3.43
Participate in Sessions	4.00	3.59	3.31
Attend social gatherings; socialize with other parents of children D/HH	2.36	3.31	3.094

What Facilitates & Impedes FI?

Facilitates

- Having skills needed to integrate strategies (91%)
- Attitudes of professionals (85%)
- Access to information (83%)
- Access to service providers (81%)
- Support of extended family (71%)
- Financial influences (55%)
- Location of services (69%)
- Access to mentors (46%)
- Cultural sensitivity of service provider (42%)

Impedes

- Time for household tasks (72%)
- Stress level (65%)
- Balancing time for all family members (57%)
- Lack of cultural sensitivity of service provider (57%)
- Financial influences (41%)
- Location of services (29%)

What do families say would be helpful?

- Written comments on surveys

“More awareness to our needs and that of our children. People know about deafness, but don’t understand the impact on our lives. Our lives have changed a lot since our baby was born deaf.”

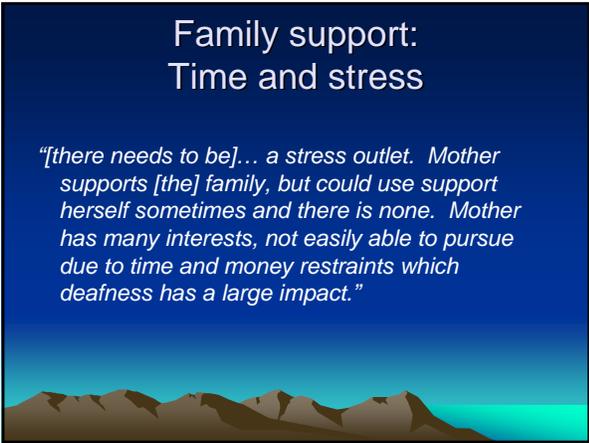
Informational Supports

"When a child is identified as hearing impaired, parents need to be educated about all communication options- regardless of their county's view."



Family support: Time and stress

"[there needs to be]... a stress outlet. Mother supports [the] family, but could use support herself sometimes and there is none. Mother has many interests, not easily able to pursue due to time and money restraints which deafness has a large impact."



Parent supports/social networks

"I would like to have a group of parents with deaf children to communicate and share thoughts with."



Family support: Emotional well-being

"Marriage and family counseling would be helpful for dealing with issues of grief and guilt and to understand the unrelenting stress having a young deaf child places on marriage and family."

Family support

"It is very hard to do this as a single parent who works all the time. We have our own form of communication. It is not verbal or sign. He gestures a lot and it makes it so much harder to be a good parent. I don't know the solution, but...if there is one let me know."

Thriving

Families have always shown remarkable resiliency, or flexible adjustment....their strengths resemble the elasticity of a spider web... the cooperation of an ant colony, and the persistence of a stream carving canyon rocks. ...This resilience is not measured by wealth, muscle or efficiency but by creativity, unity, and hope. Cultivating these family strengths is critical to a thriving human community.

Ben Silliman

Next Steps for Programs

- Identify existing family supports in your programs
- Identify areas in which additional family supports are desired
- Identify barriers to family support
- Identify program goals to enhance family support
- Identify key personnel who may serve as family resource specialists

Presenter:
Irene Forsman



Investing in Family Support

Monday, September 25, 2006
&
Tuesday, September 26, 2006

A Holistic Approach to Family Support

- Information
- Parent-to-parent support
- Adults who are deaf/hard of hearing
- Professional
- Existing communities

Goals

- Participants will develop an understanding of the multiple dimensions of Family Support
- Participants will prioritize family support goals for their state based on assessment of existing needs and resources
- Participants will formulate a written action plan to develop/expand the family support component of their EHDI program



Maternal and Child Health Bureau

Presenter:
Kathleen Watts



What is Family-Centered Care?

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- **Families will partner** in decision making at all levels.
- **The Definition: Family-Centered Care** assures the health and well-being of children and families through respectful family/professional partnerships. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high quality services.



PRINCIPLES OF FAMILY-CENTERED CARE PARTNERSHIPS

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- The foundation of Family-Centered Care is the partnership between families and professionals:
 - Families and professionals work together in the best interest of the child and family. As the child grows up, s/he assumes a partnership role.
 - Everyone respects the skills and expertise brought to the relationship.



PRINCIPLES OF FAMILY-CENTERED CARE PARTNERSHIPS

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- Trust is acknowledged as fundamental
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is willingness to negotiate.

PRINCIPLES OF FAMILY CENTERED CARE

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- Based on the Partnership, Family-Centered Care:
 - Acknowledges the family as the constant in the child's life.
 - Builds on family strengths.
 - Supports the child in learning about and participating in his/her care and decision-making.
 - Honors cultural diversity and family traditions.

PRINCIPLES OF FAMILY CENTERED CARE

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- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered.
- Celebrates successes!

Family/Professional Partnerships & Cultural Competence

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Why Important? Why Do They Go Together?

- National Survey for CSHCN**
 - Only 57% of families with CSHCN report they participate in decision making and are satisfied with services they receive
 - ½+ poor families report receiving care lacking at least one component of family centered care; 47% of Hispanic & 43% of non-Hispanic Black families
- Cross-Cutting Value**
 - MCHB/HRSA/DHHS
 - Reporting Requirements: MCHB SPRANS Performance Measures/Title V Block Grant

Family/Professional Partnerships & Cultural Competence

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Cultural Competence

... come together in a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations.

- *valuing diversity
- *cultural self-assessment
- *adapting to diversity
- *managing the dynamics of difference
- *institutionalization of cultural knowledge

(Modified from Cross, Bazron, Dennis and Isaacs, 1989, by NCCC/Source NCCC)

Levels of Family Centered Care

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- Policy
- Program
- Practice

Ways to Achieve Family Centered Care...

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- Families as Advocates
- Families as Staff or Consultants
- Families as Faculty
- Families as Users of Health Care

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Examples of Partnerships with Families

- Response – MCHB...
 - Promotes family-centered care that is culturally competent and involves meaningful family/professional partnerships
 - Promotes the inclusion of all families as decision makers at the family and systems levels-policy, program and practice
 - Promotes mentoring and training of family leaders
 - Advocates for community systems on behalf of other's rights or honor
 - Funds Family Voices, Inc. national, grassroots network, family run
 - Funds Family-To-Family Health Information Centers
 - Requires family participation in ALL Block grant and other grant programs

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Building Partnerships

Partner: one who shares with another or others for a mutual benefit

Essential Components:

- ✓ Building trust, nurturing trust
- ✓ Actively listening & engaging – open & honest
- ✓ Open to new opportunities for learning, sharing power and moving forward
- ✓ Establishing clear expectations, roles & responsibilities
- ✓ Acknowledging mutual respect for each others' cultures, values and traditions
- ✓ Commitment



Modified from "Family Voices, Inc." 2005

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Questions and Answers

Please complete the evaluation at the end of the webcast

Archives of this event and others are located at <http://www.mchcom.com>
