Decision Making Processes of EHDI Families

Sarah Wainscott, M.Ed.
Marilyn Sass-Lehrer, Ph.D.
Carol Croyle, M.A.

Gallaudet University

Funded by Gallaudet Research Institute
Decision Making Processes of EHDI Families

- Objectives of the Study
- Methodology
- Introduction of Model
- Review of Key Concepts with Quotations
  - Context
  - Information
  - Process
  - Ownership
  - Support
- Applications for Practice and Research
Objectives of the Study

Goal: To improve understanding of the decision-making processes of families engaged in the EHDI system.

Application: Empowered, competent families through better equipped professionals.
Methodology

- Qualitative, phenomenological approach
- Semi-structured interviews & surveys
- Six Participant Families
  - Hearing parents
  - Children in EHDI system ages 10-18mos.
  - Three states in Mid-Atlantic
  - 2 African-American/ 4 White
  - 1 profound, 1 asymmetrical, 2 moderate, 1 mild
Research Design Stages

- Review of Related Research
- Complete Focus Groups & Interviews
  - Families
  - Professionals
- Develop Instruments & Protocol
  - Demographic Survey
  - Interview Protocol
  - Ratings of Priorities and Perspectives
- Revise Instruments and Protocol after Pilot
- Collect Data on Decision-Making
- Transcribe and Code Interview Data
- Analyze Data for Themes and Relationships
- Validate Themes with Families
EHDI Family Decision-Making Model

**CONTEXT**
Demographics: SES, HL Level, Service Availability
Personal Characteristics: Perspectives, Priorities, Style

**Parents and/or Professionals**
Information: Identification of needs, alternatives, resources
Internet, Written Material, Observations, Systems/Centers, Personal Contact

**Priorities of Communication, Education & Future**
PROCESS: Sequence of choices by readiness
Hearing Loss → Technology → Communication → Services

**Perceptions of Self-Efficacy & Control**
Participation: Perception of involvement and ownership
Predetermined → Professional → Guided → Collaborative → Family

**SUPPORT**
Professionals: Relationships & Access
Services: Access & Effectiveness
CONTEXT of Decision-Making

- Demographic Factors
  - Socioeconomic Status
  - Level of Hearing Loss
  - Availability of Services

- Personal Characteristics
  - Perceptions of System
  - Perspectives of Life
  - Management of Stress
Families’ perceptions of how the system functions vary, and may be related to the socioeconomic status of the family.

Families’ views of “calmness” or “hopefulness” & ability to manage stress & worry shape approaches to decision-making.
CONTEXT of Decision-Making:

**Practice:**
- Learning about families’ perceptions, expectations, and perspectives may enable providers to match service-style with family style.

**Research:**
- How similar are families’ self-perceptions to those of professionals?
- How do professionals view issues of family context?
Families act as both “initiators and “receivers” in information gathering.

Families use a variety of sources and strategies to gather information.

The deaf community has the potential to impact families’ perceptions of their children & decision-making.
INFORMATION Gathering

- **Practice:**
  - Families need to have access to a broad variety of information through different media and personal contact.

- **Research:**
  - How does the quality of information vary based on the type on media?
  - How can the nature of information be improved for families who don’t use the internet?
Families highly value the communication & future education of their children.

The Decision Process for families is fluid, deliberate, & varies across the three decision areas studied.

There is a predictable pattern of progression as families move through a series of related decisions.

- Level of loss, Technology, Communication, Services
PROCESS of Decision-Making

Practice:
- Framing information in terms of communication and education relates to families’ priorities.
- An awareness of a decision sequence may help the professional guide the family effectively.

Research:
- Is the sequence observed replicable for a large sample?
- Are guiding priorities different for specific cultural groups?
OWNERSHIP of Decisions

- Families who are confident & comfortable in decisions are open to change.
- Decision Ownership occurs on a continuum; Families participate comfortably at different points.
  - Predetermined, Professional, Guided, Collaborative, Family
- Families’ levels of engagement with the system are shaped by their sense of efficacy & the degree of control that they perceive.
OWNERSHIP of Decisions

Practice:
- Families may feel a greater sense of decision ownership when their sense of efficacy and control are supported by professionals.

Research:
- How do families and professionals view advocacy differently?
- Is the continuum of ownership evident in larger samples and within other disabilities?
SUPPORT from professionals & systems

- Families desire a strong, invested relationship & competence in interactions with professionals.

- Families desire systems that provide accessible & effective services.
Practice:
- Professional training should include components on building relationships with families.
- Accessibility of services cannot be overlooked.

Research:
- What are effective strategies for building relationships with families, particularly those difficult to engage?
EHDI Family Decision-Making Model

**CONTEXT**
Demographics: SES, HL Level, Service Availability
Personal Characteristics: Perspectives, Priorities, Style

**Parents and/or Professionals**
Information: Identification of needs, alternatives, resources
Internet, Written Material, Observations, Systems/Centers, Personal Contact

**Priorities of Communication, Education & Future**
PROCESS: Sequence of choices by readiness
Hearing Loss → Technology → Communication → Services

**Perceptions of Self-Efficacy & Control**
Participation: Perception of involvement and ownership
Predetermined → Professional → Guided → Collaborative → Family

**SUPPORT**
Professionals: Relationships & Access
Services: Access & Effectiveness