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Decision Making Processes of EHDI Families

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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
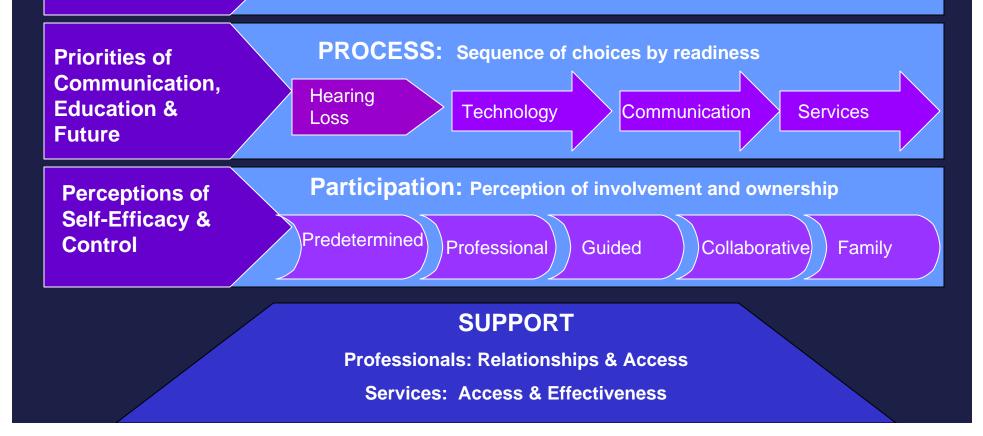- Validate Themes with Families

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

CONTEXT of Decision-Making

- 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?

INFORMATION Gathering

- 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?

PROCESS of Decision-Making

- 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.

SUPPORT from Professionals & Systems

- 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?

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