



# Tough Choices: Parental Perspectives on Decision Making

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# Overview

- Brief discussion Infant Hearing Guide
- Recognition of need to focus on decision-making strategies





# Infant Hearing Guide

- Description of what it is
  - Topics
  - Examples
  - CD
- 
- When parents were asked to provide examples and stories, the issue of decision-making and decision-making strategies were one of the predominate themes



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*To begin learning about infant hearing loss, click on a topic from the lists below.*

## **Diagnosis**

[Newborn Screening](#)  
[All About Hearing Loss](#)  
[Causes of Hearing Loss](#)

## **Taking Action**

[Introduction to Hearing Aids](#)  
[About the First Hearing Aids](#)  
[Cochlear Implants](#)  
[Introduction to Early Intervention \(EI\)](#)  
[Communication Methods](#)  
[Early Intervention Services](#)

## **Family Support**

[Family Talk](#)  
[Family Resources](#)  
[Family Tools](#)



[Introduction to cochlear implants](#)

▪ **Cochlear implant and hearing**

[View Earworks Video](#)

[Parts of a cochlear implant](#)

[View CI Video](#)

[View CI Animation](#)

[Surgery and Activation](#)

[Expectations](#)

[View Expectations Video](#)

[Issues when considering an implant](#)

[Follow-up and rehabilitation](#)

[Are cochlear implants expensive?](#)

[Frequently Asked Questions](#)

[Additional Resources](#)

## Cochlear implants and Hearing

In order to understand how a cochlear implant works, it is important to understand how we hear. The outer ear collects sound waves and sends them to the middle ear. The sound waves bounce off your eardrum and are made louder by three tiny bones: the hammer, anvil, and stirrup. The sound waves travel into the fluid filled inner ear. The waves go through the cochlea (the organ of hearing). Microscopic hair cells in the cochlea turn the vibrations into electrical impulses. Then your brain receives and interprets this energy as a sound or speech.



[Click for More Information](#)

Cochlear implants take advantage of the things an ear can still do after hair cells have been damaged or destroyed. It also takes advantage of how smart and flexible the human brain can be. The cochlear implant creates a new way of hearing. A cochlear implant consists of five basic parts; these are a microphone, a speech processor, a transmitter, a receiver/stimulator, and an electrode array.

[Click here for video](#)

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# Close



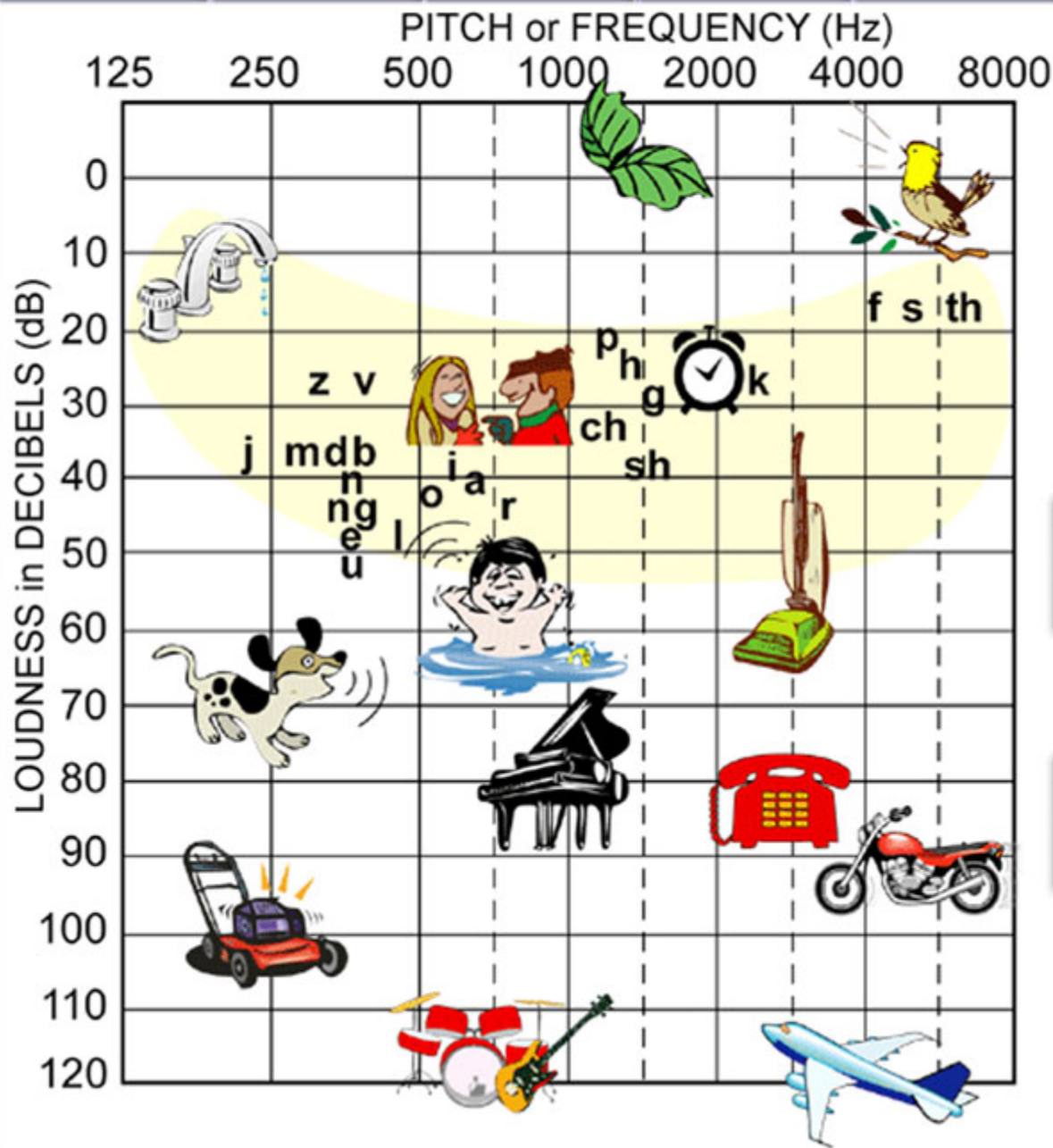
Close Video  
Volume

Video Controls



## Initial Reactions

- 1 **Traci:** My son was born in 1997. They did the screening test at the hospital when he was born.  
of They took him out and tested him. They brought him back and informed us he didn't pass the hearing test. I  
13 was puzzled. We were not sure because of fluid in the ear, the doctor's were telling us, but we said  
So they suggested going to the Department of Health.



### Sound Explorer

Click the icons to the left to hear sounds at different loudness and pitch.

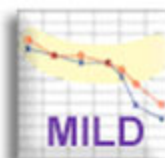
Click the buttons below to hear simulations of speech and singing at different hearing levels. These are only approximations.



SPEECH



NORMAL



MILD



MOD



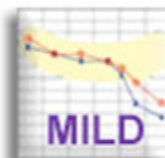
SEVERE



SINGING



NORMAL



MILD



MOD



SEVERE

[Close](#)

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*Tools for working with parents and other professionals.*

*Tools for...*

## Diagnosis

Newborn Screening

[Screening Process Diagram](#)

[Hearing Test Video](#)

All About Hearing loss

[How the Ear Works Video](#)

[Audiogram Video](#)

[Speech Sounds Video](#)

[Sound Explorer](#)

Causes of Hearing Loss

[Overview Graphic](#)

[Possible Causes Video](#)

[Hearing Loss Timeline](#)

*Tools for...*

## Taking Action

Hearing Aids

[Types of Hearing Aids](#)

[Bone Conduction](#)

[Examples of Hearing Aids](#)

About First Hearing Aids

[Troubleshooting Video](#)

Cochlear Implants

[CI Video](#)

[CI Animation](#)

[Expectations Video](#)

Early Intervention

[Communications Milestones](#)

Early Intervention Services

[Your Baby's 1st Teacher Video](#)

[Experiencing Language Video](#)

*Tools for...*

## Family Support

Family Talk

[Initial Reactions Video](#)

[Family Cultures Video](#)

[Family Advocacy Video](#)

Family Resources

[Parent Network Video](#)

Family Tools

[EI Toolbox PDF](#)







# Beliefs about Decision-Making

- Accompanying the trend toward earlier diagnosis of hearing loss is a need for earlier decision making by parents . . . (Li, Bain, Steinberg, 2007)
- Families' decisions are often based upon their views of the world, their experiences, and their goals for their children and their individual family situations (Sass-Lehrer, 2002)





# Beliefs about Decision-Making

- People can learn decision making skills (2007)
- Support for families should be designed so that families are able to make decisions, solve problems and advocate for their children and families (Bodner-Johnson, Sass-Lehrer, 1999)
- Informed family choice and desired outcome guide the decision-making process (JCIH, 2007)





# Definition of Decision-Making

The ability to choose the optimal outcome based of individual or family values and beliefs in the face of uncertainty

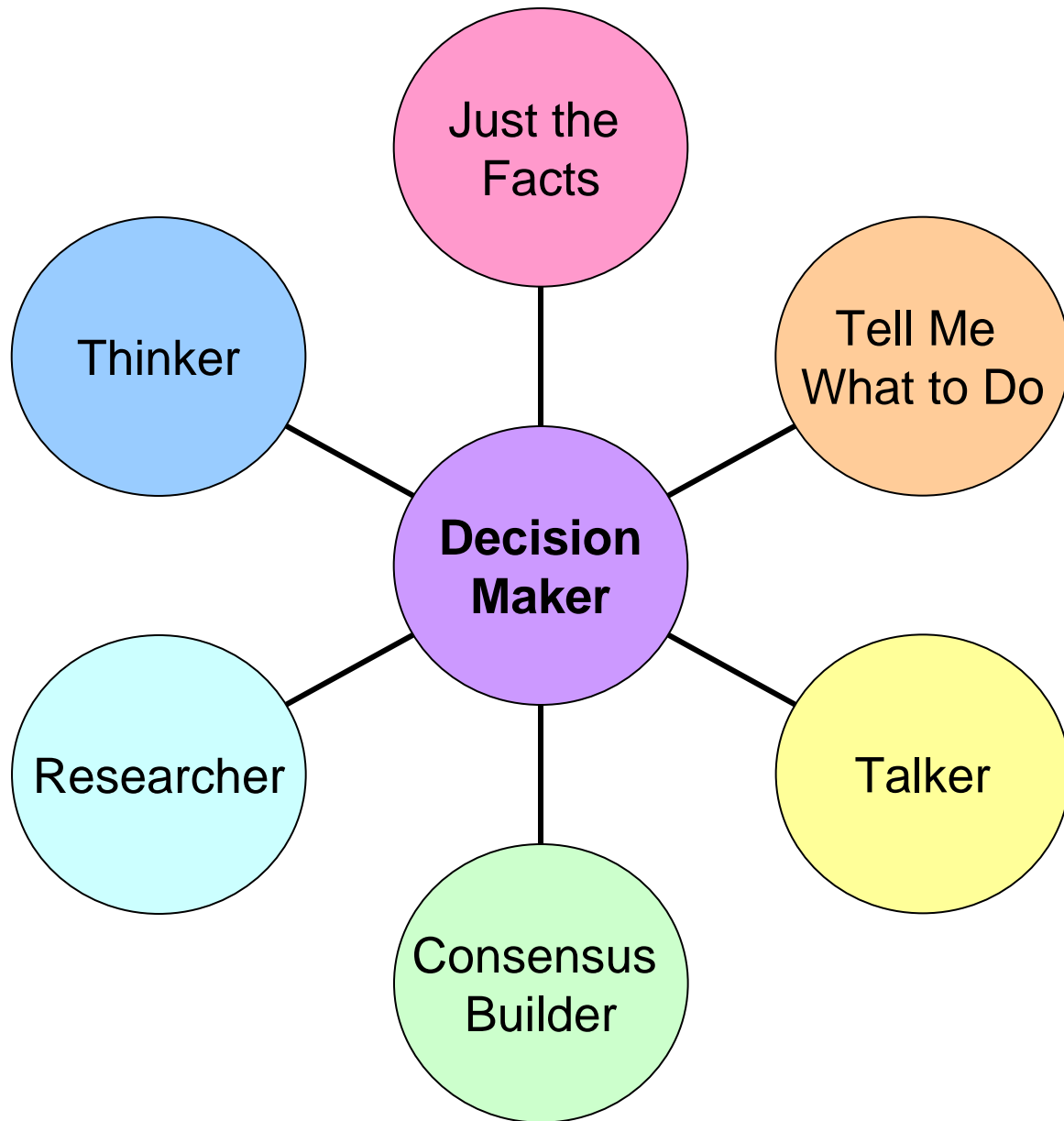




# How do people make decisions?

- Rational Decision-Making Model (Analytical)
  - Involves a cognitive process where each step follows in a logical order from the one before based on desired outcome, alternatives, consequences, choice, and action
- Intuitive Decision-Making Model (Intuitive)
  - Intuitive decision making is far more than using common sense because it involves additional sensors to perceive and get aware of the information from outside. Sometimes it is referred to as gut feeling, sixth sense, inner sense, instinct, inner voice, spiritual guide, etc.
- Recognition Primed Decision Making Model (Combined)
  - A model of how people make quick effective decisions when faced with complex situations; cues and indicators are used to recognize patterns leading to a single course of action or an 'action script' that one believes will achieve the desired outcome (Klein, 1985)







# What are the steps in the DM process?

- Define the situation and desired outcome
- Gather information about problem and potential solutions
- Generate alternatives and consider consequences
- Choose the best option from among the alternatives
- Monitor progress toward goal and reconsider choice as needed





# Parental Perspectives

- Predominate decision-making themes
  - Desired outcome
  - Communication
  - Technology
  - Education
  - Coping
    - Decision-making Clip from IHG
- Other considerations
  - Challenges faced on a daily basis
  - Strategies used by families to cope with challenges
  - Diversity of family experiences and preferences
  - Culture and specific needs of the **individual** family
    - Desired Outcome Clip from IHG





# Multi-Phase Project

- Phase I
  - Develop content for decision-making tool
- Phase II
  - Build prototype
- Phase III
  - Test prototype
- Phase IV
  - Complete development
- Phase V
  - Field test







# Phase I

- Gathered parent perspectives
  - Parent meetings
- Pilot testing questionnaires
  - Decision making
  - Self efficacy
  - Coping





# Parent Perspectives

- How will my child learn to communicate?
- What technology can help my child?
- Where will my child go to school?
- What are the realistic options for my child?
- Do I have realistic expectations for my child?





# Parent Quotes

“Sometimes the decision is who will win. We wonder, what are we going to do today to help our child today with hearing? Are we up for it? It is such a struggle everyday.”

“The best decision today might not be the best decision tomorrow.”





# Instruments

- Now we are going to talk about
- DMSI
- SPISE
- CHIP



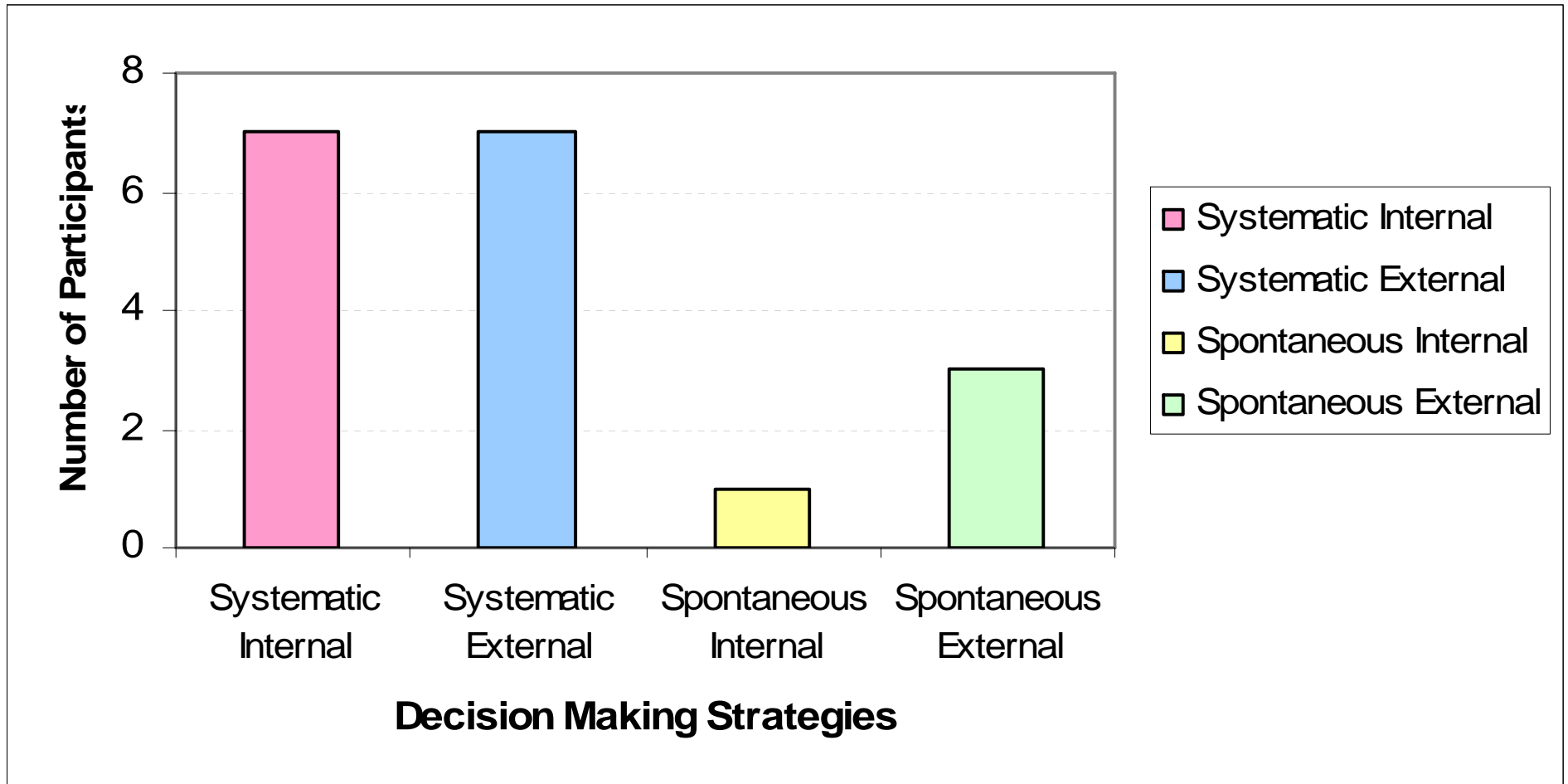


# Decision Making Style Inventory (DMSI)

- What is the DMSI
  - Reliable and valid way to understand
    - How we gather and process information
    - Dynamics of personal and professional relationships
    - Basic evidence-based decision-making styles
      - Spontaneous External
      - Spontaneous Internal
      - Systematic External
      - Systematic Internal
  - 36 statements that describe various kinds of decision situations
    - Likert type scale from 1 – 6 (never to always)



# Decision Making Style Inventory (DMSI)



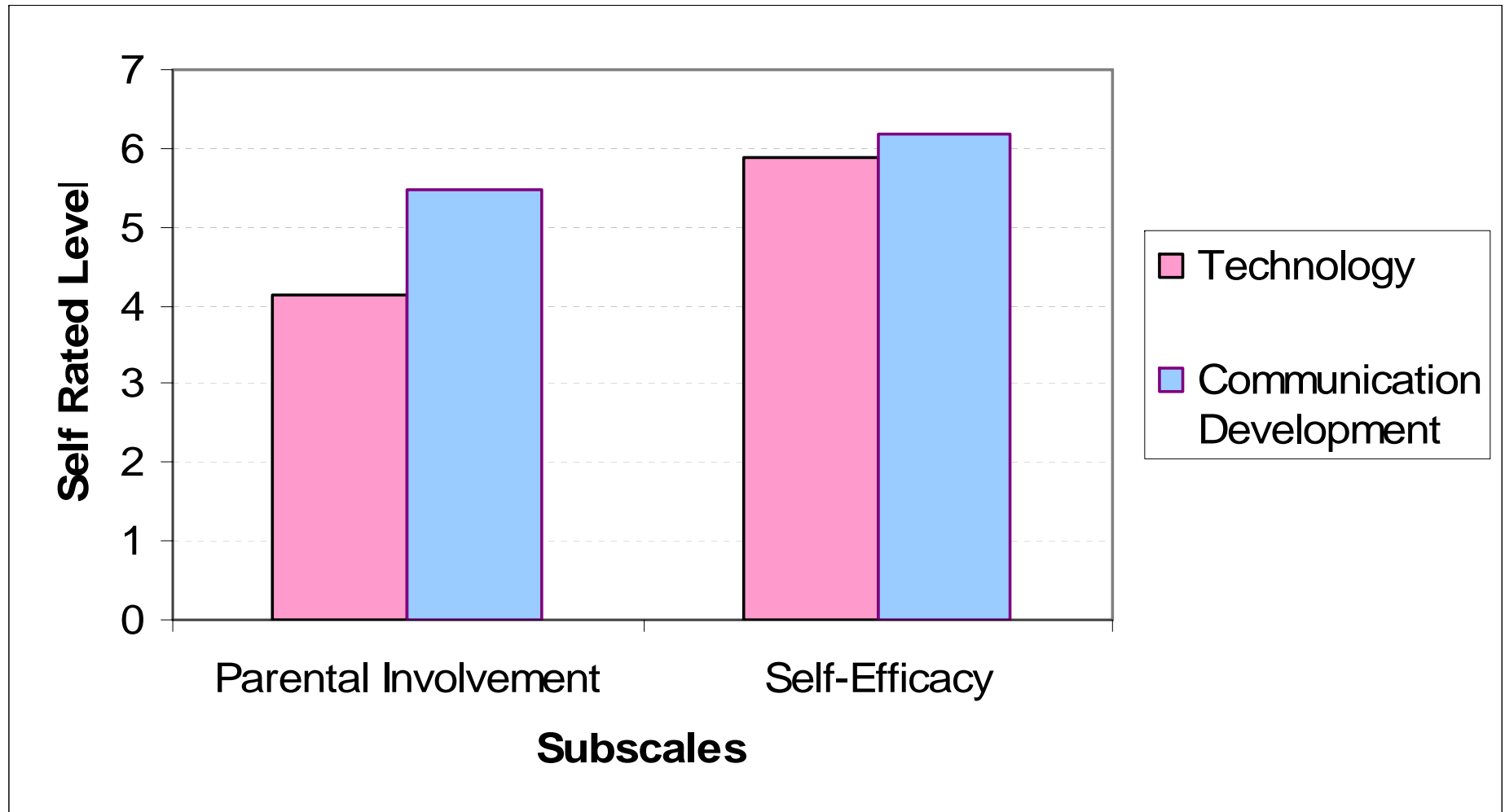


# Scale of Parental Involvement in Self-Efficacy

- Subscales
  - Parental involvement
    - Extent to which parents are involved in specific responsibilities or tasks
      - Auditory development
      - Daily amplification use
      - Speech-language development
      - Speech-language activities at home
  - Self-efficacy
    - Degree to which parents feel knowledgeable and competent in the care and follow-through
      - Auditory development
      - Daily amplification use
      - Speech-language development
      - Speech-language activities at home
  - 22 questions ranging from 1 (not at all) to 7 (very much)



# Scale of Parental Involvement in Self-Efficacy



J DesJardin (2004)





# Coping Health Inventory for Parents

- Management of family life when child has a hearing loss with/without a disability can be a challenge
- Families use different coping strategies to deal with these challenges





# CHIP Categories

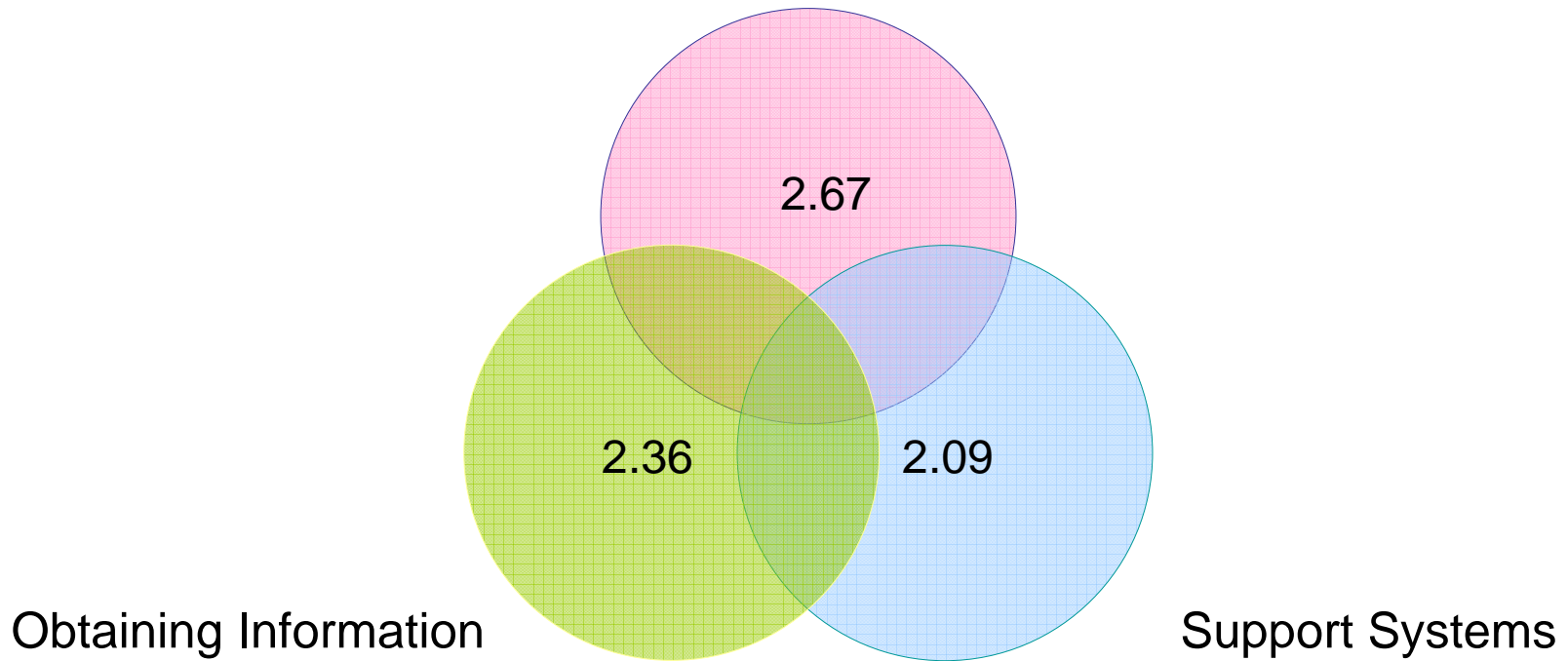
- Family cohesiveness
  - Maintaining family integration, cooperation, and optimistic attitudes
- Support system
  - Maintaining social support, self esteem, positive outlook
- Obtaining information
  - Understanding of the condition through other parents and/or health professionals





# CHIP Results

Family Cohesiveness





# Summary of what we just said





# Topic Categories

- Based on parent, literature, professional
- Communicate
- Technology
- School
- Integrated into a way to facilitate DM
- What are the realistic options for my child?
- Do I have realistic expectations for my child?





## Phase II

- Design, develop, implement, evaluate, produce and disseminate a DVD technology tool called Infant Hearing Decisions





# Infant Hearing Decisions

- Rationale for Format
  - Give families opportunity to learn together in the comfort of their own home
- Facilitate
  - Interaction, communication, and participation
  - Cooperative learning and planning activities
  - Decision-making skills to meet desired outcome of the family





# Phase III

- Pilot test prototype with 20 families of children with hearing loss
  - List outcome measures







- Tell audience about copies of IHG and contact information for anyone interested in IHD as it evolves





“But of all these paths, which will lead us most promptly to the goal? Who will tell us which to choose?”

Henri Poincare, 1906

