ADOPTION OF CHILDREN WITH HEARING LOSS: PARENTS' PERSPECTIVES
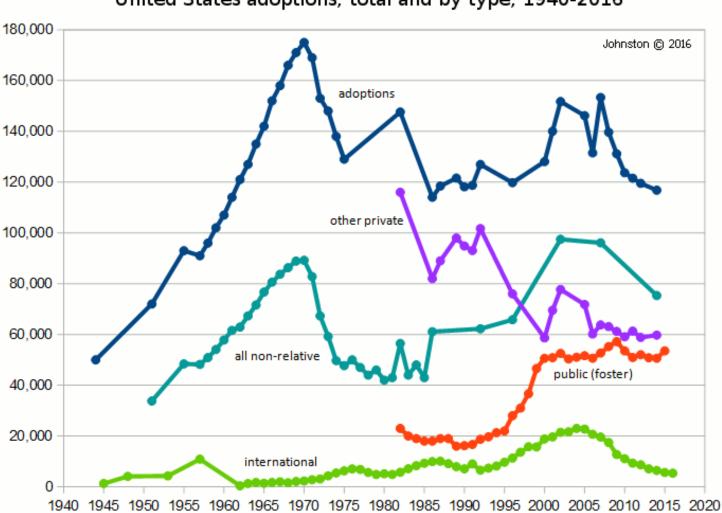
EHDI 2019
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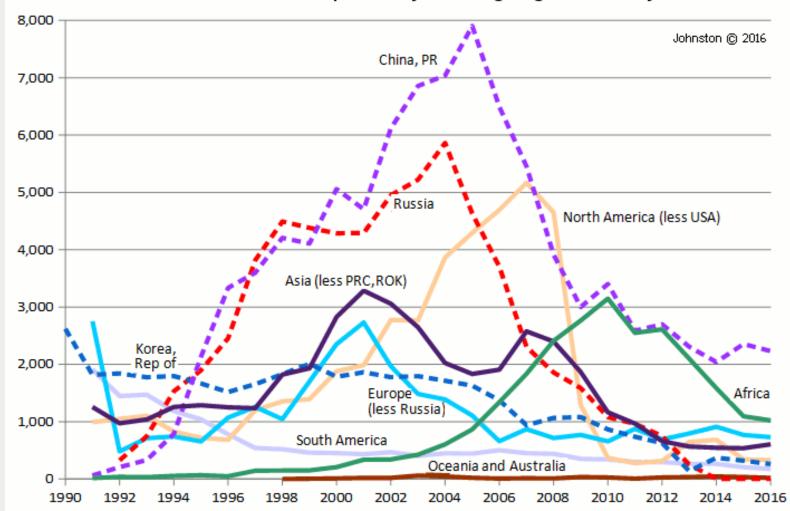MARIA HARTMAN PHD

Objectives

- Examine factors that affect communication and developmental outcomes for children with hearing loss who are adopted
- Identify common themes expressed by parents who have adopted children with hearing loss
- Apply knowledge gleaned from parent interviews to improve family-centered service delivery for this population

Statistics and Demographics

- In FY 2016, the US issued 5,372 immigrant visas for children being adopted (Department of State)
- In FY 2015, 53,500 children were adopted from the US foster care system (Children's Bureau, 2016)
- Currently, >90% of adoptions from top sending countries (e.g., China) are classified as "special needs" (Department of State, 2015)

United States adoptions, total and by type, 1940-2016

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adoptions

other private

all non-relative

public (foster)

international

United States international adoptions by sending region/country, 1990-2016

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China, PR

Russia

North America (less USA)

Asia (less PRC,ROK)

Korea, Rep of

Europe (less Russia)

South America

Africa

Oceania and Australia

Literature Review

- Research on parents who have adopted children with special needs (e.g., Rosenthal & Groze, 1990)
  - Overall positive impact of adoption on family
  - Satisfied with social work and other services
  - Some reported behavioral issues (increased with age at time of adoption)
- Parents' attitudes toward disability in general in transracial adoptions (Raleigh & Rothman, 2014)
- Parents' experiences adopting children with specific conditions:
  - HIV positive (Gibson & Fair, 2016)
  - Orofacial clefts (Cochran, Nelson, & Robin, 2014)

Literature Review

- No previous studies on experiences of parents who have adopted children with hearing loss specifically
  - Searched "deaf," "hearing loss," "hearing impaired," "hard of hearing," with "adopt*" (adoption, adopting, adoptive, adopted)-> no results!
- But we knew there is a need for this type of research
  - Professional experiences with families
  - Online communities (e.g., "Deaf/HOH Adoption" or "Deaf Adoption Late Language Acquisition")
  - Personal interest
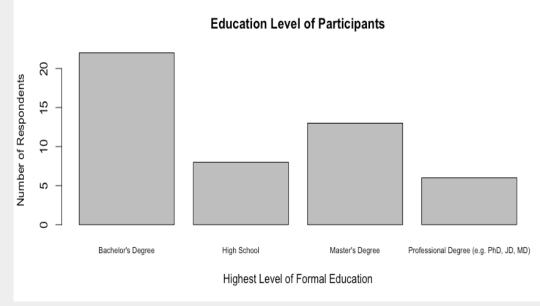
Research Question

What common motivations, experiences, challenges, and strengths are identified/experienced/described by parents who have adopted children with hearing loss, either internationally or domestically?
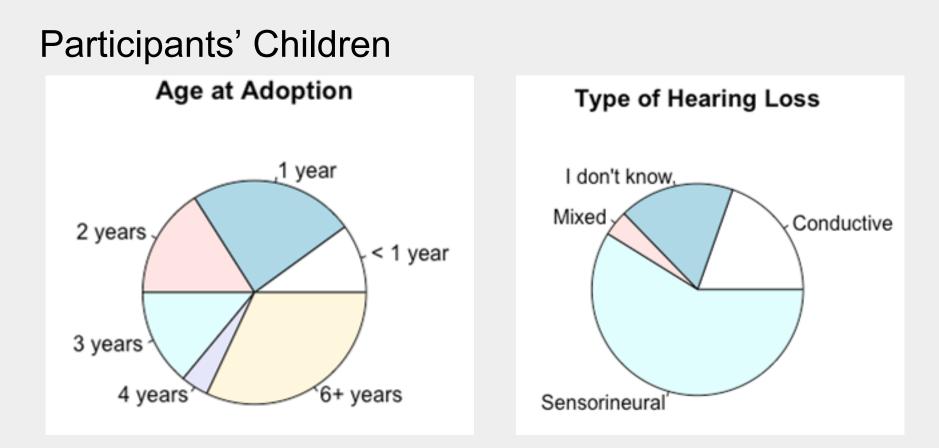
Participants

- Overall (quantitative): $N = 49$
- Qualitative: $n = 22$ (11 video interviews; 11 written interviews)
- All female
- Parents ranged in age from 25 to 60+ years
- Two had adopted > 1 child with hearing loss
- Three were deaf or hard of hearing (all others had typical hearing)
- Diverse range of professions:
    - Stay-at-home parents, business analysts, nurses, professors
    - Several worked in field of hearing loss (4 interpreters, 2 audiologists, 2 teachers of the deaf)
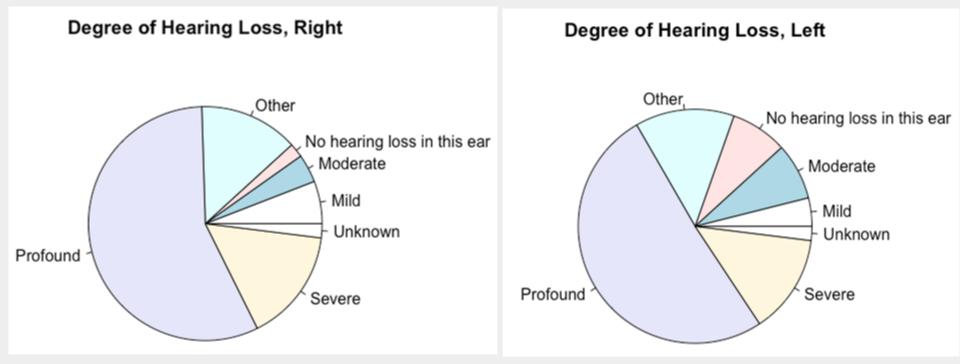
Participants

- Home languages:
  - English: $n = 36$
  - ASL: $n = 2$
  - English and sign: $n = 10$
  - Spanish: $n = 1$

Education Level of Participants

Participants' Children

Age at Adoption

Type of Hearing Loss

Participants' Children

Degree of Hearing Loss, Right

Degree of Hearing Loss, Left

Method - Data Collection

- Qualitative interview
  - Semi-structured interview (Bernard, R. 1988, 2000)
    - Interview guide - open-ended questions, prompts
    - Respondents tell their own story on their own terms
    - An interpersonal encounter
    - Inductive analysis

Interview Topics

- Motivation
- Reaction (to dx of HL)
- Communication decisions
- Technology decisions
- Services pre-adoption
- Services post-adoption
- Expectations

- Others' reactions pre-adoption
- Others' reactions post-adoption
- Adjustment/attachment
- Ethnicity/Race/Culture
- Sources of support
- Professionals
- Language

Method - Data Analysis

1. Thematic analysis (Braun & Clarke, 2006)
    a. Professional transcription of video interviews
    b. repeated, active reading by several researchers
2. Organized codes into potential themes
    a. Tables, mind-maps, discussion among team
3. Reviewed themes
    a. Internal homogeneity and external heterogeneity
4. Focused coding- Defined and named themes

Common Themes

MOTIVATION

- Religious
  - "We were called to adopt."
- Infertility
- Humanitarian
- Prior experience
  - "I had known that I would parent a deaf child, which most people don't know that, and I don't think it was something that was consistently on the forefront of my mind… I had exposure in elementary school, so starting at a pretty young age."

Common Themes

HEARING LOSS IDENTIFICATION AND DIAGNOSIS

- Unclear information about etiology, specific dx pre-adoption
  - Initially more comfortable with "hard of hearing" vs. "deaf" child
- Lack of services in the birth country.
- Connections with other parents, professionals key in how parents experienced dx
- Shocked… but relieved
- Grief
  - "I didn't go through quite the grieving process, that grieving process that parents go through when they have a newborn that fails the hearing screening. The upset that I had is the time lost, the time that we lost."

Common Themes

HEARING LOSS TECHNOLOGY AND COMMUNICATION DECISIONS

- It's not what you know; it's who you know
- Importance of online parent-to-parent support
- Missing the window for age-dependent services
  - What happens if you miss the parent coaching piece of EI and go straight to school-based services?
- Effects of L1 exposure/access accent vs. speech error, "English age"

Common Themes

HEARING LOSS TECHNOLOGY AND COMMUNICATION DECISIONS

- Changing technology/communication choices due to child's needs
    - "It's one thing to work with the d/Deaf. It's a whole other thing for that to be your child."
    - "I wanted her to have access to everything."
- Professionals knowledgeable about hearing loss OR adoption-related issues, but not both

Common Themes

PARENTS' REACTIONS

- This is harder than I thought it would be
  - Child has additional issues
    - ALL of these children have additional issues due to trauma
  - Navigating bureaucracy (both adoption and medical/educational)
- Dealing with others' insensitive reactions
  - Questions, comments, biases
- Dealing with polarization in the field
  - "They [deaf adoption support group] said we shouldn't even adopt him if we we're not going to become fluent in sign language"
  - "I don't know why anyone wouldn't learn sign language"

Common Themes

PARENTS' REACTIONS

- Mothers were purposeful, determined, and unwavering in addressing child's needs.
  - "This is sort of the only parenting world we know, and it's not always the easiest one to navigate. But I feel like there's lots of resources available. People just have to look for them and take advantage of them.
  - "[Hearing loss] is the special need that's not… It has been easy. I mean, it's been a lot as far as the language and everything like that, but she's doing so, so well. And I'm so glad that we didn't let fear get in the way and that we did say yes."
- Families embraced the ethnicity of the child as well as the hearing status.
  - Searching out cultural connections and deaf adults

Discussion/Limitations

- Sense of agency and conviction in mothers
- Desire to share and support others

- Convenience/snowball sampling
- Lack of fathers' perspectives
- Reliance on respondents' accuracy and recall

Implications for Intervention

- Hearing screen (and S/L screen) should be routine for all adoptees
- Lack of sensory input
- Lack of consistent, responsive caregiving
- Low language stimulation
- Food insecurity
- Toxic stress

Implications for Intervention

ATTACHMENT → LANGUAGE

Children who are more securely attached are more likely to…

- Cooperate with their parents
- Actively explore their environment
- Build stronger relationships with others
- Be involved in communication and literacy activities

Dodici, Draper, & Peterson, 2003

Implications for Intervention

- Hearing Age vs. Language Age vs. English Age vs. Chronological Age vs. Family Age
- Effects of second language exposure
- Fight/Flight/Freeze responses

Implications for Intervention

- Contingent responsivity
- Orienting the child to the caregiver
- Modeling scripts for emotion and self-regulation
- Sensory-smart therapy
- Routines for felt safety
- Affirming diverse families
- Family focus vs. medical, therapeutic, school based pressures

ADOPTION LANGUAGE

Negative Language −

- Real Parent
- Giving Up/Away For Adoption
- Adopted Child
- Handicap Child
- Available Child
- Illegitimate
- Is Adopted
- Natural Parent
- Abandoned/Rejected

Positive Language +

- Birth Parent
- Placing For Adoption
- My Child
- Child With Special Needs
- Waiting Child
- Born to Unmarried Parents
- Was Adopted
- Biological Parent
- Separated from Parents

Adopt & Connect

How do early childhood experiences and parenting affect language outcomes for children with hearing loss?

If you are the parent of a child with hearing loss between the ages of 3-5 years old, you may qualify to participate in this study.

Questions? Contact Elizabeth Rosenzweig at ear2178@tc.columbia.edu
SIGN UP AT: bit.ly/researchfamilies

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