Exploring Family Experiences Adopting a Child with Down Syndrome: A Mixed Methods Approach

Eleanor Bold, PhD[1,2]; Allison Meyer, PhD[1,2]; Rebecca Bernstein, BA[1]; Nicole Baumer, MD, MEd[1,2];

Anna and John J. Sie Center for Down Syndrome, Children's Hospital Colorado, Aurora CO[1]
Department of Pediatrics, University of Colorado School of Medicine, Aurora CO[2]

Children's Hospital Colorado
Affiliated with University of Colorado Anschutz Medical Campus

Background

- Children with disabilities make up a substantial portion of those placed for adoption both domestically and internationally.
- Children adopted internationally are known to have higher disability rates, experience complex healthcare needs, and increased mental and behavioral health differences.
- Higher needs have led to lower rates of adoption for children with disabilities, including for children with Down syndrome (DS).
- Little is understood about families' experiences with the adoption process.

Objectives

1. Examine the behavioural and psychiatric needs of children adopted with DS both domestically and internationally.
2. Identify the unique needs and experiences of children adopted internationally compared to those adopted domestically.
3. Examine caregiver expectations, preparedness, and access to support resources in the context of international adoption.

Methods

- *Population*: Families seen within a multidisciplinary DS clinic who reported their child was adopted. See Table 1 for more detail.
- *Measures*: Caregiver-directed measures, both created for this study, included caregiver surveys and 30-minute qualitative caregiver interviews.
- *Analyses*: Descriptive statistics to describe participant demographics; independent samples t-tests to evaluate for differences among subgroups; phenomenological thematic process (1 coder at the time this poster was printer, will expand for reliability in the future).

Results

Table 1: Participant Demographics

	International Adoption (n=12)	Domestic Adoption (n=20)
Child age at time of survey (in years)	13.93 (SD: 4.5)	11.87 (SD: 6.25)
Child age at time of adoption (in years)	4.80 (SD: 4.29)	1.37 (SD: 1.06)
Race (% White)	41.7	55
Black or African American (%)	0	20
Non-Hispanic or Latinx (%)	75	70
Asian(%)	33.3	5
Gender (% Female)	58.3	50

Table 2: Caregiver-Reported Behavioral Needs

	International Adoption (n=12)	Domestic Adoption (n=20)
Difficulty falling or staying asleep (%)	66.7	55%
Deliberate negative behaviors (%)	33.3	25

Themes from Qualitative Caregiver Interviews *(International Adoption Subgroup)*

- Strong sense of family purpose in supporting children with DS
- Adopted children experiencing a high level of medical needs following their adoption
- Valuing a strong community network and access to DS-specific medical care
- Increased time to adjust and bond with their child following international adoption compared to domestic adoption experiences

Caregiver Experience with Down Syndrome

35.5% reported having a biological family with DS prior to adopting a child with DS. Additionally, most caregivers reported **no specific training in caring for a child with developmental disabilities (59.4%) or DS (68.8%)** prior to adopting a child with DS.

Conclusions & Implications

- Children with DS adopted internationally tend to be adopted at a later age, which may contribute to increased risk for developmental and behavioral needs in the future.
- Significant concerns related to sleep and deliberate negative behaviors were endorsed in children with DS adopted domestically and internationally.
- Families highlighted the importance of access to specialty medical care due to complex healthcare needs.
- Strong community networks are also essential to families' success in adjusting following the adoption of a child with DS.
- Families have variable training and opportunity for education prior to adopting a child with DS.

Limitations

- Small sample size and resulting selection bias of participations based on responsivity.
- Limited information about children's neurodevelopmental profiles.

Future Directions

- Considerations for future directions include expanding the population of adopted children and their families, incorporating neurodevelopment profiles into child characteristics and conceptualization of behavioral needs, child participation in study measures, and consideration for biological parents of children with DS and their experiences and needs.

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