

# Tailoring Your Knowledge Translation Strategies for Your Intended Users

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Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

# Empowering Families of Children with Developmental Disabilities in Low-Resource Households

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# Families of Children with Developmental Disabilities



- Limited providers and therapists in the area with knowledge and skills
- Limited coverage by insurance/Medicaid for needed therapies, services
- Schools may have fewer resources to support educational needs
- Housing and food insecurity
- Neighborhood with few resources and supports for families (e.g., playgrounds)
- Experiences of discrimination, bias
- Limited availability of information, services, and support in native language
- Concerns about immigration

# Empowered Families...

- Increased knowledge about their child's needs
- More likely to approach service systems
- Greater confidence in accessing services
- Fewer parent mental health concerns
- Experience fewer child behavior concerns
- Reduced caregiver stress



# Current Study



## ASD Screening and Parent ENgagement (ASPEN) Program

# ASPEN Program

- Culturally adapted, parent-mediated intervention
  - Covers parenting stress, social support networks
  - Provides peer support
  - Provides coaching on naturalistic, developmental behavioral intervention strategies
  - Designed for families from diverse racial/ethnic and low-resource communities



# ASPEN Program: Eligibility Criteria



- Child Age:
  - 18 months and 6 years of age
- Child Diagnosis:
  - Autism diagnosis or high likelihood of autism
- Household Resources:
  - Medicaid
  - Primary caregiver has a high school or lower education
  - Household income  $\leq$  200% federal poverty level)
- Live in Texas

# Participant Characteristics: Children

Characteristic	Mean (SD) /% n = 72	Range
Child Age	3.88 (1.28) years	1.58 – 6.97 years
Child Sex	72.2% Male	
Child Race/Ethnicity		
Hispanic/Latino	90.3%	
White	81.9%	
Black/African American	8.3%	
Asian/Pacific Islander	2.8%	
Current Diagnosis	88.9%	
Autism	83.3%	
Speech/Language Impairment	15.3%	
Developmental Delay	6.9%	
Age of Diagnosis	2.60 (1.32) years	0.00 – 6.33 years



# Participant Characteristics: Caregivers

Characteristic	Mean (SD) /%	Range
Age	36.30 (6.19) years	22.65 – 60.36 years
Nativity	26.4% US-Born	
Years in United States	13.07 (11.04) years	1.00 – 59.00 years
Education		
High School or Less	61.1%	
Some College or More	37.5%	
Employment		
Not Employed	63.9%	
Part-Time	19.4%	
Full-Time	15.3%	
Household Income ( $\leq$ 200% of Federal Poverty Level)	93.1%	
Language	62.5% Spanish	

# Figure 1. Mean Score for Each Family Empowerment Outcome

Understanding of children's strengths, needs, and abilities



Knowledge about rights and advocacy for children



How to help children develop and learn



Having support systems



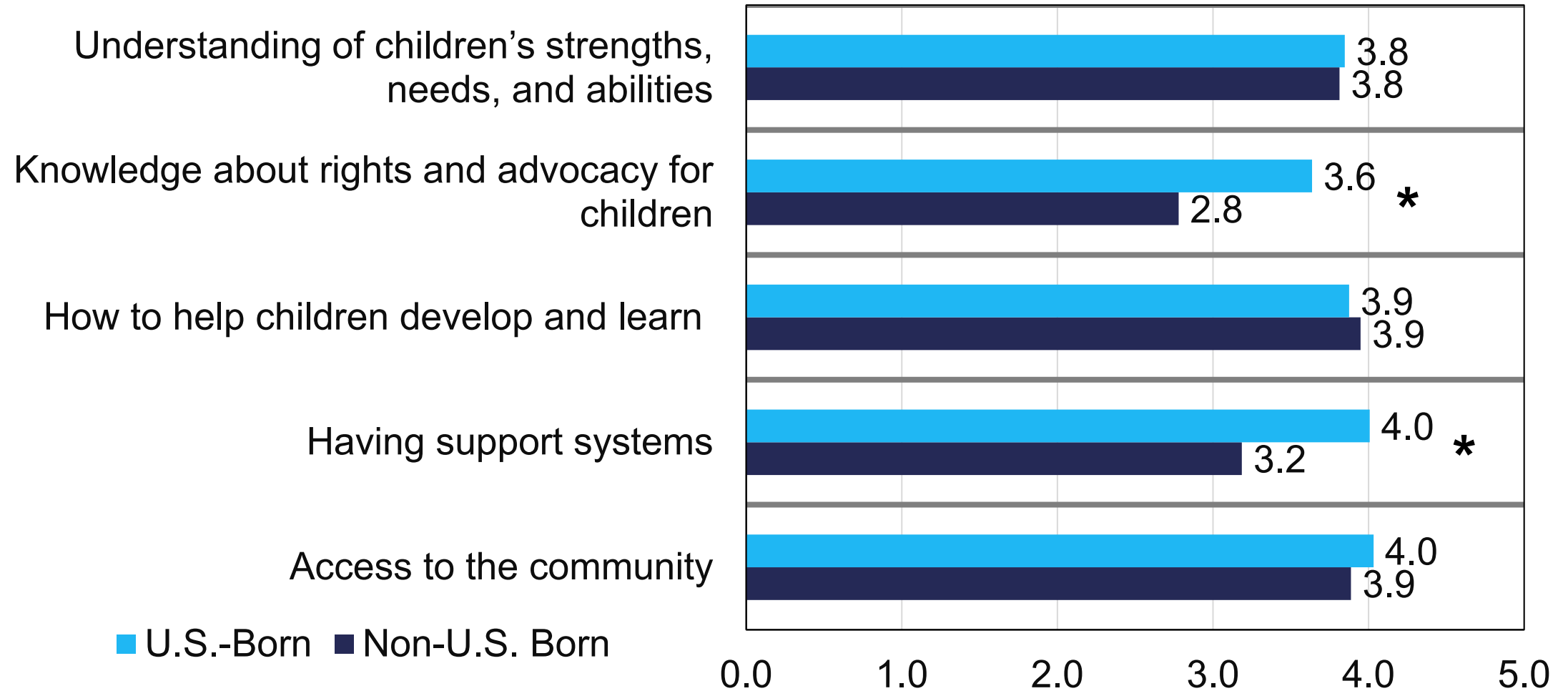
Access to the community



0.0 1.0 2.0 3.0 4.0 5.0

Higher scores = greater empowerment.

# Figure 2. Mean Score for Each Outcome, by Parent Nativity



\*  $p < .05$

# Associations between Family Empowerment and Child/Caregiver Characteristics

- Caregivers of older children reported lower access to support systems (Outcome 4)
- Older caregivers reported lower access to support systems (Outcome 4)
- Parenting stress was associated with lower empowerment (Outcomes 1-5)
- Family quality of life was associated with greater empowerment across Outcomes 2-5



# Results: Knowledge Dissemination

- Parent Workshops
- Engagement with Local Providers
  - Early Head Start/Head Start
  - Home Visiting Programs
- Social Media
  - Developmental Milestones
  - Disability Services
  - All about Disabilities
  - Weekly Strategies
  - Family Resources



# Recommendations

## ■ Practice Recommendations


- Identify the unique characteristics of the community.
- Evaluate circumstances that may need additional support.
- Identify and improve policies that may limit or create barriers for underserved families.

## ■ Research Recommendations

- Identify supports (or lack of supports) that exist in the community.
- Tailor approaches to match the needs and values of the community.
- Embed ways for research to give back to the community, even if in small ways.

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**Q&A**



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