Introduction

- Spanish-speaking mothers desire to receive information regarding their child’s diagnosis with less jargon (Sheets, Baty, Vazquez, Cary, & Hobson, 2012)
- South Asian Muslim families struggle to work with European American doctors (Jegatheesan, Fowler & Miller, 2010)
- Korean immigrants feel challenged in working with educators and healthcare professionals because of the language barrier (Park & Turnbull, 2001; Narayan, 2015)

Method

- 4 people served by Texas START
- Purposeful homogenous sample
- Brief interview and FEIS
- Translation and transcription
- Thematic analysis software
- Interrater reliability

Demographics

- Education completion ranged from elementary school to a graduate/professional degree
- 1 of 4 caregivers was a nonparental family member
- Reported family income ranged from $10,000 - 49,000
- 50% of caregivers received support from other family
- Reported average of 1.75 external services at enrollment

Abstract

The objective of this study was to examine the lived experiences of undocumented immigrant families in Texas caring for an individual with intellectual or developmental disabilities (IDD). At least one caregiver was selected from each of the Local Intellectual and Developmental Disabilities Authorities (LIDDA’s) participating in this research. While the focus of this study was Mexican-American immigrant families in the United States who are caring for a family member with a diagnosis of a developmental disability, we placed a particular focus on undocumented immigrants. Though the sample was small, these findings necessitate further exploratory research and support the need to design and tailor culturally sensitive interventions for this underserved community.

Language Barrier

- All four interviewees mentioned the language barrier as a key difficulty when seeking services for their family member. One participant stated: “He could not explain his situation. That was one of the barriers I have always come across.”

Inadequate or Incorrect Information from Professionals

- Incorrect advice from professionals was a common thread throughout the interviews. One family member reported: “Once we got [to Abilene]...she went to go see the state school and she didn’t like it. That’s the reason we ended up here.”

Limited Knowledge of Resources

- Many family members reported that they did not know services were available for their loved one and that START assisted them in accessing these services. In fact, one mother shared: “Compared from them to now, there’s more services that I see, there’s more places they can go. It’s like they can have a life of their own.”

Extreme Circumstances

- One individual was in a life or death situation before her family moved to seek better trained professionals. Her mother stated: “She could have died in Juarez because...we didn’t find any doctor who could possibly take care of her condition.”

Family or Community Support as Primary Support

- A common theme throughout the interviews was the importance of family support. One individual’s sister said: “I don’t think whether I would’ve done it or one of my siblings would’ve done it, [help for our sibling] would’ve happened.”

Impact of START Services

- Every family member shared the impact START has had on the life of their loved one. One mom offered: “It’s been very important in our life. If they weren’t in this program, they would have to stay home the whole day because they wouldn’t go to school; there’s nothing they could do. It’s been really helpful.”

Discussion

- This population hesitates to seek services
- Cultural linguistic competence is lacking
- Atypical navigation of the service system
- Self-selection out of study
- Further research needed to better understand service gaps
- Systems work aimed at building additional supports
- SIRS data and cultural competence to inform service interventions

References