

Developmental Screening with Recent Immigrant and Refugee Children

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Talya Kemper

Collaborative study

- Dr. Susanne Martin Herz
- Megumu Brownstein

The Study

- A qualitative study was done
- Investigating developmental screening for immigrant and refugee families

background

Developmental Screening

- American Academy of Pediatrics recommends screenings occur at:
 - 9, 18 and 30 months
 - In 2009 48% of Pediatricians indicated they do screenings

Barriers to Screening

- For immigrant and refugee children:
 - Language
 - Cultural differences
 - Lack of validated and reliable measures in family's primary language

Autism Diagnosis

- Later diagnosis for Latino and African American children when compared to Caucasian children
- Later diagnosis for children born outside continental US
- Later diagnosis for children whose mothers were born outside the continental US

Autism Diagnosis

- Immigrant children can be later diagnosed or receive referrals later because challenges are associated with acculturation
- This could lead to under diagnosis of Autism in immigrant and ethnic minorities.

Methods

Methods

- Interviews
- Six participants
- Caseworkers/Cultural Mediators (CCM's):
 - Five cultural groups:
 - Cambodian (2)
 - Ethiopian
 - Latino
 - Somali
 - Vietnamese

CCMs

- Provide:
 - Interpretation
 - Patient Advocacy
 - Home Visits
 - Health Education
 - Coordination of Patient Care

Questions

- Purpose of questions were to find potential barriers to:
 - Effective screening for developmental delay among immigrant and refugee groups with limited English

Data Analysis

Data Analysis

- Interviews were transcribed
- Three people coded the data
- First transcripts were read
- Individually themes were pulled out
- Consensus was then formed around key themes

Results

Main Themes

- Attitudes and Beliefs
- Barriers
- Improvements/Suggested Solutions

Attitudes and Beliefs

Theme

1. Parent Reaction
2. Cultural/Religious beliefs
3. Inherited
4. Denial

Example

1. Blame self, others, acceptance
2. Karma, child was made this way better not to intervene
3. In the nature of the person/family
4. Baby simply slow in development (will catch up), US healthcare will fix child

Attitudes and Beliefs

Example

1. Blame self, others, acceptance
2. Karma, child was made this way better not to intervene
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Quote

1. “Mother blame herself. Or blame the system, feeling guilt they didn’t provide their child the things they need”
2. “when a family has some child that has some kind of disability they always think that because of previous life and maybe they did something wrong so now they have a child, someone in this family having this kind of disability”
3. “...we just say because you inherit the behaviors, the way you act from your grandparents...”
4. “When refugee kids speak different languages, maybe little slow than mainstream, but it’s still normal”

Barriers

Theme

1. Language Barriers
2. Communication
3. Transportation
4. Childcare
5. Economic
6. Education

Example

1. Screening tools
2. Have q's don't know how to ask them
3. Access
4. Cared for at home may delay recognition
5. Need to choose between seeing MD and putting food on table
6. Power of self-confidence

Barriers

Theme

7. Family
8. Trust
9. Not understanding Process
10. Society
11. Provider

Example

7. Length of residence in US
8. Lack of faith in providers due to past misunderstandings
9. If can't see the problem don't feel it is there
10. Fear of authority
11. Ineffective communication

Barrier

Example

1. Screening tools
2. Cared for at home may delay recognition

Quote

1. “The toys or other things they might never had that chance to have all those things, to know what is triangle is what circle is. I believe most of the time it is not culturally appropriate.”
2. “the boy..is raised by the grandmother. Two elderly, non-speaking raising autism child. I don’t know how much they know about it.”

Barrier

Example

3. Need to choose between seeing MD and putting food on table
4. Fear of authority

Quote

- “Most of these parents they don’t, they can’t, it’s not that they don’t want to miss it (appointments) they can’t miss work. If they miss work they have hard time to have enough food or they going to get laid off.”
- “People like us from countries like that are scared of authorities. So many women...when you see you in uniform and your title, ...they don’t ask questions.”

Barrier

Example

5. Ineffective communication

Quote

5. “they don’t take to much time to explain or sometimes they take too much time to explain and give too much information at once, and they don’t get everything especially if people don’t have experience with that.”

Suggested Solutions

Theme

1. Transportation
2. Communication
3. Education

Example

1. Improving access
2. Be very clear about next steps/service delivery; labels may be difficult descriptions may be better
3. Educate community about developmental disabilities

Suggested Solutions

Example

1. Be very clear about next steps/service delivery; labels may be difficult descriptions may be better
2. Educate community about developmental disabilities

Quote

1. “we have to explain exactly what is going to happen and why this doctor is ordering referral” “parents don’t like the word “disabled”...so you have to use your own words to help the family to understand what is the situation...”
2. “It’s not one person problem. It’s the community’s problem. If we teach the community and teach them what to expect what from their kids and that it is normal to be disabled...how can we help the children, to be in the right school or the right place to get the right treatment, the right help so it’s the community’s education.”

Thank You!

- Look for article in Ethnomed!