“Inshallah/Ojalá: God Willing”
Perception of Autism in Immigrant Families: Implications for Screening, Diagnosis and Treatment

Roula Choueiri, MD
Neurodevelopmental Disabilities

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Boston Medical Center, Pediatrics Division
Agenda

• Introductions
• Screening & diagnosis of Autism in young children and immigrant families
  • Clinical examples/definitions
  • Concept of screening & diagnosis
  • Autism in different cultures - stigma
• Family Navigation
• Project A.N.C.H.O.R
• Conclusion
  • Tips/resources
Inshallah = God Willing
Ojalá = God Willing

“Sleeping child, on my shoulder
Those around us, curse the sea
Anxious mother turning fearful
Who can blame her, blaming me?
Inshallah, Inshallah
If it be your will, it shall come to pass
Inshallah, Inshallah
If it be your will”
Definitions

Culture

• Customary beliefs, social forms, and material traits of a racial, religious, or social group

• The characteristic features of everyday existence shared by people in a place or time

• Set of learned traditions and living styles shared by members of a society: thinking, feeling and behaving
Mentimeter

What word comes to mind when working with immigrant families?

Go to www.menti.com and enter the code 62485678
Background: Worcester
Population (Census, 2017)

- Residents below poverty level 21.8% (state: 10.5%)

- Ethnicity
  - White alone 58.6%
  - Hispanic 21%
  - Black alone 6.8%
  - Asian alone 3.7%
  - Two or more races 9.9%
  - American Indian alone 0.9%
  - Other race alone 0.1%

- 34% speak language other than English
Population Background

**MOST COMMON ORIGIN**
1. Ghana
2. Dominican Republic
3. Vietnam

**MOST COMMON LANGUAGE SPOKEN**
1. Spanish
2. Portuguese
3. West African Languages

**ETHNICITY:**
1. White
2. Hispanic
3. Black
Background:
Important Numbers

• Prevalence of Autism: 1/54 (CDC, 2020- period covered is 2016)

• Age of diagnosis: close to 4 years though clinical signs sometimes seen starting 12 months of age

• Access to diagnosis still difficult for “minorities”

• Access disparity increased with COVID

• EARLY DIAGNOSIS KEY FOR EARLY SERVICES
Clinical Scenarios:
Names have been changed

• Mario/ Francois/Naomi/Omar is 2 years old. PCP is concerned about autism and refers to DBP.

  • Clinician meets with family and interpreter. Child shows clear signs of ASD. Parent does not report concerns. Concerns discussed and second appointment made...Patient does not show up.

  • Clinician evaluates child with family and interpreter. Provides with diagnosis of Autism. Explains next steps. On follow up with clinician, patient is still not receiving treatment recommended...

• Are those families “difficult families”? Do we need to “report” them?
Assessment of Autism in Infants and Toddlers

- **Rely on certain behaviors**: history and observation
- **Require navigation of complex systems** and highly trained professionals who can communicate effectively with child & family
- **Successful intervention** must include family involvement
  - **Disability**: socially and culturally situated construct
Developmental Screening of Refugees
(Kroening et al; Pediatrics, 2016)

- Interviews and focus groups: Buthanese-Nepali, Burmese, Iraqi and Somali refugees
- Most did not have a word for “development” in their language and were unaware of developmental milestones
- Perceived barriers to identification of delays
  - Limited education
  - Poor healthcare knowledge
  - Language
  - Traditional healing practices
- Facilitators
  - Community navigators
  - Trust in healthcare providers
  - In-person interpretation
  - Visual supports
  - Education about child development
Unfamiliar concepts of autism and screening

Inherent cultural factors in the screening of autism
  • Child’s behavior may reflect cultural norms
  • Some behaviors seen as culturally appropriate

Screening tools may be anxiety provoking, and confusing
  • More involved than just translation
    • STIGMA
Maternal Stigma Video

www.maactearly.org
Examiner’s Characteristics

Demographic characteristics of examiner important role:

1. **Age**: older vs. younger
2. **Gender**: match or mismatch
3. **Ethnicity**: example
Autism screening & diagnosis rely on behavioral criteria based in cultural norms:

• Eye contact, hand movements, echoing, pointing
Screening: MCHAT-R/F

- Modified Checklist for Autism in Toddlers – Revised/Follow up interview
- Initially more questions, but questions misunderstood by different groups
- Rephrased with examples in 2013
- Translated in different languages
- Concepts culturally bound
- International Studies
Screening RITA-T

- No language
- Evaluates developmental constructs delayed early in Autism
- Item: choice between a baby’s face and rails: adding faces of infants' representative of all races
Improving Early Identification and Access to Diagnosis of Autism Spectrum Disorder in Toddlers in a Culturally Diverse Community with the Rapid Interactive screening Test for Autism in Toddlers

Roula Choueiri1, Asher Lindenbaum2, Manasa Ravi1, William Robsky1, Julie Flahive3, William Garrison1

Accepted: 16 December 2020
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Abstract
The objective of this study was to test a screening model that employs the Rapid Interactive Screening Test for Autism in Toddlers (RITA-T), in an underserved community to improve ASD detection. We collaborated with a large Early Intervention (EI) program and trained 4 providers reliably on the RITA-T. Toddlers received the Modified Checklist for Autism in Toddlers (MCHAT-R/F), the RITA-T, developmental and autism testing, and a best-estimate clinical diagnosis. Eighty-One toddlers were enrolled: 57 with ASD and 24 with Developmental Delay (DD) non-ASD. Wait-time for diagnosis was on average 6 weeks. The RITA-T correlated highly with autism measures and EI staff integrated this model easily. The RITA-T significantly improved the identification and wait time for ASD in this underserved community.

Keywords Screening · Autism · Interactive · Toddlers · Access · Underserved · Cultural diversity · Early intervention · Community · RITA-T (Rapid Interactive Screening Test of Autism in Toddlers)
Implications for Evaluation, Referrals, and Treatment

- Learn about the families you work with

- *Each family is unique*

- **History of their country**
  - Health system, education system
  - Demographics: age, expectancy; maternal/infant mortality rates; average literacy
Learn about the families you work with…

• Did they witness wars?
• Did they witness violence?
• Were they refugees in camps?
• Were they detained or separated upon arrival to the US?
Important Questions to Ask Families

• What do you know about autism/developmental delay?
• What do you think causes autism/developmental delay?
• Have you talked to family or friends about your child’s development?
  • What did they tell you?
  • What do you think?
Challenges with the term “autism”

- Not Translated to all other languages/cultures or difficult meaning...

- **English**: Autism - coined from Latin “Autismus” in 1910 by psychiatrist Bleuler to describe schizophrenia. Latin word derived from Greek, “Autos”: self.

- **Chinese**: “Loneliness Disease”; “Closed self-disease”

- **Hmong**: Ib qho kev tsis taus uas yog puas rau phab kev nrog lwm tus tham thiab koom nrog lwm tus...Kev tsis taus no yuav tshwm sim tawm rau thaum muaj hnub nyoog 3 xyoos thib yuav muaj mus tas lub neej. Hom uas tshwm sim tsis loj yog hom hu ua Aspe

- **Somali**: Cilladaha ootiisamku waxaay saameyn karaan maskaxda. Waxa dhacda in carruuraha qaba cilladaha ootiisamku sida ay bulshada ula dhaqmaan, hadlaan, ama u fakiraan ay ka duwan tahay carruuraha kale. Marxalado aad u adagna yeelan karaan

- **Spanish**: Autismo
## Parental Beliefs about Causes of their Child’s Autism

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<th>Parents beliefs about the cause of their child’s autism</th>
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<td>• Impact on decisions regarding future health care, family planning, <em>maternal mental health</em></td>
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<tr>
<td>• Those attributed to <em>God’s will or fate: less stressed</em></td>
</tr>
<tr>
<td>• Those who assumed responsibility were the most stressed (punition of parents’ sins)</td>
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## Autism

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<th>Link between beliefs and choice of interventions</th>
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<td>• Non-traditional treatments</td>
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<th>No definitive information on cause, course or treatment</th>
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<td><em>Parents come to their interpretation of the disorder</em></td>
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Catch a Cod

Cultural Perception
What is Family Navigation?
What is Family Navigation?

The Family Navigator role falls under the umbrella of community health worker.

Community health work was established to target health disparities by addressing social determinants of health (i.e., wealth, unstable housing, substandard education, etc.).

Navigators help their patients overcome barriers to wellness and empower them to make meaningful changes in their lives.
What is Family Navigation?

Family navigation is a unique intervention designed to help families in pediatrics navigate medical, community, and government systems with the goal of improving health and wellbeing.

Family navigation is founded on the same core principles as patient navigation and Motivational Interviewing.

Together with a foundation in family systems theory and ecological systems theory, we help families address their needs and concerns when providing care for children.

We are advocates and we empower families to take charge of their health.
What is Family Navigation?

The Triple Aim of all Healthcare Providers

- Improve Quality of Care
  (fewer no-shows, assist with insurance enrollment, address social needs)

- Reduce Costs
  (fewer emergency room visits, lower rates of readmission)

- Improve Health
  (encourage adherence, support management of chronic illness)

- Reduce Health Disparities
  (strengthen relationships with underserved populations)
Why is Patient Navigation useful?

- Patient Navigation reduces or eliminates systemic barriers in healthcare
  - Uncoordinated care

- Health disparities
  - Why do some populations experience worse outcomes for certain diseases?

- Barriers specific to vulnerable populations
## Family Barriers

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<th>Child behaviors/diagnosis</th>
<th>Homelessness/Housing issues</th>
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<td>Migratory status</td>
<td>Food insecurity</td>
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<tr>
<td>Transportation</td>
<td>Other children with disabilities</td>
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<tr>
<td>Language</td>
<td>Domestic violence</td>
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<tr>
<td>Lack of family support</td>
<td>Isolation/Depression</td>
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<tr>
<td>Money</td>
<td>Lack of knowledge/insecurity</td>
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Family Navigator Role

- Build Relationships
- Empower and support families by building self-efficacy
- Provide education and information
- Problem-solve barriers
- Navigate families through the health care system and through community-based systems to help access services
- Manage and organize information with families
Scope of Work

"Entry Points"
1) Daily huddles
2) Provider referrals
3) Navigators' patient lists

Care coordination
(e.g., multiple appointments, PT1s, medical records, coordinating with internal/external providers)

Patient education
(e.g., why a referral was made, the impact of lead paint, asthma education)

Problem-solve barriers to health management
(e.g., create action plan to help family keep appointments)

School advocacy
(e.g., advocacy for issues impacting child's health in school)

Medical follow up
(e.g., work with medical staff on health management issues, medication management)

Parent and child mental health screening and referrals
(e.g., integrated behavioral health)

Referrals for basic/specialty needs
(e.g., food insecurity, housing needs, specialty services)

General follow up
(e.g., address ongoing health and social needs, coordinate next steps)

Scope of Work
Why was my child diagnosed with ASD and what does it mean?

- Cultural issues
- Stages of reaction
- Services and resources
## Ways to Reduce Disparities in Access and Care for Immigrant Families

| Utilize... | principles of Family Navigation to promote family-centered, culturally responsive identification, screening and referral to resources to support family well-being |
| Build... | community networks - trust in community and in healthcare providers |
| Educate about... | child development |
| Have... | culturally appropriate resources available to facilitate families |
Project A.N.C.H.O.R

• Family Navigators: Grant Funded or philanthropy
• NEW IDEA: Build capacity by training Early Childhood providers in community centers
• Funded by Remillard Community Grant
• Strengthen network to support families
• Learn early detection, support, create resources and a community
Meet the Team

- Project A.N.C.H.O.R Trainers:
  - Ivys Fernández-Pastrana, JD
  - Yaminette Diaz-Linheart, LCSW, MPH

- Principal Investigator:
  - Roula Choueiri, MD

- Project Coordinator:
  - Valerie Tokatli, BA
Project A.N.C.H.O.R Goals

• Learning Community for Worcester-area community organizations

• Participants will
  • Understand child development through a culturally responsive and family-centered lens
  • Learn to identify early signs of neurodevelopmental disorders
  • Develop a network for ongoing learning
Timeline

- Total of 6 Online Sessions weekly then monthly meetings for a year
- March 2021 to March 2022
- Combination of independent work and one-hour live sessions
- Pre- and Post- Surveys to discuss and understand impact of our Learning Community
Project A.N.C.H.O.R Website

Website link:
- https://www.umassmed.edu/DBP-ANCHOR

Content on project/training information, curriculum
Tool kit

Community Resources

Build a community Forum
Practical Tips

• Clarify if an interpreter is needed before the visit

• Explain testing of young children for early intervention

• Ask open ended questions

• Communicate slowly and clearly

• Cultural liaison
  • Early Intervention provider

• It can sometimes take multiple conversations to discuss concerns with families and work towards referral
  • “HOW” more important than the “WHAT”:
  • PATIENCE, COMPASSION: CROSS CULTURAL
Resources

• MA Act Early - https://www.maactearly.org/

• www.umassmed.edu/DBP-ANCHOR

• Considering Culture in Autism

• Translated material including Parent Information Sheets, ASD screening Fact Sheets, and other helpful material in 21 different languages

• 1, 2, 3 Grow! – Online shows provides equal access to information about healthy development in young children as well as what to do and where to go when concerned.
MA Act Early Culturally Competent Autism Screening Kit

Promoting the early identification of autism spectrum disorders across culturally and linguistically diverse populations.

Our experts highlight unique considerations in the screening and referral process when working with culturally and linguistically diverse populations. These tips may help you find a new approach to your typical process meets with challenges.

1. Be aware that discussions about a problem, concern, or potential diagnosis such as autism can be anxiety-producing and confusing for most parents, and even more so for families with children with disabilities or other chronic health conditions.
2. Some families may not have seen children with ASD included in their community or in their country of origin.
3. Media campaigns around ASD awareness may not reach many of these populations.

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Learn the Signs. Act Early.

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MAACTEarly.org

CULTURALLY COMPETENT AUTISM SCREENING KIT

More information at:

- www.MAActEarly.org
- www.cdc.gov/actearly

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We believe that this resource will prove valuable in helping navigate the ASD screening and referral process with all children and their families.

For more information, please contact Karina Galaburda, MA Act Early Ambassador & State Team Leader at Karina.Galaburda@MassachusettsActEarly.org

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Clinician Tips

PUTTING IT ALL TOGETHER

Clinician Tips

Culturally Competent, Autistic Screenings

Clinician Tips

THINK PROCESS

Family Stories

NEXT STEPS: Referral for Further Evaluation

- Consult the medication specialist (e.g., development pediatrician, pediatric endocrinologist or others) directly to discuss any concerns the family might have.

- Develop a relationship with speaking and interpreting staff and teach them about the family and their interests.

- Schedule a follow-up visit for two to three weeks after the initial visit to discuss what happened and see what is known.

- Use a phone interpreter service to ensure consistency of service and to help facilitate communication.

- Explore the possibility of using a visual history to help the family better understand and communicate.

Questions to ask families

- What is the most recent assessment date?

- What kind of things do you think would help your child with his/her social, communication, plays skills, self-advocacy, etc.?

- What have you done in the past to help your child?

- What has worked for your child in the past?

- What would happen to your child’s school and developmental progress?

- What would happen to your child’s family?

- What are the immediate concerns?

- What are the long-term concerns?

- What would be the best course of action for your child?

- What do you think would be the best course of action for your child?

- What would you like to happen in a month’s time?

- What would you like to happen in a year’s time?

- What would you like to happen in five years time?

- What would you like to happen in ten years time?

- What would you like to happen in twenty years time?

- What would you like to happen in thirty years time?

- What would you like to happen in forty years time?

- What would you like to happen in fifty years time?

- What would you like to happen in sixty years time?

- What would you like to happen in seventy years time?

- What would you like to happen in eighty years time?

- What would you like to happen in ninety years time?

- What would you like to happen in a hundred years time?

- What would you like to happen in a thousand years time?

- What would you like to happen in ten thousand years time?

- What would you like to happen in a hundred thousand years time?

- What would you like to happen in a billion years time?

- What would you like to happen in a trillion years time?

- What would you like to happen in a quadrillion years time?

- What would you like to happen in a quintillion years time?

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- What would you like to happen in an octillion years time?

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Translated Materials

Listed below are translated Parent Information Sheets, ASD Fact Sheets, and other helpful materials. Some languages have more materials than others. Thank you to the Autism Consortium, the Vermont Family Network, the University of Southern California's UCECO, and the CDC "Learn the Signs, Act Early!" Campaign for translating these materials.

Find materials in your primary language below:

**English**
- Developmental Screening Facts.pdf
- VT ASD Fact Sheet for Parents.pdf
- How to Help Your Child.pdf
- "It's Better to Know" Poster.pdf
- AC Parent Information Packet.pdf
- Tips for Talking to Parents.pdf
- Act Early ASD Fact Sheet.pdf

**Spanish**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- How to Help your Child.pdf
- "It's Better to Know" Poster.pdf
- AC Parent Information Packet.pdf
- Tips for Talking to Parents.pdf
- Act Early ASD Fact Sheet.pdf

**Haitian-Creole**
- AC Parent Information Packet.pdf
- Tips for Talking to Parents.pdf

**Vietnamese**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- AC Parent Information Packet.pdf
- Tips for Talking to Parents.pdf

**Portuguese**
- Developmental Screening Facts.pdf
- VT ASD Fact Sheet for Parents.pdf
- AC Parent Information Packet.pdf
- Tips for Talking to Parents.pdf

**Sinhala**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Korean**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Arabic**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Bosnian**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Nepali**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Parsi**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Italian**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Burmese**
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf

**Tagalog**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf

**Japanese**
- Act Early ASD Fact Sheet.pdf
- VT ASD Fact Sheet for Parents.pdf
- Tips for Talking to Parents.pdf
Community Resources

• Interviews with Marcia Fontes, LICSW, Pediatric BH Consultant & Hilda Ramirez, Executive Director, Latino Education Institute – Brazilian and Latino families

• Immigrant families are community oriented - more trust in each other than in clinicians

• Delivery of care needs to be oriented to better serve diverse communities
Community Resources

• Utilize interpreters as much as possible

• Have translated material ready to give to parents/families

• Reach out to community Cultural Brokers whenever possible

• Latino Education Institute
  • Empower parent model: provide parents with education and resources to make them health ambassadors
    *Promotoras de Salud*

• Autism Alliance of Metrowest
  • Support group for Brazilian families with a child who has an Autism diagnosis
  • 1881 Worcester Rd #100a, Framingham, MA 01701
Community Resources on Project A.N.C.H.O.R Website

[Website Link] www.umassmed.edu/DBP-ANCHOR

Email us with resources you have! Valerie.tokatli@Childrenshospital.Harvard.edu
THANK YOU FOR JOINING US!

Mentimeter Results & Questions