

Barriers to care, and the Importance of cultural competence in delivering care to children with neurodevelopmental disorders belonging to diverse ethnic minorities.



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Driven to DiscoverSM

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Introduction:

- Low-income and ethnic minority families continue to face critical disparities in accessing diagnostic, treatment services and community resources for neurodevelopmental conditions such as autism spectrum disorder.
- Research suggests that minority groups are diagnosed with ASD at a significantly lower rate than their white peers despite evidence indicating that rates should be invariant across cultures. There are various socioeconomic and cultural barriers faced by low-income ethnic minorities in accessing care.
- There is underrepresentation of ethnic and income diversity in neurodevelopmental research which is necessary for development of culturally competent clinical and preventive interventions.
- The factors which contribute to lack of participation- lack of familiarity with research and medical systems, poor English language fluency, lack of measures available in the native language.

Aims:

- To highlight the barriers family/children from diverse ethnic minorities face when accessing care for neurodevelopmental disorders
- To emphasize the role of cultural competence for improving access to care among diverse ethnic minorities.

Barriers to care

Patient factors

- ✓ Lack of English language fluency
- ✓ Reduced Knowledge of US healthcare system, and public resources
- ✓ Deficits in knowledge of ASD, and ADHD
- ✓ Concerns about deportation, and interaction with legal system
- ✓ Lack of familiarity and comfort with clinical research

Healthcare/systems related factors

- ✓ Lack of insurance
- ✓ Long waits to see providers
- ✓ Instruments in different languages
- ✓ Lack of best practices guidelines
- ✓ Lack of diverse representatives on the health care teams to deliver comprehensive services and supports
- ✓ Lack of ethnically culturally sensitive treatment teams

Minnesota experience in delivering care to Ethnic Minorities (Somali)

- In 2009, Minnesota department of health published a study revealing that children of Somali parents in Minneapolis were 2-7 times more likely to receive ASD special education services than children of non Somali parents.
- Somali Living in America Call Autism the “Western disease” because there is no word for autism for the Somali Language, and many believe it doesn’t exist in Somali.

Minneapolis Somali Autism Spectrum Disorder Prevalence Project



- About 1 in 32 Somali children aged 7-9 years in 2010 was identified as having ASD in Minneapolis.
- Somali and White children were more likely to be identified with ASD than Black and Hispanic children.
- **Somali children with ASD were more likely to have an intellectual disability than children in other racial and ethnic groups in Minneapolis.**
- The age at first ASD diagnosis was around 5 years for Somali, White, Black, and Hispanic children.

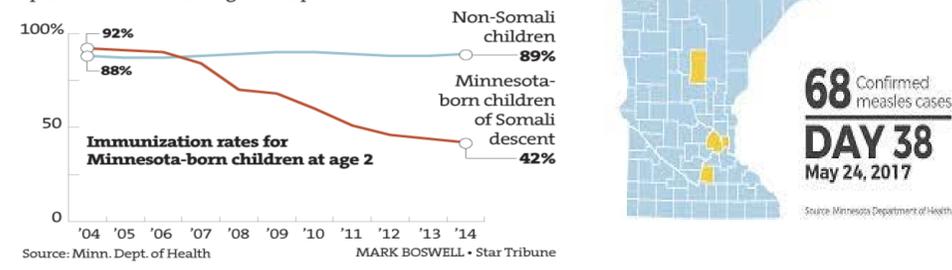
| Group Prevalence | Overall 1 in 48 |
|--------------------|-----------------|
| Somali | 1 In 32 |
| White | 1 in 36 |
| Black (non-Somali) | 1 in 62 |
| Hispanic | 1 in 80 |

Most common perceptions about etiology of autism¹

| Rank | Hmong | Somali | Latino |
|------|---|---|---|
| 1 | Medical condition/genetics/neurological | Vaccines | Unclear what autism is |
| 2 | Unclear what autism is | Unclear what autism is | Developmental condition |
| 3 | Developmental condition | Mental problem/illness | Mental problem/illness |
| 4 | Spiritual | Spiritual | Medical condition/genetics/neurological |
| 5 | Mental problem/illness | Medical condition/genetics/neurological | Vaccines |

SOMALI VACCINATION RATES FALL

The Somali backlash against the measles vaccine is new; their kids' vaccination rates matched the general population until 2008, when fears of a link between the vaccine and autism sparked a reaction among Somali parents.



Most common system related challenges associated with late identification¹

| Rank | Hmong | Somali | Latino |
|------|--|--|--|
| 1 | Long wait for services to start/wait lists | Language problems | Long wait for services to start/wait lists |
| 2 | Navigating system complex | Long wait for services to start/wait lists | Navigating system complex |
| 3 | Insurance & costs | Cultural issues | Immigrant/refugee status |
| 4 | | Navigating system complex | Insurance & costs |

Most common family/individual challenges associated with accessing services¹

| Rank | Hmong | Somali | Latino |
|------|-----------------------------------|-----------------------------------|-----------------------------------|
| 1 | Competing demands | Emotional trauma/stress on family | Emotional trauma/stress on family |
| 2 | Emotional trauma/stress on family | Lack of knowledge of resources | Lack of knowledge of resources |
| 3 | Lack of knowledge of resources | Competing demands | Competing demands |
| 4 | Stigma/shame | Fear for child's safety | Fear for child's safety |

Most common providers related challenges associated with accessing services¹

| Rank | Hmong | Somali | Latino |
|------|------------------------|----------------------------|------------------------------------|
| 1 | Language issues | Language issues | Discrimination |
| 2 | Lack of providers | Cultural competency issues | Provider communication |
| 3 | Provider communication | Discrimination | Cultural disconnect with providers |
| 4 | | Provider communication | Language issues |

Most common system related challenges associated with accessing services¹

| Rank | Hmong | Somali | Latino |
|------|---|------------------------------|---|
| 1 | Wait lists/wait for services | Insurance & cost of care | Insurance & cost of care |
| 2 | Insurance & cost of care | Housing | Lack of parent/ family support services |
| 3 | Navigating system complex | Wait lists/wait for services | Navigating system complex |
| 4 | Transportation | Navigating system complex | Wait lists/wait for services |
| 5 | Lack of parent/ family support services | Transportation | Immigrant status |

Recommendations for clinicians:

- ✓ Clinicians need to think about culture broadly, beyond race and ethnicity. Do not make assumptions or stereotype patients based on their racial or ethnic identities.
- ✓ Clinicians might benefit from using caution while administering ASD assessment tools since most of them have not been validated for use with different cultural groups.
- ✓ Providers need to develop partnerships with pediatricians, school, and community leaders since cultural minority groups may not directly seek mental health services.
- ✓ Clinicians should continuously explore their own biases, and the power and privilege they inherently hold, by the nature of their role.
- ✓ Using interpreters consistently when working with cultural minority families who do not speak English fluently.
- ✓ Provide psychoeducation in a culturally sensitive manner.
- ✓ Elicit level of knowledge and familiarity with ASD, provide information in a manner, and at a level, that patients can understand. Whenever needed, translated written materials should be provided.

References:

1. A Qualitative Study of Families of Children with Autism in the Somali Community: Comparing the Experiences of Immigrant Groups. Minnesota Department of Health. Report to the Minnesota Legislature 2014.
2. The assessment and treatment of Autism Spectrum Disorder: A Cultural Examination. Roche ML, Bush HH. Practice Innovations 2018;Vol 3, 107-22.
3. Autism spectrum disorder (ASD) prevalence in Somali and non-somali children. Hewitt, A., Hall-Lande, J., Hamre, K., Esler, A., Punyko, J., Reichle, J., Gulaid, A., 2016. J. Autism Dev. Disord. 46 (8), 2599-2608
4. Minnesota Department of Health, 2009. Autism and the Somali Community e Report of Study. www.health.state.mn.us/omh/projects/autism/index.cfm.