Minnesota's Changing Population Diversity

Source: MN State Demographer
The generation of younger Minnesotans is much more diverse than the older generations.
Among younger Minnesotans, there is also more diversity within communities of color. 5% 7% 8%

Race/ethnicity of Minnesotans of Color and Native Americans
2010 Census
Home and community-based long-term services and supports* are becoming more diverse over time

Program participants ages 0-64 years

Program participants ages 65 years and older

*Includes Brain Injury (BI), Community Alternative Care (CAC), Community Alternatives for Disabled Individuals (CADI), Developmental Disability (DD), and Elderly Waivers, Alternative Care, Personal Care Assistance, Private Duty Nursing, and Home Health programs.
In fact, the majority of Minnesotans under age 65 using home care services* are now people of color or Native American.

*Includes Personal Care Assistance, Private Duty Nursing, and Home Health programs.
In 2008, Somali parents and others in the Twin Cities raised concerns about disproportionately high participation rates of Somali children in special education preschool programs for children receiving Autism Spectrum Disorder (ASD) services as compared to the overall percentage of Somali children in the city’s public schools.

Out of this concern, in 2009 the Minnesota Department of Health (MDH), conducted a study of this sub-group of preschoolers in the Minneapolis Public Schools. It seemed to confirm a higher prevalence of documented autism among Somali children (up to seven times higher than their non-Somali peers), consistent with findings from other international studies (MDH, 2009; Barnevik-Olsson, Gillberg, & Fernell, 2008; 2010, four and five times higher).
This study raised concern at the national level and lead to a Minneapolis Prevalence Study, conducted by the U of MN and funded by Centers for Disease Control and Prevention, National Institutes of Health, and Autism Speaks.

The study sought to determine whether there is a higher rate of autism among Somali children compared to non–Somali children. (Amy Hewitt et.al., Research & Training Center on Community Living (RTC), Institute on Community Integration (ICI) Published December 2013)

DHS also recognized the concern and in April of 2013 held a “community listening session” for Somali parents of children with autism, as part of a community needs assessment. This listening session led to a pilot “multicultural community outreach and training” position which coincided with the study. This is now a full time position at DHS.
<table>
<thead>
<tr>
<th>Race and ethnicity 95% Confidence interval*</th>
<th>Children with ASD identified/Total MPLS population</th>
<th>Prevalence estimate (prevalence per 1,000 children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>255 of 12,329</td>
<td>1 in 48 (20.7 per 1,000)</td>
</tr>
<tr>
<td>Somali</td>
<td>31 of 1,007</td>
<td>1 in 32 (30.8 per 1,000)</td>
</tr>
<tr>
<td>White</td>
<td>120 of 4,336</td>
<td>1 in 36 (27.7 per 1,000)</td>
</tr>
<tr>
<td>Black (non Somali)</td>
<td>53 of 3,312</td>
<td>1 in 62 (16 per 1,000)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>30 of 2,399</td>
<td>1 in 80 (12.5 per 1,000)</td>
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*Amy Hewitt et.al., Research & Training Center on Community Living (RTC), Institute on Community Integration (ICI) Published December 2013*
### Children with ASD who were also identified as having co-morbid Intellectual Disability (ID)

<table>
<thead>
<tr>
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<th>Percentage of children with ID</th>
<th>Percentage of children missing IQ scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>33%</td>
<td>28%</td>
</tr>
<tr>
<td>Somali</td>
<td>100%</td>
<td>35%</td>
</tr>
<tr>
<td>White</td>
<td>20%</td>
<td>26%</td>
</tr>
<tr>
<td>Black (non-Somali)</td>
<td>30%</td>
<td>19%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>22%</td>
<td>40%</td>
</tr>
</tbody>
</table>

Amy Hewitt et.al., Research & Training Center on Community Living (RTC), Institute on Community Integration (ICI) Published December 2013
In 2012 the Minnesota (MN) Legislature authorized a qualitative study of the experiences of having a child with autism among the Somali community.

The purpose of the study was to understand the “cultural- and resource-based impacts of autism spectrum disorders (ASD) that are unique to the Somali community”.

The Minnesota Department of Health approved the study to also include the Hmong and Latino communities for comparative purposes.
Study objectives are 3-fold:

* To describe challenges in early identification of autism

* To identify the challenges families experience when accessing services

* To develop recommendations to address the challenges faced by families

Link to report: [www.health.state.mn.us/divs/cfh/topic/autism/reports.cfm](http://www.health.state.mn.us/divs/cfh/topic/autism/reports.cfm)
Autism Study Collaborators

* Confederation of Somali Community in MN (CSCM)

* Somali Latino and Hmong Partnership for Health & Wellness (SoLaHmo)

* University of Minnesota

* MN Department of Health
Main Themes from Key Informant Interviews

* Many parents wait to get help because they hope their child will develop normally.
* Many parents do not understand what autism is.
* Many children are older when diagnosed.
* Getting services is hard because many parents do not know what services are available or where to go for services.
* Parents and families have many strengths that need to be recognized.
Many parents said they do not understand what autism is.

In fact, the term “autism” does not exist in the Hmong and Somali languages.

Education about child development and signs and symptoms of autism would increase early detection and treatment.
Parent Interview Results
Knowledge of Autism

* Many Hmong and Somali parents said they believe there are spiritual causes of autism.

* Many parents in the Somali and Latino communities said they believe autism is linked to vaccines.

* Some parents said they think of autism as a developmental and medical condition.
Parents reported barriers to early identification at:

* **Individual-Level**: e.g., lack of knowledge about available resources, stress of caring for child with autism and fear for their safety, competing work and family demands, impact on parents and family health as well as financial well-being.

* **Provider-Level**: e.g., language barriers, concerns providers held back information about services, lack of follow-up by providers, subtle/overt discrimination.

* **System-Level**: e.g., long wait lists for services, complexity of system, lack of support services for parents and other family members, language and cultural barriers, transportation issues.
Parent Interview Results
What Makes it Hard to Get Services

* Parents often are the first to notice that something is wrong, however time lapse between noting a problem and obtaining a diagnosis and treatment was a source of frustration for parents.

* Parents identified that difficulty in accessing services is compounded by:
  * Immigration status (some Latino)
  * Problems with housing (Somali)
  * Families feeling alone/isolated (all groups, particularly Hmong)
  * Families suffered trauma in their home country and/or in refugee camps and still struggle with this trauma.
Parents said their children with autism need better access to:

* Speech and Occupational therapy
* Applied Behavior Analysis
* Personal Care Attendant Services

Parents identified a need for new types of services:

* Family support services
* After school activities for children with autism (social activities & sports)
* Respite care provided by members of their own cultural community
* Services for adolescents and adult with autism
<table>
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<tr>
<th>Recommendations Parents Made to Improve Services and Reduce Barriers</th>
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<tbody>
<tr>
<td><strong>Hmong</strong></td>
</tr>
<tr>
<td><strong>1</strong></td>
</tr>
<tr>
<td><strong>2</strong></td>
</tr>
<tr>
<td><strong>3</strong></td>
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<td><strong>4</strong></td>
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<tr>
<td><strong>5</strong></td>
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</tbody>
</table>
Recommendations

1. Build on the existing capacity of parents to support other parents in these communities.

2. Develop culturally specific resource centers housed in the community. (one stop center)

3. Provide resources to form support groups for families. (fund community based organizations to sponsor support groups)

4. Build capacity in the system to provide culturally sensitive services and decrease wait times.

5. Continue to address problems with access to insurance coverage and costs.
Focus on the strength and resiliency of families

* Tremendous love, devotion and resiliency of parents in spite of stress and barriers

* Parents willingness to reach out and support others represents a potential untapped resource in the community.

* Parents are not passive – they are not patiently waiting for someone to connect them or their child to services.
Principal Standard:

1. Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

2. Advance and sustain organizational governance and leadership that promotes CLAS and health equity through policy, practices, and allocated resources.
3. Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and workforce that are responsive to the population in the service area.

4. Educate and train governance, leadership, and workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.

5. Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.
6. Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.

7. Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.

8. Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

Reference to CLAS standards
https://www.thinkculturalhealth.hhs.gov/Content/clasvid.asp
Next Steps

* Community advocates and parents continue to raise awareness of the studies and encourage legislators and others to read and understand the implications of the studies for improving policies and practices.

* The results of these studies should be used to inform policies and practices including legislation to improve outcomes for multi-cultural families living with autism.
Conclusions

* The increasing prevalence of autism requires collaborative efforts across public health, medical, educational and human services.

* There are additional impacts and barriers in access to services within our multicultural and linguistic communities.

* Minnesota’s Somali families, in spite of their struggles, are becoming more engaged and empowered in addressing the issue of autism in their community.
Conclusions

* Many children with severe autism who have not had access to the full range of needed services are now transitioning into young adulthood.

* Concrete actions must be taken to address barriers in access to services.

* Without concrete, specific action, we are at risk of losing a generation of children to autism from the diverse cultural communities that make up Minnesota.
Hired a new position for multi-cultural outreach and education

* Improve culturally specific education around Autism Spectrum Disorder.
* Provide culturally meaningful resources and supports for immigrant families and children.
* Provide cultural competency training to clinicians and providers, timely access to resources and improved long term outcomes and quality of life for individuals with ASD and their families can occur.
What is working

* DHS ASD Advisory Council membership expands to include many new Somali parent members.

* On November 2013 Somali Parents’ Autism Network support group was formed.

* Cultural competency training/Autism basics and trends in multi-cultural families in MN provided to our metro counties is in effect.
What is working

* DHS is part of the Somali Disability Resource Network collaborative.

* Cultural competency training provided to University of Minnesota’s Developmental-Behavioral Pediatric faculty.

* Minneapolis Public Schools Early Childhood Education and Hennepin County are collaborating on multi-cultural outreach and education on Autism and Developmental Disability.
What is working

* Multi-cultural families are engaged in shaping these activities

* Interagency collaboration on promoting screening early intervention.

* Interagency collaboration to implement the state wide autism strategic plan.
ASD Related Free Translated Materials

CDC’s free Act Early materials to order:
* http://www.cdc.gov/ncbddd/actearly/downloads.html#languages

MN DHS Pathways To Services for Children with Autism

MDH link with Autism Fact Sheet translated to 3 languages:
* http://www.health.state.mn.us/divs/cfh/topic/autism/index.cfm

For copies of the Developmental Milestones wheel in different languages:
Minnesota Department of Health
MN Children with Special Health Needs
PO Box 64882, St. Paul, MN 55164
IC #141-0761
Contact Information

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