MN ACT Early Delegate Project

University of Minnesota
MN LEND Program
Changing Cultural Landscape

- Significant population growth in diverse communities—almost 30% of population growth

- Largest East African Somali population in US

- Southeast Asian Hmong
  - 2nd largest in US

- Growing Latino Population
  - Triple by 2035
Background: ASD Research In Minnesota

• Community reports of higher rates of ASD in Somali Community

• MDH conducted study on administrative prevalence in MPS in 2008-2009)

• Somali: non-Somali ASD ratios ranged from 2-7 times greater for Somali children.

• ASD for Asian, Native American children strikingly low.
## MN ASD Prevalence
### University of MN

<table>
<thead>
<tr>
<th>Race and ethnicity</th>
<th>Children with ASD identified/Total population</th>
<th>Prevalence estimate (prevalence per 1,000 children)</th>
<th>95% Confidence interval*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>255 of 12,329</td>
<td>1 in 48 (20.7 per 1,000)</td>
<td>18.3 – 23.4 per 1,000</td>
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<tr>
<td>Somali</td>
<td>31 of 1,007</td>
<td>1 in 32 (30.8 per 1,000)</td>
<td>21.6 – 43.8 per 1,000</td>
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<tr>
<td>White</td>
<td>120 of 4,336</td>
<td>1 in 36 (27.7 per 1,000)</td>
<td>23.1 – 33.1 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>
<td>12.2 – 20.9 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>
<td>8.7 – 17.9 per 1,000</td>
</tr>
</tbody>
</table>

Note: We are unable to report on Asian/Pacific Islanders and Native Americans due to their low numbers.  
* 95% confidence interval is the range in which an estimate is likely to fall.
MN ASD Research

- About 1 in 32 Somali children (7-9 years) identified with ASD.
- Somali and White children were about equally likely to be identified with ASD.
- The ASD estimates from Minneapolis are higher than most other communities where CDC has counted ASD.
- Rates in other cultural communities (Asian, Latino, African American) significantly lower.
- Age of Dx averaged 5.3 years
Community Feedback Qualitative Data

- Families need **support and education** around ASD
- Parents need to **understand early signs** of ASD
- Help **de-stigmatize** ASD
- Build **capacity in communities** and with providers
- Message needs to come from **community and parents**
MN Act Early Outreach

- Develop a **network of MN Act Early Delegates** to conduct outreach in diverse communities.
- **Parent to parent leaders** in the culturally diverse communities
- Promote **early developmental monitoring and early screening** in diverse communities.
- **Build capacity and relationships** in diverse communities
Grant Partnership

Increase Early Screening

MDH Minnesota Department of Health

Cultural Communities

University of Minnesota
Act Early Goal

Awareness of Developmental Milestones & Early Screening

Screening

Early Intervention
Act Early Delegates

- Act Early Outreach in cultural community with families with young children.
- Creative and innovative ways for outreach.
- Share Act Early and Help Me Grow materials with families with young children.
- Promote early screening and early intervention in your community.
- Regular communication with liaison.
**Audience**

- Outreach in the community
- Families with young children (Birth-5)
- Health care professionals
  - Pediatricians, family physicians, nurses
- Child care and early education providers
- Children who have not been screened, general population
Act Early Delegate Meetings
MN Act Early Delegate Project

- Trained 25 community leaders (delegates and liaisons) in diverse communities
- 1000s hours of community outreach
- 3 of liaisons applied to LEND program for 2016-2017
- Built significant capacity in diverse communities
- Strengthened Relationships
- Matching Funds
Outreach

- Large Cultural Festivals
- Large health care clinics
- Large events with families with young children (e.g. Head Start Resource Fair, workshops, etc.
- Day care and Preschools
- Places with families with young children (Birth-5)
Outreach Events

- Hmong Resource Fair at the Eastside St Paul YMCA
- Hmong New Year in St. Paul, MN
- Help Me Grow Latino outreach
- Somali delegate at Act Early retreat
LOCAL RADIO Stations

Quick PSAs about “Learn the Signs. Act Early.” message

• Hmong Radio Station
• Somali Language Radio Program
• Latino Radio Station
The MN LEND and MN Act Early are partnering on innovative community outreach projects to promote early screening in diverse communities using the "Learn the Signs. Act Early." materials and resources. The MN Act Early Delegate Network recruited and trained Hmong, Somali, and Latino delegates to conduct outreach on the importance of developmental monitoring, developmental screening, and acting early if there are any concerns. In October 2015 the MN Act Early Delegate Network held an October 2015 Community Kick Off, where two MN LEND Fellows, Barite Gemada and Ashwak Hassan, became inspired to help promote early screening in their respective Oromo and Somali communities. Barite, who noted the absence of an Oromo Act Early delegate, decided to step into this role. Oromo is one of the largest East African communities in the Twin Cities. Barite is partnering with Ashwak, who additionally hopes to destigmatize mental illness, to create an Oromo and Somali video for YouTube and social media that promotes the importance of early screening and intervention as part of their MN LEND Fellowship.
LEND Partnership
LEND Partnership

- [http://rtc.umn.edu/autism/](http://rtc.umn.edu/autism/)
- Podcasts (in Somali & Subtitled)
  - What is Autism or Autism Spectrum Disorders?
  - Parent story
  - Current Treatments

- One page summary
  - Findings
  - What is Autism
  - Who I should talk to
Document and Share

- **Document** your outreach work.
- **Share** with other liaisons and other delegates.
- Build **relationships!!**
- Work with your liaison and delegate team to **coordinate outreach activities.**
Use MN Act Early Materials

- Local Customized MN Act Early Materials
- Connect with Help Me Grow
- Document activities
- Communicate with Liaisons
- Training on MN Act Early website: [https://ltsaemn.umn.edu/](https://ltsaemn.umn.edu/)
Outreach Materials
Key Program Components

• Regular Meetings
• Ongoing Training
• Check Ins with Liaisons
• Leaders in the Community
• Invoicing and Activity Logs
• Key target events
• Balance of Flexibility and Ongoing Support
Program Evaluation: Focus Groups Themes

- **Connections** (Elders & Community Leaders)
- **Communication** (verbal)
- **Relationships** (takes time & resource)
- **Family knowledge = strength**
- **Respect and Trust**
- **Information is Empowering**
- **Education**
- **Pride and Hope**
Focus Group Quotes

• “Information needs to come from trusted sources. Act Early message provides information; the liaison connection provides hope.”

• “Relationships are central to building trust, and occur over time….The materials are the last thing for me. I get them to connect first. I share my story, then the materials.”

• “People won’t just take the materials; they need to have a 1:1 connection to help them understand what’s in the materials. Then encourage them to share with other parents in community.”
Lessons Learned

• Investment in relationships takes time.
• Connections to elders and community leaders
• Start with development and then signs of concern or delay (do not start with ASD)
• Translated materials have been beneficial to support discussion.
• Invoices & Timelines
• Balance of Flexibility, Structure and Support
Thank you!

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