



# **ADDRESSING HEALTH CARE AND OTHER RESOURCE BARRIERS AMONG SOMALI FAMILIES OF CHILDREN WITH AUTISM**

**DAKOTA COUNTY PUBLIC HEALTH**

January 2019

## **Addressing Health Care and Other Resource Barriers Among Somali Families of Children with Autism**

Minnesota Department of Health  
Center for Health Equity  
PO Box 64975  
St. Paul, MN 55164-0975  
651-201-5813  
[health.equity@state.mn.us](mailto:health.equity@state.mn.us)  
[www.health.state.mn.us](http://www.health.state.mn.us)

*Upon request, this material will be made available in an alternative format such as large print, Braille or audio recording. Printed on recycled paper.*

As requested by Minnesota Statute 3.197: This report cost approximately \$1,266.43 to prepare, including staff time, printing and mailing expenses.

# Table of Contents

- Executive Summary .....i
- Background.....1
- Project Overview .....1
- Project Implementation .....2
  - Partnerships and Community Engagement.....2
  - Activity Highlights .....3
- Evaluation .....4
- Looking Forward .....6
  - Challenges and Lessons Learned .....6
  - Sustainability .....7
- Conclusions.....7

# Executive Summary

In fiscal year 2018, the Minnesota Legislature directed the Commissioner of Health to award a grant to Dakota County to partner with a community-based organization with expertise in serving Somali children with autism. The purpose of the grant was to address barriers to accessing health care and other resources by providing outreach to Somali families on available supports as well as training to providers on Somali culture.

The Minnesota Department of Health (MDH) awarded a \$100,000 grant to the Dakota County Public Health department (Dakota County) to implement the Somali Autism Support project for the period June 30, 2017 to June 29, 2018. The grantee's main responsibility was to partner with one or more community organizations to provide outreach and training for Somali families of children with autism, and to oversee the work of the partner organization. Grantee duties included implementing a targeted public awareness campaign on autism in the Somali community, forming family support groups for education and resource sharing, and training healthcare and community service providers on Somali culture. Dakota County, its primary partner Isuroon, and other community partners carried out all these duties through multiple activities.

This project found that both families and providers faced barriers when dealing with an autism diagnosis. Issues such as mistrust from negative experiences, racism, acclimation to fraud in refugee camps, language barriers, financial barriers and lack of information deterred families from accessing services, despite the medical, school-based, federal, state, and local services available. At issue was the general shortage of community resources to bridge language gaps and provide culturally responsive navigation assistance necessary for families to access support services. From providers' point of view, knowledge of Somali history, values and norms was lacking in the provider community. They needed trainings that targeted areas where misunderstandings and mistrust have occurred between them and the Somali families with whom they worked.

This grant made it possible to listen to the concerns of families disproportionately impacted by autism, and for them to receive culturally appropriate and culturally responsive services from a culturally specific organization. The partnership with MDH provided essential resources to support the efforts of Dakota County and Isuroon. Their evaluation outcomes consisted of:

- Raising awareness in the Somali community regarding autism and available support services,
- Connecting the families of children with autism with other families to share knowledge and experience,
- Increasing providers' knowledge of Somali culture, and,
- Creating a community of practice for professionals, advocates and educators to increase engagement with Somali families impacted by autism

Dakota County and Isuroon plan to continue the services and networking opportunities and to seek funding for the work even after the grant has ended.

## Background

In fiscal year 2018, the Minnesota Legislature directed the Commissioner of Health to award a grant to Dakota County to partner with a community-based organization with expertise in serving Somali children with autism. The purpose of the grant was to address barriers to accessing health care and other resources by providing outreach to Somali families on available support as well as training to providers on Somali culture. Furthermore, the grantee was to report to the commissioner and the chairs and ranking minority members of the legislative committees with jurisdiction over health care policy and finance on the grant funds used and any notable outcomes achieved by January 15, 2019.

The Minnesota Department of Health (MDH) awarded a \$100,000 grant to the Dakota County Public Health department (Dakota County) to implement the Somali Autism Support project for the period June 30, 2017 to June 29, 2018. As a grantee, Dakota County's main responsibility was to partner with one or more community organizations to provide outreach and training for Somali families of children with autism, and to oversee the work of the partner organization including:

1. Implementation of a targeted public awareness campaign on autism in the Somali community,
2. Formation of family support groups as a platform for education and resource sharing, and
3. Training of healthcare and community service providers on Somali culture.

Dakota County contracted with Isuroon to carry out these duties. This legislative report summarizes all grant activities and outcomes from these activities for the grant period based on Dakota County's final report.

## Project Overview

The goal of the Somali Autism Project was to increase support for Somali families of children with autism living in Dakota County. The objectives were to:

1. Provide the families with information on autism and available support resources,
2. Connect the families with others who share a common experience,
3. Help the families navigate various supports systems,
4. Promote more culturally responsive services to the families, and
5. Increase engagement with the Somali community in Dakota County.

Strategies used in order to accomplish the objectives were:

1. One-on-one contact with the families,
2. Parent support groups,
3. Training for families on navigating support systems,
4. Training for community providers on Somali culture, and
5. Establishing a network of professionals and advocates working with the Somali community in Dakota County.

Specific activities implemented were:

1. Made personalized contacts with Somali families to provide information on autism and available support services,
2. Recruited families to participate in the parent support groups to connect them with other families that have the same experience,
3. Conducted trainings for families on navigating various support systems (medical, educational, social service, etc.),
4. Conducted trainings for community service providers on Somali culture to promote more culturally responsive services, and
5. Connected professionals and advocates committed to increasing engagement with Somali families in Dakota County.

Over the course of the project, the focus shifted from raising awareness on autism in the general Somali community to raising awareness among Somali families already impacted by autism. As the grant team learned of the significant stigma associated with autism in the Somali community, the necessity of focusing efforts toward bringing individual families “out into the open” became clear. Through targeted outreach and support group meetings, the project reached families previously described as “in hiding” and connected them to Dakota County services for additional support and resources.

Dakota County’s primary partner in the project was Isuroon. *Isuroon*, a Somali word for “a woman who cares for herself,” is a women-led, community-driven nonprofit organization that acts as a cultural bridge by connecting Somali families with wellness information, trusted health care providers, financial literacy education, and civic engagement and leadership opportunities. It provides culturally competent training and research to health care providers and policymakers to improve health outcomes and decrease disparities. Isuroon staff had already been working with Somali families struggling to find support for their children with autism. The partnership with Dakota County allowed Isuroon to provide its staff with more in-depth training on autism and support resources, thus enhancing its capacity to engage effectively with Somali families of children with autism.

## Project Implementation

### Partnerships and Community Engagement

Dakota County was required to partner with one or more community organizations to provide outreach and training to Somali families of children with autism. Isuroon was the contracted partner agency that implemented all grant-required activities. Services provided included support groups; one-on-one home visits; training on topics such as autism as a diagnosis, housing, legal services, and the importance of respite; and individualized support applying for county and state services.

Other partners in the project included:

- Project Advisory Committee – a pre-existing advisory committee, formed by Dakota and Ramsey counties for the Respite for Individuals with Autism Grant project funded by the Minnesota Department of Human Services, served the same function in the project. It was comprised of a variety of stakeholders involved in the autism community, from researchers and practitioners to family members and advocates.
- Somali Engagement Community of Practice - served as an informal advisory group for the project whose purpose was to share knowledge and support collaborations to improve community engagement. Participants included professionals, advocates and educators serving the Somali community in Dakota County.
- Dakota Child and Family Clinic – a nonprofit community clinic which hosted support group meetings and referred families to the project, and
- Somali Disability Resource Network – an informal network of Somali practitioners that served as a connector, identifying culturally specific resources and connecting Somali professionals to the families.

Stakeholder feedback was gathered through interviews and listening sessions, and used to design activities. Stories told by parents of children with autism revealed that many of them were exhausted from being the primary caregiver; they felt isolated in their experiences and unequipped to care for their child; many were in crisis, facing eviction from their homes or with children receiving school suspensions; and they faced language, transportation, and health literacy barriers when accessing services. It was imperative to build trust with these families and ensure connection to appropriate resources. The support groups and individual home visits with Isuroon helped establish more relational supports for families.

Project staff heard from professionals that knowledge of Somali history, values and norms was lacking in the provider community. Training sessions therefore targeted those areas that have led to misunderstandings between providers and Somali families. A number of professionals engaged early in the process later attended family support groups to provide information and resources.

## Activity Highlights

Project activities fell under three main areas as required in the grant: targeted public awareness campaign on autism in the Somali community, family support groups as a platform for education and resource sharing, and training of healthcare and community service providers on Somali culture.

### 1. Autism public awareness campaign

The grant coordinators conducted an outreach and engagement campaign to gain understanding of the strengths and opportunities within the Somali community. Individual meetings with Somali families and advocates in Dakota County produced more and more contacts to engage, leading to a decision to host a community meeting at the Dar-Us-Salam mosque in Burnsville to share information about the grant and recruit participants. Parents and children affected by autism shared their stories. Other outreach and engagement activities included hosting or attending community resource fairs, attending conferences and community meetings, and hosting the Somali Engagement Community of Practice meetings. Staff also created and

distributed flyers to promote autism services. Conferences attended and/or exhibited included the South of the River Resource and Education Fair hosted by Dakota County’s Mental Health Collaborative, Autism Society of Minnesota annual conference, Minnesota Association of Children’s Mental Health annual conference, and School District 196 Somali Education and Cultural Conference. In total, the grant team and Isuroon attended more than 12 outreach events and made contact with an estimated 300 community members.

**2. Family support groups**

Parents from 27 families participated in 16 support group meetings and workshops at various locations including the Isuroon office, YMCA and Dakota Child and Family Clinic. Monthly support group meetings offered parents an opportunity to connect with one another and build relationships, while also learning about autism and available support resources. Examples of topics covered were strategies for self-care, the importance of respite to parents’ mental health, and services available through the county. During the sessions, families received resources (e.g., school supplies, food assistance and gift cards for self-care activities) intended to help reduce family stress and get parents in the habit of caring for themselves.

**3. Service provider training**

The project held four trainings on Somali history and culture (Somali Culture 101) to increase cultural competence among service providers and county staff. Fartun Weli, the founder and executive director of Isuroon, and a Somali parent advocate who has two children diagnosed with autism, served as co-presenters. To build mutual understanding, the trainings focused on the differences and similarities between traditional Somali culture and mainstream service systems in the U.S. Among the 272 people who attended the trainings were staff (public health and library) from Dakota and Ramsey counties, staff from at least eight health care and/or social service provider agencies, educators from local schools, and interested community members. Based on feedback surveys, 83 percent of attendees felt better prepared to serve the Somali community after the training.

**Evaluation**

**Table 1** shows the project’s selected success measures and findings for the one-year grant period. The project exceeded their outcome targets and achieved unexpected outcomes in the process.

**Table 1. Somali Autism Project evaluation results, June 30, 2017-June 29, 2018**

| Outcome/Target   | Evidence   |
|--|--|
| At least 30 families of children with autism are engaged | 53 families received information on autism and available support services through in-person contacts |



| Outcome/Target   | Evidence   |
|--|--|
|  | An additional 300 community members (estimate) were reached in 12 outreach events  |
| At least 14 families are recruited to participate in support groups  | 27 parents attended group meetings and workshops to learn about other family's experience with autism and receive support  |
| 3 community providers receive training on Somali culture   | <p>272 people representing 8 providers attended trainings about culturally responsive services to Somali families</p> <p>Based on post-training surveys, 83 percent of attendees reported that as a result of the training they were better prepared to serve the Somali community</p> |
| A network of providers committed to increasing engagement with Somali families in Dakota County is established | <p>Over 20 professionals and advocates attended 5 meetings during the grant period.</p> <p>The group agreed to continue meeting to collaborate on engaging the Somali community.</p>   |

The project also realized unexpected outcomes:

- At the second Somali Culture 101 training session which was geared towards county human services staff, a small number of attendees reported frustration at being asked to adapt their work to meet the cultural needs of one group, and having to combat the perception that they were not doing enough for Somali families. This feedback led to the reformatting of future sessions. They included more discussions of shared challenges and then framed as a platform for getting answers to frequently asked questions about how to serve the Somali community more effectively.
- The number of families inquiring about autism support resources grew as the project progressed, including those from outside Dakota County. Isuroon connected them with resources even though these activities occurred outside the scope of the partnership with Dakota County.
- A community support network formed among parents of children with autism and service providers. For parents, it served as a reliable and culturally appropriate source of information on autism and related disabilities, resources and ways to navigate the various systems. For social service, medical, and school professionals, they received training on how to engage and meet the needs of their Somali clients.
- The grant team has been able to share information about the project and lessons learned. For example, they had a well-received presentation at the Minnesota Association of Children's Mental Health annual conference on community engagement activities undertaken as part of this grant.

### Participant Story

*One of the monthly meeting participants was a single mother with seven children, three of them diagnosed with autism. Because of her children's intensive needs, it had been a challenge to maintain employment and housing, not to mention taking a break from caregiving duties. She said, "The only way I could rest is if I were arrested and put in jail," yet she kept coming to the meetings. With the help of Isuroon staff, she was able to hire a family friend to help care for her children. She regarded her visits to Isuroon as respite care that allowed her to maintain good mental health. She now wants to find permanent housing and get her driver's license. Isuroon is helping to connect her with resources to pursue these goals.*

## Looking Forward

### Challenges and Lessons Learned

The Dakota County grant staff and Isuroon experienced several challenges and learned lesson that they took into consideration during implementation and that can help inform future efforts.

1. **Building trust with an underserved community within a short time period.** Relationship development takes time and the project team felt rushed to produce outcomes before it had fully established that trust. Families also expressed concerns about services continuing after the grant and were reluctant to participate due to previous experience with short-term supports ending suddenly.
2. **Lack of Somali interpreters with adequate knowledge of support systems.** Many parents in the project required language interpretation but this was sometimes insufficient. Isuroon's Somali-speaking staff often filled an ad-hoc interpreter role to help people understand the technical aspects of support programs. There is general shortage of community resources to bridge language gaps and provide culturally responsive navigation assistance that are necessary for families to access support services.
3. **Parents' questions and concerns were not limited to autism.** Parents were very open and honest in discussing their experiences with and challenges of parenting children with autism, but also those related to relationships, physical health and wellness, housing, transportation and their own education and career goals. Parents wanted to be strong for their children in order for them succeed, and it can only be possible by addressing these other concerns.
4. **Somali parents access resources less frequently than mainstream families.** While there are medical, school-based, federal, state, and local services available to support parents of children with autism, issues such as mistrust from negative experiences, racism, acclimation to fraud in refugee camps, language barriers, financial barriers and lack of information deter families from accessing services. This project sought to understand and empower Somali parents and their use of informal systems of care, and provided additional support by connecting them to formal resources.
5. **Bringing parents together serves more than just an educational purpose.** Parents value time to come together to talk and share their knowledge, feelings and experiences as much as learning about autism, respite, and resources. Some attendees reported that workshops contained "too much information" and

not enough time to talk and connect, and they missed the chance “to chat.” More effort must go into facilitating these gathering spaces beyond support groups and one-way trainings and workshops.

6. **Parents of children with autism themselves are the biggest champion of this work.** While many were initially hesitant to participate in a short-term project, over time they saw Isuroon and the grant team’s commitment to honoring their experience and empowering them in the process. Because of frustration with short-term projects among parents, the grant team focused on creating a long-term support network, both in terms of building relationships between parents and with professionals who could offer support, but trust and transparency were key to this process.
7. **Critics can become champions.** Because Isuroon was new to the autism community, many professionals supporting the Somali community initially expressed reservations about their motivations and long-term intentions. Involving these professionals in the process was essential to building relationships and leveraging their expertise. Over time, many of these same professionals began supporting Isuroon and the families by sharing resources, making connections and promoting their services. The Somali Engagement Community of Practice was critical in bringing various people together to discuss shared values and collaboration opportunities. They expressed interest in further training on Somali culture.

## Sustainability

Isuroon plans to continue supporting the families beyond the grant period. They have secured grant funds from other sources and are exploring providing similar support services through existing disability services programs. More families in and outside Dakota County are requesting help as word of Isuroon’s services spread. This grant helped Isuroon establish an important parent-to-parent resource network; now there is a need for ongoing funding through billable services options, such as peer mentoring services, the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit or Adult Rehabilitative Mental Health Services (ARMHS).

The Somali Engagement Community of Practice will continue. This collaboration between Dakota County Public Health and Social Services, health and community services providers, advocates and educators aims to improve resource options for Somali families in Dakota County. The group will continue to meet bi-monthly to share knowledge, resources and support efforts to increase engagement with the Somali community.

## Conclusions

Autism affects families in different ways. Devoting the time to care for and support their child with autism also affects other parts of their life such as relationships, work, finances, and other family members. It can shift priorities and resources towards providing treatment and interventions. In cultural communities, traditions, values and beliefs also affect how people deal with the situation. Seeking professional support is hard when there is a lack of information about autism and available supports, and especially when there is stigma attached, as is the case with the Somali community in Minnesota. Parents choose to go in hiding to shield their child from misguided labels of mental health illness. Thus, many Somali families struggle to understand what their child is going through and to find appropriate care.

Their concerns and fears are valid. In 2008, the Minnesota Department of Health (MDH) began discussions with the Somali community regarding their concerns about an unexpectedly high number of Somali children in an autism pre-school program in the Minneapolis Public Schools.<sup>1</sup> According to MDH, the program enrolled two to seven times more Somali children than non-Somali children (the study had limitations). Another study in 2010 by the University of Minnesota, the Centers for Disease Control and Prevention, and the research and advocacy group Autism Speaks found high rates of autism in the Somali and white populations, although it did not look into the reasons for such levels of prevalence.<sup>2</sup> It reported that about one Somali child in 32 and one white child in 36 in Minneapolis were on the autism spectrum (the national average is one in 88).

This project found that both families and providers faced barriers when dealing with an autism diagnosis. Issues such as mistrust from negative experiences, racism, acclimation to fraud in refugee camps, language barriers, financial barriers and lack of information deterred families from accessing services, despite the availability of medical, school-based, federal, state, and local services. At issue was the general shortage of community resources to bridge language gaps and provide culturally responsive navigation assistance that were necessary for families to access support services. From providers' point of view, knowledge of Somali history, values and norms was lacking in the provider community. They needed more trainings that target areas where misunderstandings and mistrust have occurred between them and the Somali families with whom they worked.

This grant made it possible to listen to the concerns of families disproportionately impacted by autism, and for them to receive culturally appropriate and culturally responsive services from a culturally specific organization. The partnership with MDH provided essential resources to support the efforts of Dakota County Public Health and its partner Isuroon. Through this grant, they were able to:

- Raise awareness in the Somali community regarding autism and available support services,
- Connect the families of children with autism with other families to share knowledge and experience,
- Increase providers' knowledge of Somali culture, and,
- Create a community of practice for professionals, advocates and educators to increase engagement with Somali families impacted by autism

Plans are to continue the services and networking opportunities and to seek funding for their work even after the grant has ended.

---

<sup>1</sup> Minnesota Department of Health (2009). [Autism and the Somali Community](#).

<sup>2</sup> University of Minnesota Institute on Community Integration (2013). [Minneapolis Somali Autism Spectrum Disorder Prevalence Project](#).