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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

February 15, 2014

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February 1, 2014

Submitted by the Autism Research Team:

- University of Minnesota, School of Public Health
- The Confederation of Somali Community in Minnesota
- West Side Community Health Services -- Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo)



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We gratefully appreciate the Minnesota State Legislature and Minnesota Department of Health for funding this research project as well as encouraging the utilization of Community-Based Participatory Research (CBPR).

The key informants from the community who worked with families who have a child with autism were essential for helping us to understand the system and to begin to understand the most important challenges that families face when trying to get services for their children.

We extend our thanks to Glendale and Brian Coyle Community Centers for use of their facilities for our research meetings. These are welcoming places to work and made our group meetings enjoyable and Productive.

Most importantly, we thank the parents from the Somali, Latino, and Hmong communities who took the time to share their experiences and teach us. There were more parents who wanted to participate than we could interview due to time constraints. We learned much more than can be expressed in this report and came away with increased understanding of the complex effect autism may have on families. We were deeply impacted by the love, dedication, and activism parents had in providing their children with the best quality of life possible and hope that this report adequately highlights the challenges that families face, as well as their incredible fortitude and perseverance.

- *Autism Research Team*

Executive Summary

Background

In 2012 the Minnesota (MN) Legislature authorized a study of the experiences of having a child with autism among the Somali community. The study was intended to understand “cultural- and resource-based aspects of autism spectrum disorders (ASD) that are unique to the Somali community.” With the approval of the Minnesota Department of Health, the study was extended to also include the Hmong and Latino communities.

Objectives

- To describe challenges in early identification of autism;
- To identify the challenges families experience when accessing services; and
- To develop recommendations to address the challenges faced by families.

Methods

The study used community–based participatory research (CBPR) to fully involve members of the community in all aspects of the research from specifying research questions through implementation of the research, formulating recommendations, and dissemination.

Researchers from The University of Minnesota, School of Public Health, the Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo) of West Side Community Health Services and the Confederation of Somali Community in Minnesota (CSCM) partnered to implement the research.

The research was conducted in two stages. First, we interviewed 33 key informants including spiritual leaders, medical and other autism service providers, advocates, researchers, staff from disability and autism centers, county workers and professionals involved in autism services in the educational system. The purpose of these interviews was to better understand the challenges faced by parents with a child with autism and identify the specific research questions to focus on in the second stage of the research.

In the second stage of the research, we interviewed 70 parents: 38 from the Somali community, 15 from the Hmong community and 17 from the Latino community. The interviews included both focus groups and individual interviews. Questions focused on perceptions of autism, delays in getting a child with autism properly identified or diagnosed, challenges trying to get services, services most needed, and recommendations for improving access to services.

Results

Knowledge of autism:

- A common theme across key informants and parent interviews was a general lack of understanding about autism, and the belief that education about child development and signs and symptoms of autism would increase early detection and treatment. In fact, the term “autism” does not exist in the Hmong and Somali languages.
- Although many parents perceive autism as a developmental and medical condition, parents in the Somali and Latino community believe it is linked to vaccines. Hmong and Somali communities also hold beliefs about spiritual causes of autism.

Early identification of autism:

- For the most part, parents were the first to notice something was different about their child and many attempted to seek help early.
- The time lapse between noting a problem and obtaining a diagnosis and treatment was a source of frustration for parents.
- Parents report barriers to early identification occur at the individual- (e.g., lack of knowledge about autism and available resources, denial or normalizing child’s behavior, stigma associated with disability), provider- (e.g., misdiagnosis, discrimination, language barriers), and system-level (e.g., long wait lists to see specialist for diagnosis as well as treatment, problems navigating system and locating resources exacerbated by language barriers, problems with insurance coverage and costs – particularly in the Latino community).

Challenges accessing services:

- Parents report problems seeking and accessing autism-related resources that also occur at the individual- (e.g., 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 wellbeing, lack of knowledge about available resources), provider- (e.g., language barriers, concerns providers held back information about services, lack of follow-up, discrimination), and system-level (e.g., long waitlists for services, complexity of system, lack of support services for parents and other family members, language and cultural barriers, transportation issues). In addition, Somali parents reported significant challenges to finding safe housing.

- Challenges to accessing services are intensified by concerns about unauthorized immigrant status among Latino parents (whose children are likely US born).
- Parents valued services and noticed improvements for their child with autism. However, insurance does not cover enough autism services (e.g., services not covered, caps on number of covered services, providers not accepting more Medicaid patients). Parents reported difficulty accessing Medicaid; some indicated that one parent had to stop working in order to meet the income threshold for Medical Assistance.

Gaps in services:

- Parents report a desire for more of existing services such as speech and occupational therapy, applied behavior analysis, and personal care attendants.
- Additionally, parents indicated that there is a need for new types of services. For example:
 - Family support services that go beyond traditional counseling and support group services by extending the focus to the families of children with autism. This support would be community specific and parent-driven, providing an opportunity to share lessons learned with members of their own community.
 - Extracurricular, social and sports related activities for children with autism.
 - Services to young adult children with autism; fill the current void after children leave the school system.
 - Respite care provided by members of one's own cultural community.

Strength and resiliency of families:

Although not a specific focus of the study, several observations consistently emerged:

- The tremendous love, devotion and resiliency of these parents in spite of the stress and barriers faced in caring for a child with autism.
- Parents' willingness to reach out and support others represents a potential untapped resource in the community.

Recommendations of parents:

The survey asked parents what they would most like to tell decision-makers to do to improve services and reduce barriers. All communities recommended:

- More awareness or education around autism that is culturally and linguistically appropriate; and
- Support services for families

In addition, the Somali community emphasized culturally sensitive services; the need for a culturally appropriate community center/autism center to provide resources and services and the need for safe, affordable housing. The Hmong community also recommended further financial support and grants for services not covered under insurance and increased funding for organizations focused on autism. Both the Latino and Hmong communities recommended improved insurance coverage, with the Latino community also recommending coverage for undocumented families with autism.

Conclusions and recommendations

Despite enormous frustration that parents expressed as they told stories of the challenges they faced trying to get the services they felt their children needed, they are not passive – they are not patiently waiting for someone to connect them or their child to services. Instead, many parents told stories of actively seeking services for their children, trying to educate themselves and their families about the disorder and going to extraordinary lengths to get their child services while juggling other family and work demands. Not one of the seventy parents interviewed rejected the value of services for their child; those with access to consistent services talked about the positive impact on their life and the life of their child. Parents are engaged and showed an eagerness to learn and to teach us about their experiences and challenges.

At the same time, while parents persevere and are engaged, the system has failed them. The obstacles to getting quality services are enormous and unnecessary. The fact that the Somali community has been actively engaged in advocating for autism-related services for more than a decade now, yet still face unbearable barriers to getting help for their children is unacceptable. The problems faced by families in the Latino and Hmong communities have not received as much attention, but should also be seen as intolerable. We are amidst what can be referred to as a public health crisis considering the effects autism has on the Minnesota community. We have a population of Somali families, who in spite of their struggles and engagement, are faced with a dire situation where they have children with severe autism who are transitioning into young adults. Families are under massive stress as too are our communities. It is the responsibility of decision-makers to take concrete action to begin to redress the failures in the system. Otherwise,

we risk losing a generation of children to autism, and doing irreparable harm to the cultural communities that make up Minnesota.

Parents have told us what they face and what they need. Our recommendations are based on their suggestions.

Recommendation 1

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

- Establish a program of community workers (Community Autism Workers) modeled after Community Health Workers program, where parent-leaders can educate peers, provide information about resources, advocate, help with health system navigation and connect families to resources.
- Ensure community workers are linguistically and culturally competent.
- Include members of each community as partners in decision-making on all task forces, grant opportunities and policy-making bodies on matters related to autism.

Recommendation 2

Develop resource centers housed in the community.

- Fund one-stop resource centers in the communities to provide easy access to information.
- Support the development of an autism center specifically for Somali community, that targets culturally appropriate services to children with the most severe disabilities.
- Staff centers with linguistically and culturally competent staff who are knowledgeable about autism and autism resources.

Recommendation 3

Provide resources to form support groups for families.

- Fund community agencies to hold support groups for families within these communities on a regular basis.
- Identify and support culturally and linguistically appropriate respite care providers.

Recommendation 4

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

- Support workforce development for autism service providers including community workers.
- Implement an autism surveillance system that tracks wait times by cultural community.
- Dedicate staff at the county level who are specialists in autism, reflect the linguistic and cultural backgrounds of the population they serve and who can act as resources to Community Autism Workers.
- Set targets for wait times, monitor and evaluate progress.
- Education of physicians about proper screening and evaluation of autism.
- Develop and pilot an intervention such as the ‘Right Question Project’ to improve communication between professionals and parents.
- Bring mobile screening services to the community, including staff that are culturally and linguistically competent.
- Monitor disparities in services, include waivers provided to publically insured children.
- Ensure that schools have the capacity to provide quality, evidence-based services to children with autism.
- More frequent meetings between parent and school where interpreters are available.
- Greater accountability of school system for quality and adequacy of autism services provided.

Recommendation 5

Continue to address problems with insurance coverage and costs.

- Monitor the impact of autism insurance reform on use of services by children from different cultural communities.
- Ensure that comprehensive autism services are specified as “Essential Health Benefits” in health exchanges.
- Include non-documented children in Medicaid coverage.
- Provide help with enrollment and benefit information that may be viewed as trustworthy and non-threatening, for example reimbursing the support of Community Autism Workers.